

# MSA

NEWS



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— RAISE A CUP —

*For msa*

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 Lower Road, London SE16 2XB  
 Tel: 0333 323 4591  
[www.msatrust.org.uk](http://www.msatrust.org.uk)

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 voluntary donations.**

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 Company Number 7302036

**MEMBERSHIP AT  
 SEPTEMBER 2015**

Current MSA members 1,185  
 Carers, relatives & friends 2,080  
 Healthcare professionals 2,158

**Total 5,423**

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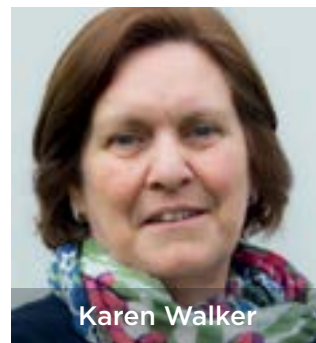
## Multiple System Atrophy Trust

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



Our Interim Chief Executive Karen Walker writes her first introduction, and it's all go...

A warm welcome to all our readers. I've been getting out and about to meet some of our amazing staff who support people living with MSA around the country. I have also had the pleasure of meeting with some of you and enjoyed very much the wonderful welcome I received in Newcastle for a barbecue in aid of MSA Trust. A fantastic £1250 was raised on the night and I learnt a new quiz game – Irish Bingo.. For other fantastic fundraising ideas, check out our fundraising page and go online to register for your pack for the **Milk, Sugar And Tea** party. We want as many people as possible to invite their friends to tea, enjoy an afternoon of company and gossip and raise funds for your favourite charity!

We have also been busy at our office and I am delighted to inform you of our office move. We are really pleased to have found spacious and better value premises in South East London. These new offices will enable our teams to work more effectively together.

We will also be able to continue attending meetings and campaigning on your behalf for better services for people living with MSA; please look out for the blogs on our website where we are starting to explore some of the policy areas we know are important to you.

**51 St Olav's Court, City Business Centre, Lower Road, London SE16 2XB** is our new home and our new number is **0333 323 4591**. We look forward to welcoming supporters there in the coming months.

I wish to extend a warm welcome to two new Trustees to our Board following the resignation of two of our long serving members; Darcy Hare, Chair of the Research committee and Mike Evans, former Chair of the Board. We are sorry to lose such dedicated and influential members and thank them for their amazing support over the years. Our two new members are Amy Couture and Helen Craik, who both come with specialisms that I know the members of the Board and staff at the Trust will find useful in the coming months, particularly as we begin to make plans for our 20th anniversary celebrations in 2017.

On a sadder note, I would like to direct you to an obituary in the magazine, written by our founding Chair Eileen, Lady Strathnaver, following the death of one of our first Trustees, Valentine Fleming. Val was an inspirational figure and a lifelong friend of Sarah Matheson, our founder. He will be missed. **MSA**

**Karen Walker**  
Interim Chief Executive Officer

# RESEARCH UPDATE



Aoife Kiely

Dr Aoife Kiely, from the University College London Institute of Neurology, brings us up to speed with two pieces of research being funded by the MSA Trust that she is involved with.

“My research is completely focused on understanding MSA. One of the biggest questions for me has been whether the brain’s own defence system might be trying to repair the brain, or could itself be broken and be making the disease worse. This defence system is called ‘neuroinflammation’ and acts as the immune system of the brain. Like the immune system of the body, in the brain tiny worker cells respond to signals to either destroy damaged brain areas or heal and repair them. Our work has already found that, similar to what we see in Alzheimer’s and Parkinson’s disease brains, one of the tiniest worker cells of the brain’s immune system, the microglia, is behaving in a more aggressive way in brains affected by MSA (“MSA brain”).

We wanted to look more closely at these microglia, and also other inflammatory signals in an MSA brain, which could tell us more about what is going on there and why.

To do this we chose to use a state of the art technology called NanoString (see <https://youtu.be/85h3vYt3KYg> for a video). We took samples of brain regions affected by MSA from a group of MSA brains and from non-disease cases. Then the samples were scanned by NanoString machinery to detect hundreds of signals, each of which can represent either the good or the bad sides of neuroinflammation.

This data will give us a far better understanding of how neuroinflammation is behaving in MSA brain. Using future grants we may be able to investigate the leads and new targets that we find in this study. This could lead us towards the creation of disease modifying treatments similar to those which are under development for other neurodegenerative diseases.

However, my work with MSA will continue. For the next year and a half I will take a slightly different route and

will be investigating whether the break down and cleaning out of the sticky protein alpha-synuclein, which is believed to cause the damage in MSA, is working properly in brains of people living with MSA. We will then investigate whether we can improve the cleaning out of alpha-synuclein in a cell culture dish model. After that I plan to continue in MSA research, and hopefully get fellowship funding so that I can continue to understand neuroinflammation and how alpha-synuclein behaves in MSA brain. The more we learn about what happens as MSA progresses, the closer we will get to disease modifying therapy.

It is only with the support of the MSA Trust and its supporters, and the generosity of brain donors that all this work is made possible, so thank you.” **MSA**

# NEWS ROUND-UP

## VAL FLEMING

It is with great sadness that we report the death of Val Fleming, one of the Trust's founders and greatest friends. He died peacefully at home after a long illness on 21st July. He was the rock on which the Trust was founded and he will be sorely missed.



When Val's great friend, Sarah Matheson, was first diagnosed with MSA they were both deeply concerned that there was no organisation dedicated to providing information and support to people with MSA in the UK. So together they set up the Trust – with a determination and dedication that was typical of both of them. That was in 1997.

In the years that followed Val worked tirelessly to grow the Trust, and expand the range of services our members deserve. He was for many years the Treasurer, ensuring sound management of our accounts and the increasing success of our fundraising efforts, but he did so much more as well. With his wise counsel and unflagging commitment he oversaw the establishment of the firm foundations on which the Trust has continued to expand and flourish ever since.

We owe him so much and will be forever indebted to him. We send our condolences to his wife, Elizabeth, and to his whole family. **MSA**

## ALL CHANGE

As you will have seen in Karen Walker's opening article we have moved offices, so please make a note of our new contact details:

### ADDRESS

51 St Olav's Court, City Business Centre,  
Lower Road, London SE16 2XB

### NUMBER

0333 323 4591 - (numbers starting 03 are  
charged at local rates in the UK)

We are also in the process of creating a new website. Our current site was designed in 2009 before tablets and smartphones were commonplace, and now needs a freshen up. We hope the site will be up and running by the end of the year, so look out for changes and let us know if you have any ideas or suggestions. **MSA**

## WHO NEEDS TO KNOW

We have had some feedback from members to say that they would find it useful to have a small pack that was easy to carry and take around to appointments or hospital visits. It would detail specific information about your needs and medication, and enable healthcare professionals to gain an initial understanding of MSA and how best to support you. Please let us know what you think about this idea and whether you would use a resource like this. **MSA**



# GOING MOBILE

“I felt like a racing driver, the wheelchair went so fast”

So said one of our Support Group attendees about a powered wheelchair she had been sold and had struggled to control.

One of the subjects that comes up on a regular basis at support groups and on our telephone service, is how to choose a suitable wheelchair if it's required.

The Trust has a leaflet which covers the range of mobility equipment that may be useful to you and you can download this at [www.msatrust.org.uk/wp-content/uploads/2014/06/FS131-Equipment-Posture-and-Mobility\\_v1.0.pdf](http://www.msatrust.org.uk/wp-content/uploads/2014/06/FS131-Equipment-Posture-and-Mobility_v1.0.pdf)

This article looks very briefly at what things you may need to consider when accessing a wheelchair.

There are a number of ways to get a wheelchair, including from the NHS, hiring or purchasing one.

You will need to think about the following:

Will it be self-propelled, electric powered or pushed by somebody else?

Is it for occasional use only and is it for indoor and outdoor use?

Will it need to be moved in and out of a car?

The design of a wheelchair will affect its use, so:

Has it got large rear wheels which make it easier to manoeuvre?

Is it lightweight and can it be folded or dismantled easily?

How comfortable will it be for longer term use?

NHS wheelchair services offer assessments to work out what type of wheelchair or mobility equipment you may be entitled to. You can be referred to the service by your GP, consultant or occupational therapist and it normally takes two to four weeks to get an assessment. It's worthwhile taking a carer, friend or your own therapist with you to help you make the right choice. A direc-

tory of wheelchair services in the UK is available online at [www.wheelchairmanagers.nhs.uk](http://www.wheelchairmanagers.nhs.uk).

In Ireland a useful link [www.isassistireland.ie](http://www.isassistireland.ie).

If you are considering buying or hiring a wheelchair or mobility aid then it is still worthwhile getting an NHS assessment. You may be able to get one for free, but they will also be able to advise which ones are most suitable.

Used equipment may be a better option for some people and the Scope website enables people to find and list used mobility and other disability related equipment to buy and sell. Look under the independent living section of their website for more information on this or call 0808 800 3333.

This is only a brief guide, go to [www.nhs.uk/Conditions/social-care-and-support-guide/Pages/mobility-equipment-wheelchairs-scooters.aspx](http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/mobility-equipment-wheelchairs-scooters.aspx) for further useful information -and do let us know how you get on. **MSA**

# A LETTER FROM OUR NURSES



*Dear Member*

We are asking you to host a **Milk, Sugar And Tea** party on or around World MSA Day, Saturday, 3 October, to raise awareness and much needed funds to deliver the Trust's vital MSA Nurse Specialist Services.

"My older sister died of MSA three years ago, and the thing I found hardest to cope with was the feeling of not being able to do anything to help. Raising money for the Trust has at least given me a chance to help other people and their families."- a MSA Trust member

As we travel the length and breadth of the UK and Ireland supporting families, we are constantly asked what they can do to raise awareness of the devastating disease that is MSA. Well, the fundraising team together with a few of you, have developed just such an event, one that all our friends and supporters can take part in.

All you have to do is register with us to host a **Milk, Sugar And Tea** party – our fundraising team will do the rest. You will receive our Tea Party Pack, with all the information and materials you will need to host a successful **Milk, Sugar And Tea** party. To register, please telephone 0333 323 4591, email [fundraising@msatrust.org.uk](mailto:fundraising@msatrust.org.uk) or visit our website at [www.msatrust.org.uk/getinvolved](http://www.msatrust.org.uk/getinvolved). It's that easy!

However, if you are unable to host a tea party, we would be grateful if you would consider making a donation towards the cost of our MSA Nurse Specialist Services. Thanks so much for your support.

*Jill, Samantha & Katie*

MSA Nurse Specialists

## JOIN OUR ONLINE COMMUNITY

More and more of you are communicating with us by social media and online through our new blog.

This is great as we want to talk to you in the way that suits you best.

We started blogging in June and it's proved an excellent way for our members, supporters and volunteers to get views and stories across.

Chris Blake's recent blog 'Being diagnosed with MSA at age 39' received 20 comments on the

website and reached over 4,000 people on Facebook. We know that MSA can cause isolation, so the more that people affected by the disease can connect, the better.

The blog has also proved useful in talking to you about NHS reform, changes to social care and government cuts. Services are constantly changing and we want you to know that the Trust is here to support you. If you need our help please let us know. You can reach us through social media, our web-

site, telephone and even traditional pen and paper – we just want to hear from you.

**Like us/follow us/talk to us on:**



**Multiple System Atrophy Trust**



**@MSAtrust**



**Multiple System Atrophy Trust**

# MEMBERS STORIES



## Douglas McBride – Winger for Rangers!

I set off for Glasgow, my hometown, to visit places I have not seen for many years. Little did I know this was to be one of my most memorable days ever, naturally only surpassed by my Wedding Day (my wife/carer may be reading this!)

Glasgow Rangers Football Club tops my itinerary, my team and heroes since childhood. Once outside Ibrox Stadium, my mind goes into overdrive, I go through the famous oak panelled doors. I ask the gentleman at the desk, “is it possible to be photographed at the doorway?”. “We can do better than that sir, would you like a tour of the stadium”. Barely controlling my emotions, I answer, “oh yes please”.

The guide escorts me around then I hear ... “Would you like to go out to the pitch?”. Wow! Suddenly I am being taken down



the famous tunnel, on to the pitch, and as if by magic, I am running down the wing, passing three players, I cut inside, I turn and shoot –GOOOAL! Well may be another day.... no this was my day!

Thoughts of famous footballers, the roar of the crowds,

for one brief moment in time my MSA did not exist, a miracle cure, if only it were that simple, no, adrenaline was that powerful medicine. Thank you to all at Rangers Football Club.

Walking in the footsteps of my heroes. **MSA**



# SERVICE OF LIGHT 2016

*Service of Light offers the chance for families and friends to remember and reflect on the lives of their loved ones.*  
Our annual Service of Light memorial events will be returning in **March 2016**:

We would love the MSA community to come together in a sensitive and meaningful way to celebrate the lives of those lost to MSA. We are asking for a voluntary donation of £10 for members to attend, with all proceeds going to MSA research.

**Saturday, 12 March 2016**

St Paul's Church, Covent Garden, London - 4pm

**Saturday, 19 March 2016**

St Ann's Church, St Ann's Street, Manchester - 3pm

Please visit our website or contact Melissa on 0333 323 4591 or email [melissa.tindle@msatrust.org.uk](mailto:melissa.tindle@msatrust.org.uk) for more details or to reserve your place.

## *In Memory*

Sandra Toft

Alexander Kennedy-Trench

Colin Hutton

Brenda Kemp

John Mitchell

David Jennings

Pauline Blance

Susan Reader

Edgar Appleby

Martin Daniels

David Playfoot

John Luca

Robert Forbes

Christina Yvon-Durocher

Michael McCarthy

Ronald Halsey

Jill Barrow

James Emblen

Paul Pemberton

David Powell

Elizabeth Seabourne

Teresa Dunkley

Robert Seaman

Michael Buckel

John Joll

Gary Cox

Tony Cripps

Eileen Porter

Patricia Stoney

Sheila Pickworth

Keith Fosker

# KNOW YOUR RIGHTS - BENEFITS



**Life with MSA can be costly – But help may be at hand.** Andy Barrick, the Trust's Head of Services looks into what you might be able to claim:

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Some of our Support Groups have found it useful to invite speakers along to talk about what benefits people with MSA and those caring for them might be entitled to. We know that living with MSA often incurs substantial additional costs and that it is therefore vital to make sure that, where applicable, people claim whatever support is available.

Whilst entitlement is based on individual circumstances, there are certain benefits that

people with MSA and those caring for them are most likely to be able to claim. These can be summarised as follows but note that due to benefits complexity this is guidance only and based on UK benefits:

## **SUPPORT FOR DAILY LIVING AND MOBILITY NEEDS**

For people who are under 65 and who need support, a benefit called **Personal Independence Payment (PIP)** can

help. It is for people who need help participating in everyday life or who find it difficult to get around.

It is tax free, is not means tested, not based on National Insurance contributions and is almost always paid in full on top of other social security benefits.

## **IT HAS TWO COMPONENTS:**

**A daily living component** - which looks at things like dress-

ing and undressing, preparing food, eating and drinking, washing, bathing, managing toilet needs and communication.

**A mobility component** – which looks at the difficulties people have in walking and moving around. The guidance suggests that any distance covered should be done safely, repeatedly and in a reasonable time period. This means that falls or risk of falls can also be taken into account.

For both elements you will need to have been experiencing problems throughout the three months prior to any claim. This can be waived in specific circumstances where a person is terminally ill (defined as someone whose death can be reasonably expected within six months) and can be dealt with under Special Rules.

Both components are paid at an enhanced rate and a standard rate and if somebody's condition gets worse they can go from the lower to the higher.

For the daily living component the current weekly rates are £55.10 for the standard rate and £82.30 for the enhanced.

For mobility, the rates are £21.80 and £57.45 respectively.

Claims can be made by calling 0800 917 2222 and the date of claim will be from the date of the call. Always have the relevant National Insurance numbers handy when you call.

For people over 65 **Attendance Allowance** can be payable to help with personal care or supervision in order to remain safe. Again if eligible the benefit is non means tested and

normally paid in addition to other benefits.

The qualifying conditions mean that you must have needed care for the six months before you claim but again Special Rules as mentioned earlier can apply.

As with PIP there are two rates, the lower weekly rate is £55.10 and the higher £82.30 and to claim call 0345 605 6055.

**Carer's Allowance** is a benefit for people who spend at least 35 hours a week caring for a severely disabled person. It isn't means tested and entitlement can give the carer National insurance contribution credits. Earnings of less than £110 a week do not affect Carer's Allowance.

Basic weekly rate is £62.10 but this can be added to if there are dependents. To claim call 0345 608 4321 (Northern Ireland 0800 220 674).

The rules about entitlement and how it relates to other benefits are a bit more complicated than PIP or Attendance Allowance so if you are unsure it is best to get advice, the Carers UK Adviceline can help on 0808 808 7777.

If you are on a low income you may be able to claim Income Support, Universal Credit or Pension Credit and entitlement to any of the above may increase these benefits. To meet housing costs you may be able to claim Housing Benefit, Council Tax Benefit and you may be eligible for certain grants for adaptations to your home from your local authority.

Also you can claim a reduction on your Council Tax

(and water rates in Scotland) if somebody in the home is substantially and permanently disabled and one of the following is met.

- there is an additional bathroom or kitchen needed by the disabled person; or
- there is a room (other than bathroom, kitchen or toilet) needed by or predominantly used by that person; or
- you have enough space in your home for that person to use a wheelchair indoors.

If you were entitled previously the reduction can be backdated for up to six years.

This is only a snapshot of some of the benefits that you may be entitled to. You can call us on 0333 323 4591 for basic information, but also look at the website [www.turn2us.org.uk](http://www.turn2us.org.uk). Turn2us provide an anonymous online benefits calculator and can provide other sources of financial support.

In Ireland you may wish to look at [www.citizensinformationboard.ie](http://www.citizensinformationboard.ie).

If you think you might be entitled then do claim. Millions of pounds worth of benefits go unclaimed each year, benefits which are specifically designated to support people struggling to cope with the demands of disability and long term illness, which can make lives both easier and fuller.

# HOW TO MARK WORLD MSA DAY? **PUT THE KETTLE ON!**

When Melissa Tindle joined the Trust this time last year, she was determined to start a community fundraising and awareness raising event that everyone, including people living with MSA, could get involved with. So a year later, to mark World MSA Day on Saturday, 3 October, we're delighted to launch our **Milk, Sugar And Tea** party.

## **JUST YOUR CUP OF TEA**

We want the tea party to suit everyone's needs – so that people who are passionate about raising awareness of MSA and funds for the Trust can make it their own event. So if traditional high tea, cocktails and nibbles, beer and a burger, or a cuppa with

crumpets is your thing that's fine with us. And if 3 October doesn't work for you, choose another date that fits in with your diary.

## **IT'S ONLY THE BEGINNING**

We see this as the first of many **Milk, Sugar And Tea** parties

and will look to build on the awareness and funds raised this October for many years to come. We are sure 3 October is already a key date in your calendar but we hope it's going to take on extra significance now. We believe that as our support and awareness grows, so will the tea parties.

Although 3, October isn't far away, we would be delighted if you held your tea party at any time during the month of October.

Our members and supporters are always asking what they can do to assist the Trust so, for the first time, we'll have an annual focus point that **everyone** can join in with. We want people with MSA, their families, carers and friends to have fun while raising money so that the Trust can continue to deliver vital services and fund research to find the cause, and one day, cure for MSA. It's also a great way to raise awareness which in turn can help ease the isolation so often experienced by people living with a rare disease.

We've obviously been busy during August and September promoting the tea parties on our website, Facebook, Twitter and in the media but if this is the first time you're finding out about it, don't worry, it's not too late to organise your own **Milk, Sugar And Tea** party. Get in touch and we'll send you a pack, including invites and donations boxes. However, if you can't host a tea party this October there's always next year. Put **Milk, Sugar And Tea** party, 3 October 2016, in your diary today.

For 2015, any money raised at your **Milk, Sugar And Tea** party should be sent to us before Friday, 27 November so that we can enter you into our prize draw.

### **FURTHER AFIELD**

Of course, it's not just us marking World MSA Day.



Partner organisations in North America and Belgium are also working hard to use the day to raise awareness.

The MSA Coalition will hold their annual conference in Seattle to coincide with World MSA Day and a celebration of light will be held at an evening reception on Friday, 2 October. Over 100 people will use LED candles to light up the room as a way of standing side by side with people affected by MSA.

In Belgium, our partner organisation, MSA-AMS, has invited and paid for our Interim Chief Executive Officer, Karen Walker, to be one of the key speakers at a conference on Friday, 2 October to mark World MSA Day. Other speakers include Dr Niall Quinn, a member of the Trust's Scientific Advisory Panel.

Karen's main focus will be how the MSA Trust works with health and care professionals to raise awareness about MSA so

that they can improve the care they provide to people with the disease. She said:

"I'm delighted that I have been invited to speak at this wonderful event and look forward to meeting with the organiser, Ritje Shouppe-Moons and other colleagues and healthcare professionals from Europe to share ideas and research; and to consider how we can work more collaboratively to improve the lives of the people we serve."

### **FINAL WORD**

If you're hosting a **Milk, Sugar And Tea** party, or lucky enough to be invited to one, we hope you have a fantastic time. Please send us your photos and tea party stories. Please remember to send any money raised to us before Friday, 27 November.

**THANK YOU. MSA**

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



## Brian Nisbet 1959 - 2015 Poet.

You may have seen an article about Brian in The Guardian during August. Here his wife Emily describes Brian's life and selects a poem that illustrates what a talent he was.

"Brian was an extraordinary person who filled the years since his 2007 MSA diagnosis with adventures, love, our wedding, friendships, the springer spaniel, trips across the world and Creative Writing at Oxford University. His acceptance of MSA was full of grace. There was no room for anger or frustration as he focussed on the many friends he gathered, meals to cook and enjoy, and the poems still to be written. I am so proud that he managed to publish his collection 'Now You Know' from his hospital bed, and made it back home to celebrate two launch parties. Brian had such fun in his last eight years. Though his poetry never denies the realities of the illness, it demonstrates above all that happiness, hope and

the potential to blossom are there even in the face of MSA.

'Now You Know' has been selected for the national collection at the Poetry Library ([www.poetrylibrary.org.uk](http://www.poetrylibrary.org.uk)).

'Now You Know' is for sale at £5:00 (plus £2:00, UK p&p) by email from: [emilywhite7676@hotmail.com](mailto:emilywhite7676@hotmail.com).

Also direct from Reception, Department of Continuing Education, Rewley House, Wellington Square, Oxford and Orb's Bookshop, 33a Deveron Street, Huntly, Aberdeenshire, AB54 8BY 01466 793765.

Further examples of Brian's poetry (including several set to music and read by Brian himself) can be found at [www.briannisbet.com](http://www.briannisbet.com)." MSA

### *Home is Where the Dog Is*

*Scruffy was a street dog  
with a smoker's bark  
tousled hair  
heart of steel;  
tried to conceal  
how much she cared.*

*Sleepy head Jake  
could spot a fake  
at fifteen paces.  
He knew mysteries,  
not least, the zen  
of dogginess.*

*Juno the turbo dog  
highly sprung  
propeller for a tail  
burr hung ears  
hose pipe tongue  
a chase me grin.*

*My pack over years  
ridiculously pleased  
to greet me,  
even in defeat.  
A man with a dog  
is never homeless.*

# ADVERTISEMENT



## ***Do you have patients diagnosed with Multiple System Atrophy?***

Multiple System Atrophy (MSA) is a rare, sporadic, progressive, neurodegenerative disorder of the central and autonomic nervous systems. Although the etiology of MSA is unknown, the generation of cytotoxic oxidants by the enzyme myeloperoxidase (MPO) may play an important role in the disease process. AstraZeneca is conducting a Phase 2 clinical trial with AZD3241, a potent, selective, brain-permeable MPO inhibitor .

The study, entitled “*A 12-Week, Multicenter, Randomized, Parallel-Group Study to Assess the Safety, Tolerability, Pharmacokinetics, Biomarker Effects, Efficacy, and Effect on Microglia Activation, as Measured by Positron Emission Tomography, of AZD3241 in Subjects with Multiple System Atrophy*” has started in the first half of this year. The study is double-blind and placebo-controlled, and will investigate two dosage levels of AZD3241. The study will be conducted at sites in the United States and Europe. Future studies are planned, including a study of longer duration focusing on safety and efficacy.

The primary objectives of this study are:

To assess the safety and tolerability of AZD3241 in subjects with MSA.

To determine the effect of AZD3241 on microglia activation, as measured by PET imaging of [<sup>11</sup>C]PBR28 binding at baseline and after 12 weeks of treatment (2 scans per subject), in subjects with MSA.

A secondary objective is:

To determine the biomarker effects of AZD3241 in subjects with MSA.

Exploratory objectives are:

To assess the pharmacokinetics of AZD3241 in subjects with MSA.

To assess the efficacy of AZD3241 in subjects with MSA. Exploratory efficacy outcome measures include the Unified Multiple System Atrophy Rating Scale (UMSARS), the Composite Autonomic Symptom Scale (COMPASS) Select Change Scale (CCS), and the MSA–Quality of Life scale (MSA–QoL).

Patients may qualify for the study if they:

Are 30-80 years old.

Meet criteria for diagnosis of possible or probable MSA (parkinsonian- or cerebellar-subtype) according to the consensus criteria.

Do not have significant neurological disease other than MSA that may affect motor or autonomic function.

Potential patient eligibility will be confirmed by an independent clinical expert. A Data and Safety Monitoring Board (DSMB) will monitor unblinded safety data on an ongoing basis to ensure the continuing safety of subjects. The study involves:

A participation period of approximately five months for each subject

Twelve weeks of treatment with study medication

Approximately twelve study visits, including two visits to one of five global PET centers

Imaging procedures, including the use of a radioligand

Physical and neurological examinations

Blood draws, ECGs, and vital signs assessments

Administration of questionnaires



***If you'd like more information and global clinical centers participating on this study please see [www.clinicaltrials.gov](http://www.clinicaltrials.gov).***

# SUPPORTING & HELPING EACH OTHER

Our Support Group network is vital to our members and is expanding rapidly year on year. Emma Rushton, our Support Services Officer, highlights some of the learning generated from the latest meetings...

**W**e currently have 35 support groups running across the UK and Ireland, with hopefully another by the end of the year. We have had two new groups start recently, in Worcestershire, North Yorkshire, and next month we will see our first group in Wales, held in Cardiff.

We couldn't keep the support groups going without our dedicated volunteers that not only facilitate the meetings, but also sort out the refreshments (or persuade others to do them!). We are always on the lookout for people who can volunteer at support groups, especially those that our nurses currently run and which we would love to secure a leader for. If you think this is something you would be interested in please contact me on the details below.

Now for the hints, tips and shared experiences:

At our Shropshire group there was discussion around where to find phones with large keypads. Members suggested that the Parkinson's UK website [www.parkinsons.org.uk](http://www.parkinsons.org.uk) had a range of different telephones with this option. In addition they also have a phone with a voice amplifier option and also computer keyboards with enlarged keys.

During both the Haltwhistle and Settle support groups questions were asked about who can help with filling out and completing ap-

plication forms for disability benefits and Continuing Healthcare. The Trust can offer basic advice on these but organisations such as Age UK, the Citizens Advice Bureau and Parkinson's UK can offer support with, and guidance when, completing these forms.

At the Belfast meeting, a member asked about using Botox to help with antecollis (when the person's head becomes fixed in a down and forward position). The advice was that if this affects you it may be worth asking your consultant for an assessment on whether Botox could be appropriate. However, be aware it might not be an option for everyone if the muscles causing the problem are not accessible to inject into.

We are more than aware that some members can't get to our support groups. To address this we are looking at the possibility of starting 'virtual' support groups, using web based services such as Skype or Adobe Connect. Please do get in touch if you might be interested or have any views on this. **MSA**

If you have any questions or would like to enquire about your local support group please contact me at [emma.rushton@msatrust.org.uk](mailto:emma.rushton@msatrust.org.uk) or call me on 0333 323 4591.



# MSA SUPPORT GROUP DIRECTORY

Local support groups are a great way to meet other people who understand life with MSA and we are expanding our network all the time.

Please contact Emma Rushton at the Trust's Office on **0333 323 4591** or email her at **[emma.rushton@msatrust.org.uk](mailto: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
Kent	Room B028, University of Greenwich, Central Avenue, Chatham Maritime, ME4 4TB	Thur, 1 Oct - 2.00pm
Cornwall	Echo Centre, Barras Place, Liskeard PL14 6AY	Mon, 5 Oct - 1.00pm
Fife	Burnside Hall, Balmullo KY16 0AW	Wed, 7 Oct - 1.30pm
Surrey Carer's lunch	Please contact the Trust office for more details	Thur, 8 Oct - 12.30pm
Worcestershire	Droitwich Spa Community Hall, Heritage Way, Droitwich Spa WR9 8YB	Fri, 9 Oct - 11.00am
Dorset	Trinity Methodist Church Hall, Southbourne Road BH6 5AQ	Mon, 12 Oct - 11.00am
East Yorkshire	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wed, 14 Oct - 1.30pm
Cardiff	Ty George Thomas Hospice, Whitchurch Hospital Grounds, Cardiff CF14 7BF	Wed, 14 Oct - 2.00pm
Lincolnshire	Franklin Hall, Halton Road, Spilsby PE23 5LA	Wed, 14 Oct - 10.30am
Cambridge	Barton Bowls Pavilion, High Street, Barton CB23 7BG	Thur, 15 Oct - 2.00pm
Essex	Great Tey Village Hall, Great Tey, Essex CO6 1JQ	Mon, 26 Oct - 2.00pm
Norfolk/Suffolk	Roydon Village Hall, High Road, Roydon, Diss IP22 5RB	Wed, 28 Oct - 2.00pm
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Fri, 6 Nov - 2.00pm
Northumberland/Cumbria	Greenholme Court Community Room, Greenholme court, Haltwhistle Hospital, Westgate Haltwhistle NE49 9AJ	Tue, 10 Nov - 1.30pm
Aberdeenshire	The St Mary's Centre, St Mary's Place, Inverurie AB51 3NW	Wed, 11 Nov - 1.30pm
Kent	Room B028, University of Greenwich, Central Avenue, Chatham Maritime, ME4 4TB	Thur, 12 Nov - 2.00pm
Cheshire	Allstock Village Hall, Chapel Street, Allstock, Knutsford WA16 9LN	Tue, 17 Nov - 11.00am
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Mon, 7 Dec - 1.30pm
Gloucestershire	Whitminster Village Hall, School Lane, Gloucester GL2 7NT	Thur, 10 Dec - 1.30pm
Surrey	Shalford Village Hall, Kings Road, Shalford GU4 8JU	Thur, 10 Dec - 2.00pm
South Yorkshire	St Peter and St Paul Church, Todwick, Sheffield S26 1HN	Wed, 16 Dec - 1.30pm
Somerset/Bristol	Locking Castle Church, Jasmine Way, Weston-Super-Mare BS24 7JW	Wed, 16 Dec - 1.00pm

# FUNDRAISING ROUND-UP

JUNE

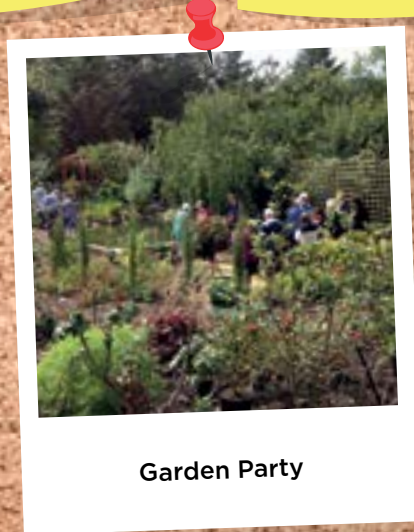
Oliver Davis put on his trekking boots and climbed Mount Kilimanjaro for the Trust raising over **£2,500**.

Andrew Oliver took on a Half Iron Man challenge successfully raising **£1,535**.

Congratulations to the new Mr and Mrs Rossiter who tied the knot and celebrated their nuptials, raising a whopping **£3,500** in aid of the Trust.



Andrew Oliver



Garden Party

## THINKING AHEAD

The MSA Trust Christmas Raffle – Christmas is only three months away and we are launching our 2nd Christmas Raffle by including a book of raffle tickets with your copy of MSA News.

Joyce Heath one of our winners last year said, “Thank you for the opportunity to win tickets to see David Hare’s ‘Beyond the Beautiful Forevers’. I took one of my sons with me and we both enjoyed it immensely.”

Prizes this year include a Weekend Log Cabin Break for two, National Theatre tickets, Luxury Christmas Hampers, Champagne and more. Please fill in your details on each ticket, and return the completed stubs along with any payment to MSA Trust, Christmas Raffle, 51 St Olav’s Court, Lower Road, London SE16 2XB. For more tickets, please telephone 0333 323 4591. Winners will be drawn and announced on Friday, 11 December 2015 and the winners will be notified.  
**Good luck!**

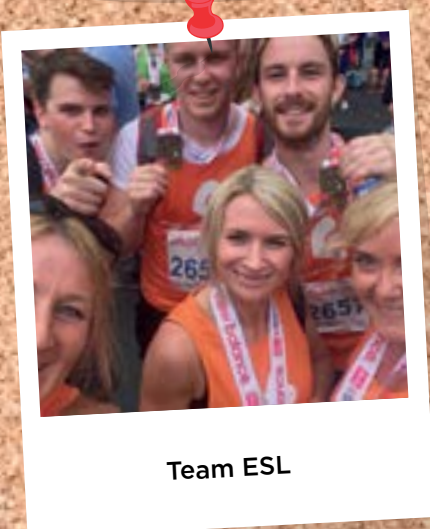


JULY

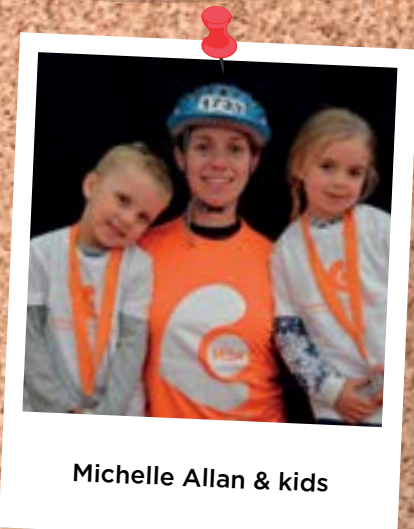
A very busy month. 13 runners including six staff from our corporate partner, ESL took on the Vitality British 10K raising over **£4,200** for the Trust. You can follow in their footsteps by signing up for next year's race.

Well done to Michelle Allan who cycled 50km in Scotland's Cycletta event, whilst her two children Lucy (five) & Matthew (three) donned their cycle helmets to take part in Scootathlon in memory of their Grandpa Sander. Collectively they raised **£500**.

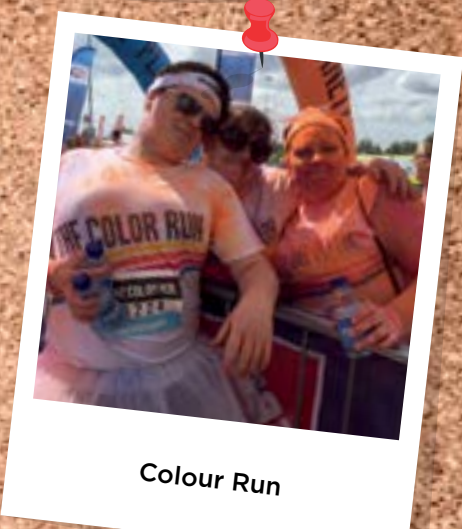
July was the month of the colour runs! We had three separate groups of fundraisers take on the Colour Run, Run or Dye and the Color Obstacle Rush bringing in **£800** for the Trust. Cosatto Ltd donated **£1,843.50** to the Trust, after staff member and Trust supporter, Sarah Alcock nominated the Trust to benefit from the company's quarterly charity profit share scheme.



Team ESL



Michelle Allan & kids



Colour Run

AUGUST

This year's RideLondon saw four cyclists brave the 100 mile route and raise nearly **£3,000** in the process.

John and Jeannette Mclean raised over **£800** by opening their beautiful garden to the public.

Many thanks to Sam Goodhind, who took part in the UK Coast to Coast Cycle Ride in memory of his grandad, Peter, raising **£860** and counting.

# MSA TRUST'S 2015 CHRISTMAS CARDS

NOW AVAILABLE TO PURCHASE!

This year we are also featuring a pack of Christmas Cards painted by acclaimed and award winning artist, Mrs Lulu Wong Taylor. Lulu was diagnosed with MSA in 2013. Please see the Back Page for this year's designs and order form.

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](http://www.msatrust.org.uk/get-involved) or email [fundraising@msatrust.org.uk](mailto:fundraising@msatrust.org.uk). If you are happy to do it, then we'll be happy to support you.

# SUPPORT THE TRUST THIS CHRISTMAS

Give a loved one a Christmas card and help raise awareness of MSA.



Village Scene



Robin in the Snow



Nativity Scene - By  
Lulu Wong Taylor



The Brightest Star

Our four designs each have a greeting inside reading:

*Season's Greetings and Best Wishes for the New Year*

Each Christmas card design comes in a pack of 10 and costs £4.00 plus postage and packing. Please see our cost table for prices if buying multiple packs. Return the slip below or order online at [www.msatrust.org.uk/our-shop](http://www.msatrust.org.uk/our-shop).  
**Thank you for your support.**

Pk(s)	1	2	3	4	5	6	7	8	9	10
<b>COST incl. P&amp;P</b>	£5.00	£9.30	£13.30	£17.80	£22.65	£26.65	£30.65	£34.65	£38.65	£42.65

## MULTIPLE SYSTEM ATROPHY TRUST CHRISTMAS CARD ORDER FORM

Name:.....

Address:.....

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

Village Scene (Qty):..... Robin in the Snow (Qty):..... Nativity Scene (Qty):.....

The Brightest Star (Qty):..... Total payment enclosed £.....