

MSA

NEWS



MSA Trust Members Magazine | ISSUE 46, 2016 | www.msatrust.org.uk

Onwards & upwards
to our **20th**
anniversary celebrations

Our growing
community of members

MSA RESEARCH
Here & spreading
around the world

From small acorns
G R E A T T H I N G S G R O W

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MEMBERSHIP AT JUNE 2016

Current MSA members 1,259
 Carers, relatives & friends 2,291
 Healthcare professionals 2,319

Total 5,869

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.**



RESEARCH UPDATE FROM OUR SCIENTIFIC ADVISORY PANEL <i>Part two</i>	04
NEWS ROUND-UP	05
KEEPING YOU INFORMED <i>What new Fact Sheets are available to you</i>	06
TRY OUT OUR NEW WEBSITE <i>Give it a go...</i>	07
ADVERTISEMENT	08
MEMBERS STORIES	09
IN MEMORY	10
INTERNATIONAL CONGRESS ON MSA <i>Worldwide research</i>	11
THE ROLE OF A COMMUNITY MATRON <i>How they can support you</i>	12
FUNDRAISING ROUND-UP	14
MEMBERS STORIES	16
20 TH ANNIVERSARY CELEBRATIONS <i>Help us celebrate this milestone</i>	17
SUPPORTING AND HELPING EACH OTHER <i>Members share their tips</i>	18
SUPPORT GROUP DIRECTORY	19

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WELCOME TO MSA NEWS



Karen Walker, the Trust's CEO, brings you up to date with what's been going on, and what will be going on, at the Trust.

Welcome to your latest edition of MSA News. As I write, I am looking forward to getting out to cheer on some of our keen marathon runners and eventers around the country. We always love to know if you are holding an event and where possible we will try to get a volunteer, a member of the office team or a Trustee to come along and support you and help make your event a success.

I am pleased to welcome a new member of our fundraising team, Ben da Silva, who has joined us to develop our corporate and individual giving. Ben is planning to get out and about and meet people so keep an eye out for him if you are at an event. The sad part to welcoming Ben is preparing for Joan Smith's departure to a well-earned retirement at the end of June. Joan came to the Trust as maternity leave cover for our Head of Fundraising and has ended up staying almost two years, doing a brilliant job and keeping us on the straight and narrow with fundraising regulation and best practice. I will have to make sure I have her on speed dial when she leaves! Thank you Joan for your hard work and dedication to the charity.

I would also like to mention our two office based Information and Services colleagues who have agreed to major changes to their roles within the Trust. I am delighted to let you know that Andy Barrick our Head of Services has accepted the role of Deputy Chief Executive, and Emma Rushton has moved into a new role of Information and Services Manager. These changes al-

low us to further develop the Services team to respond to our growing contact with people living with MSA, their families, carers and friends, health and care professionals. We now have almost 6,000 people on our database, all with a connection to MSA.

On a sad note, I would like to say how sorry we all were to hear of the death of Andrew Hulkes earlier this year. You may have read about him in previous editions of MSA News or seen him in the film about MSA we produced. Andrew worked tirelessly to raise funds for the Giger MD locomotion machine situated in Benfleet Physiotherapy in Essex, which can be used by anybody with MSA to help them exercise, a fitting legacy to him.

Finally, just a reminder that it's that time of the year when you need to start planning your next tea party. There's a slip to sign up for your pack on page 15 so please let us know where you will be having your **Milk Sugar And Tea Party** for World MSA day during October.

I hope you enjoy reading this edition of MSA News. **MSA**

Karen Walker
Chief Executive Officer

A MEETING OF (GREAT RESEARCH) MINDS - PART 2

This is the second of our reports on the recent Scientific Advisory Panel (SAP) prepared by the Board of Trustees Chair, Professor Clare Fowler.

Dr Aoife Kiely updated us on her progress working in the Queen Square Brain Bank (QSBB) with Professor Janice Holton. Inflammation in the brain is mostly brought about by the activity of a group of cells called microglia. Although one group of microglia are probably harmful, there are others which have restorative effects. It has been shown that the numbers of microglia in the brains of those who have died of MSA are increased. Aoife has been looking at whether these large numbers of microglia are aggressive or helpful types. It appears that **both** types are increased, leading to questions about the particular inflammatory environment in MSA. The British Neuropathological Society (BNS) funded a study allowing Aoife and colleagues to use NanoString technology looking at genes involved in inflammation in MSA and healthy control brains. They found that 13 genes were significantly altered in MSA brains. The remainder of this BNS funding will enable the further investigation of these genes.

Aoife also gave a progress report on a collaborative investigation being carried out between the QSBB and the Neuropathology Department at Bristol University considering why abnormal amounts of alpha synuclein accumulate in MSA brains. She is using protein analysis and refined microscopy techniques to look at whether these enzymes are present at healthy levels and whether they are in the right locations to be working properly. She has extracted material from parts of the brain where alpha synuclein is known to accumulate and sent these precious samples to Bristol

who will be using new techniques to measure the activity of those enzymes.

Prof Henry Houlden then reviewed research by Dr Lucia Schottlaender who began investigating a gene called COQ2 after it was reported to be a possible genetic cause of MSA for some Japanese patients. Although initially Lucia found no changes in the COQ2 gene in MSA brains, this did spark her interest. The protein COQ2 works in the mitochondria, which makes the energy for the cell and while doing so makes another protein called COQ10. Lucia measured the levels of COQ10 in different regions of the brain connected with MSA. Interestingly, COQ10 is significantly decreased in the cerebellum (the organ of balance and known to be much affected) in MSA compared to other conditions.

Dr Sandrine Wauters is continuing to investigate whether mitochondria are working properly in MSA. Sandrine has tested the activity of the individual components of the electron transport chain (ETC), a chain of proteins which work together inside mitochondria to make energy. By examining each of these proteins, Sandrine is able to see if there is a weak link in this chain in MSA. Interestingly she has found the most significant weakness seems to be with protein chain members working with COQ10, an exciting confirmation of Lucia's work. The consequences of low availability of energy in parts of the brain include the start of what can be a domino effect of damage to the cell and surrounding tissue. **MSA**

NEWS ROUND-UP

Neurological Alliance Questionnaire

In June and July please look out for a survey that we hope people with MSA will want to participate in.

The survey, the second of its type, is currently being finalised by the Neurological Alliance and its member organisations (including us). It is intended to develop a picture of the experiences of people living with neurological conditions, covering key issues such as diagnosis, health care, social care and access to benefits. The survey will be used primarily to improve understanding of neurological conditions and identify the areas requiring improvement. It will apply to people living in England only.

We will put references to this on our social media at the time but if anybody wants to flag up interest now, please contact us and we will make sure you get a copy of the survey when it is ready to roll. The previous survey helped us get a good picture of the circumstances of people living with MSA so we hope as many of you as possible will be able to complete this new one. **MSA**

Lucky Lottery Racing

Lucky Lottery Racing is a new and innovative way to support the MSA Trust and other causes, whilst giving you a chance to win cash prizes! Lucky Lottery Racing was launched through the Obscure Disorder and Disease Support Society (ODDSS), as a way to help raise funds for the MSA Trust. Eric Armitage lost his battle with MSA in March 2015 and his family including his wife, Angela and brother Stewart, aim to raise £1million for the Trust in Eric's memory. For further information on how you can get involved and raise much needed funds for MSA research, please visit the website at www.luckylottery racing.co.uk, Twitter: lucky lottery racing @Llroddss and Facebook: ODDSS Lucky Lottery Racing. Good Luck and Happy Racing! **MSA**

New MSA Clinic Opens In Southampton

This month sees the opening of a new specialist clinic for people with MSA in Southampton. Two Neurology Consultants, Dr Boyd Ghosh and Dr Luke Massey, will be seeing patients from Hampshire, Dorset and Wiltshire in this clinic, although people from other areas would be welcome. Based in the Royal South Hants hospital, it will cater for people with any atypical Parkinsonian condition. The aim of the clinic is to provide excellent care for people with MSA, with as much community support as possible. Although it has just started, they hope to involve therapists, community teams and nurses from the areas that people come from in the clinic. This close working will foster the strong links needed to provide better care for people with MSA close to home. Jill Lyons and Samantha Pavey, our two MSA Nurse Specialists for these regions, will be participating in the clinics as a first step to providing the continuity of care that is so important.

If you want to know if there is a similar clinic available to you in your area, do contact your MSA Nurse Specialist who will be able to advise how you might get a referral and discuss the best options for you. **MSA**



KEEPING YOU INFORMED

By providing you with an ever growing range of information the Trust aims to keep responding to members' needs. Andy Barrick looks at new publications produced in the last few months that are now available to you.

We have had a busy time lately reviewing all our factsheets and developing new resources based on the issues you ask us about. We now have 25 factsheets for people affected by MSA and have also just produced two additional Guides for Health Professionals, one for Speech and Language Therapists and the other for Occupational Therapists.

As mentioned elsewhere in this edition all of these are available online or on request from the Trust.

Here's some highlights of the new or updated resources:

Although the Government thankfully backtracked on proposals to change the benefits assessment for Personal Independence Payment we are still aware that many people are not claiming the benefits to which they are entitled, and which can make a real difference with the extra costs incurred through living with MSA. Our new leaflet on Basic Benefits and Entitle-

ments outlines what you could be claiming and signposts you to sources of further help and advice.

In the last MSA News we looked at how hospice support can contribute to overall wellbeing and our revised leaflet Palliative Care builds on this by explaining what support might be available and how to access it.

We are also often asked about what people can do to manage how they are feeling and take more control of their health needs. Our new factsheet Complementary Therapies explains how treatments might enhance a sense of physical, spiritual and mental wellbeing. Although complementary therapies are in no way meant to be an alternative to prescribed medications or treatments, many people tell us they do feel a benefit, enabling them to feel more able to cope. There are many complementary therapies covered such as Pilates and Tai chi as well as homeopathy, massage and art

therapy. There is also a section that explains how to make sure you access therapies safely and from reputable therapists.

Finally we have also developed a resource around relationships, sex and MSA. This is an area that can often have a significant impact but can be difficult to talk about and discuss. This factsheet explains what some of the most common issues are, why they happen and also suggests how people may address these and who else can help.

To access any of these and to find out what other publications we produce please visit our website, www.msatrust.org.uk or contact the office on 0333 323 4591. **MSA**

If you have any suggestions for any other information resources you would find useful please let us know and we will do our best to meet your needs.

TRY OUT OUR NEW WEBSITE

To coincide with MSA Awareness month, the Trust launched our new website. Andy Barrick outlines what's available and why members should make it a "favourite" bookmark.

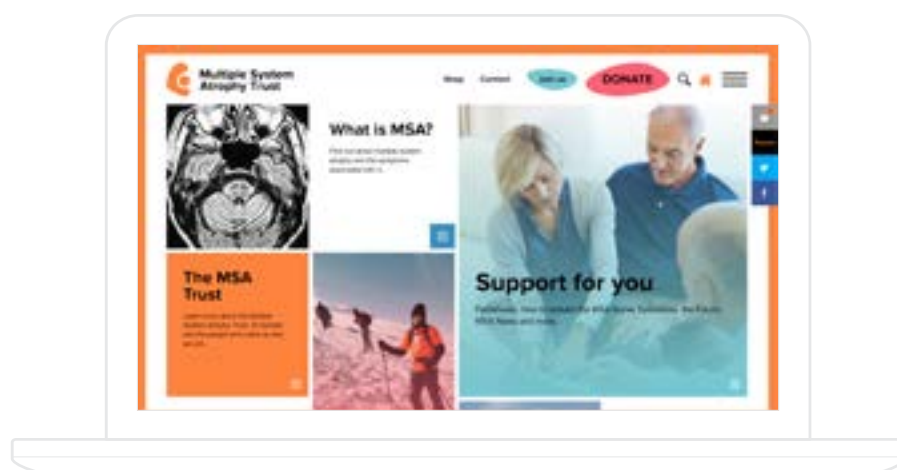
Our original website was built in 2009 and was starting to show signs of its age. We therefore decided to give it a complete overhaul and introduce new features and sections.

If you haven't had a look lately do have a browse as you are bound to find something of interest or relevance to you.

First, there is a whole host of information about MSA and about specific symptoms and management. This ranges from basic information (useful to point friends and family in this direction if they need an explanation of what MSA is) to more detailed information, such as equipment or therapies that can help. All our factsheets are on our website for you to download as and when you need them.

There is also a section on **Local Support** where you can find out about when your Support Group is meeting and other nearby events.

As you would expect we also have a section about the Trust and how you can get involved, both as volunteers, and in sup-



porting us raising funds for our work and research.

The **What's New** section has latest news and blogs and we also have a section specifically for **Health and Care professionals**.

Last, but not least, we have our **Forum**, where you can ask questions and share ideas with one another. Topics range from just being diagnosed to treatments, health and wellbeing and issues around caring for people with MSA. Since we transferred over to the new site participation has dropped so why not have a look and get involved yourself? You will find out how

others deal with things as well as being able to support members with the invaluable experience you have picked up.

Simply follow the instructions about registering and setting up or changing passwords for the Forum, but don't hesitate to contact us if you need more help with this.

For those of you who really, really don't want to use the internet our phone line will always be available for you.

But for those of you who can, please take a look, get involved and tell us what else you would find useful. **MSA**

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MEMBERS STORIES

During Carers week in June we celebrated all of you who dedicate yourselves to caring for people living with MSA. One of these is Chris Ryan, wife and carer for her husband Richard. Chris writes about how they try to find the humorous side of the situations they find themselves in...

Years of searching for the causes of a multitude of odd symptoms came to an end last March when my husband was diagnosed with MSA.

This was a condition we had never heard of, and after googling it, wished we never had. I'm sure there will be difficulties ahead and times when we don't find much to laugh at, but I will do my damndest to try to find humour wherever I can. It can be found in unlikely events, and my husband passing out in the shower was one such.

Low blood pressure not infrequently causes him to pass out, so we have a shower routine to minimize the risks. While he showers, I get undressed in the bathroom, and then we swap places. That way I am always around.

On the day in question I had just completed undressing when he gasped my name and proceeded to crumple into an un-

tidy mound in the shower tray. I managed to slide the door of the shower open and turn off the shower. He was out like a light and didn't come round as he usually does when he becomes horizontal. Although the time he was unconscious could probably have been measured

“
Thank goodness, before I could make a decision about what was the correct etiquette for dealing with collapsed husbands, nakedness and ambulance crews, he came round.
”

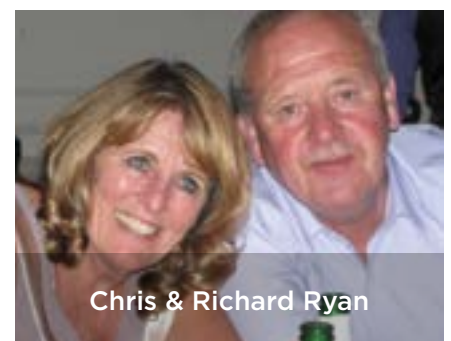
in seconds rather than minutes, it was long enough for my mind to run through what should happen next.

If I was going to ring 999, should I then return to stay with my prone husband and thereby be forced to answer the door to the ambulance crew draped in a towel, or do I go and get dressed, leaving my husband in a heap in the shower all alone, which seemed a bit heartless. If I opted for the former and the medics suggested

I go with my husband, would they wait while I got dressed or insist I went as I was. It really only takes seconds for all this to whizz through your brain.

Thank goodness, before I could make a decision about what was the correct etiquette for dealing with collapsed husbands, nakedness and ambulance crews, he came round.

We still have the same routine, but a stool in the shower has thankfully diminished his propensity for passing out. It wasn't funny at the time, but the pictures it conjured up were, on reflection, rather amusing. **MSA**



Chris & Richard Ryan

YOUR REMARKABLE SUPPORT

MSA TRIBUTE FUND

Ben da Silva reflects on his impressions so far and launches MSA Tribute Fund.

I recently joined the Trust in April, taking on responsibility for individual giving and working with companies to develop partnerships. From day one I was astounded by the energy and generosity of you the members and how you continually support the Trust and all the work we undertake.



Ben da Silva

I have been particularly overwhelmed by the generosity of our members after the sad loss of a loved one, as I know how hard it can be to find the strength and energy at such a difficult time. Setting up a Tribute Page can be a lasting way to remember the life of someone special and raise much needed funds for the Trust. **MSA**

Welcome to the MSA Tribute Fund, where you can create a positive memorial of your loved ones. You can create a page by visiting www.msatrust.org.uk/memorygiving. You will be able to add photographs, poems and messages. Once you have created your Tribute Page, do remember to share with family and friends asking them to leave a gift in memory.

For help or further information please telephone me on 0333 323 4591 or email fundraising@msatrust.org.uk. **MSA**

In Memory

Steven Margrave
Brian Tomlinson
Lulu Taylor
Joan Hawton
Peter Johnson
Stephen Robinson
Theresa Dicker
Ernest Holloway
Christy Campbell
Ann Shellum
Christine Martin
Sally Winder

Findlay Wilson
Colin Davison
Edna Dean
Nona Clout
June Punnett
Joan Golby
Rashmikant Parikh
Adrian Turner
Alison Collins
Caroline King
Ruthven Whisker
Sylvia Pinner

Robert Vassen
Brian Cridlin
Jean Curtis
Edith M Symons
Selina Nicholson
Andrew Hulkes
Duncan McNaught
Margaret Appleton
Joan Hawton
Margaret Hennessey
John Flavell
Rita Redmond

Anne Spink
Linda Howe
Vivienne Owen
Jeremy Knapp
Paul Norman
Christine Hood
Ramesh Patel
Tony Morss
David Tolson



INTERNATIONAL CONGRESS ON MSA

Jill Lyons, one of our MSA Nurse Specialists, was invited to speak at a recent conference in Italy. Here she tells us what it was all about...

I was delighted to attend the 15th International Congress on Multiple System Atrophy in Salerno, Italy in April. The Congress was held at the Fondazione Ebris, which is in fact, on the site of the first recorded medical school dating back to 900AD. I attended along with 133 other international delegates to hear the latest from the key researchers and clinicians with a special interest in MSA from all over the world. There were representatives from support associations from France, Belgium and the MSA Coalition from America who also sponsored the event.

There was an extensive poster display of 33 posters featuring the current studies of researchers from all over Europe as well as South Korea, Mayo Clinic USA, Serbia and Montenegro, Israel, Japan and Australia. It was great to talk to the researchers who answered questions on their research studies.

This included a study on swallow and speech difficulties in MSA and their relationship to quality of life. Others included genetic studies and studies of gait looking at a piece of equipment that monitored gait to see if it was an early diagnostic indicator.

The congress comprised of four sections. First on the Friday, five talks on the pathogenesis of MSA, and second a series of five sessions on MSA registries and networks concluding with a session I presented on MSA Trust support and nurses in the UK and Ireland. This session was well received and it was encouraging to note there are also specialist nurses in France and USA. We often get international enquiries so it was good to meet the representatives of the support groups from other countries. People from many countries visit our website and translate our fact-sheets so we would always en-

courage other organisations to develop their own services if able.

On the Saturday the sessions were on imaging and biomarkers and therapies and future therapies. These included very interesting sessions on managing sleep related problems and issues arising from autonomic body functions, including postural hypotension. The meeting concluded with oral presentations of the abstract submissions.

The congress included a social dinner at the Castle of Alechi - a wonderful setting (shame it rained) and an opportunity for the MSA community to get to know each other while enjoying the local food. Many thanks to all those involved in funding and contributing to such a productive conference and it is very encouraging that so much is happening across the world in relation to MSA. **MSA**

THE ROLE OF A COMMUNITY MATRON

Community matrons are experienced, skilled nurses who are there to help people living with a long term condition such as MSA. Our MSA Nurse Specialist, Samantha Pavey, discusses the role with Rachel North who is a Community Matron in Bedfordshire.

What is the role?

The role of a Community Matron is to support people to live independently and to prevent hospital admissions. They do this by planning and organising care for people with long term or complex conditions. They work with patients in their own homes, residential homes and nursing homes. They take care of patients' physical, mental, emotional and social needs by working closely with a range of health and social care professionals, voluntary services and carers. They also act as advisors for other nursing staff and have the opportunity to train and mentor junior colleagues.

What sort of things do they do?

The role may involve:

- carrying out physical examinations
- deciding on and carrying out treatments, or referring patients to appropriate specialists
- checking patients' conditions and providing an advanced nursing assessment of their care needs
- managing the care and support that patients receive
- identifying patients who may be at risk of being admitted to hospital when they don't need to be
- managing services to make sure that the focus of care is in the home and community for as long as possible
- teaching patients, carers and relatives to spot changes that could lead to conditions getting worse
- organising extra support, such as home care or respite care
- making sure that policy guidelines and procedures are followed
- maintaining accurate and up-to-date patient records.



Rachel North, Community Support Matron

Question & Answer...

What made you decide to work in the Community Matron (CM) role?

Whilst working as a District Nurse I was offered the opportunity to take part in a pilot project working as a Practice Matron in a Doctor's in Dunstable. Being successful, this is now a permanent position in which I offer a community based, proactive response to complex long term conditions and social problems. I seek to improve care in order to reduce the level of unplanned hospital admissions and to make sure people can get early appropriate discharge from hospital. Whilst people under the age of 75 are generally not eligible for inclusion on my caseload, my professional judgement allows flexibility with this.

What long term conditions do most of your clients live with?

I care for clients with several long term conditions in addition to MSA, such as chronic obstructive pulmonary disease, heart failure, Parkinson's Disease, dementia and frail older people at risk of falls and deterioration of their general health. I offer support to bereaved clients and their family and carers and am available for general advice and support.

Had you come across anyone with MSA before the person you are currently supporting?

No as MSA is quite rare it

was a condition I hadn't come across before. This has been a great learning curve and I have had excellent support from the MSA Nurse Specialists.

What do you find most satisfying about your role?

I feel privileged to be able to visit clients in their home environment and love the rapport you get working with people and their families. My job allows me to provide holistic care and I enjoy liaising with specialist nurses and other agencies in order to help support people to manage better and promote their independence. Additionally being GP practice based means that I get to know people well and am highly visible to them and everybody else who works here. This really helps communication on a daily basis and means I am well placed to pick up 'opportunistic' work as it arises. I am also able to access client information (with their permission) and help to initiate tests promptly.

And most frustrating?

The most frustrating aspect of my job are the time constraints. However when I encounter these I prefer to think of them as challenges and that means I am constantly learning - which can only be a good thing!

Thanks Rachel.

Most areas in the UK will have a Community Matron in post, but unfortunately this is

not the case for all areas. You should ask your GP if there is one in your area, and if there is, ask if you can be referred.

If you would like any more information please do contact the MSA Nurse Specialist for your area:

MSA Nurse Specialist (NORTH)



Katie Rigg

01434 381 932

katie.rigg@msatrust.org.uk

MSA Nurse Specialist (EAST)



Samantha Pavey

0203 371 0003

samantha.pavey@msatrust.org.uk

MSA Nurse Specialist (WEST)



Jill Lyons

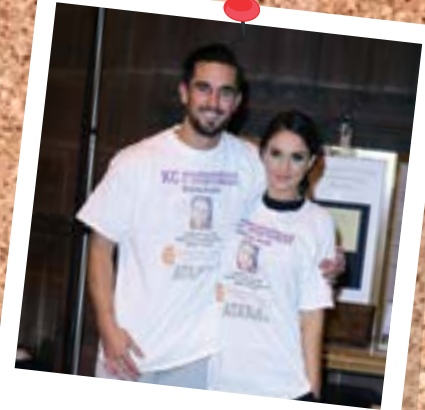
01934 316 119

jill.lyons@msatrust.org.uk

FUNDRAISING ROUND-UP

Elizabeth Francis completed her #30in15 Challenge, which saw her complete 30 running events in 2015 raising **£2,485**.

Judge Geordie star Alex Cannon and reigning "I'm a Celebrity" winner Vicky Pattison, valiantly abseiled down Liverpool Cathedral raising nearly **£3,500** for the Trust and bringing national media exposure for our work.



Alex Cannon & Vikki Pattison

MSA Trust Trustee Helen Craik hosted a rare films film night and tea party raising over **£1,100**.



Helen Craik - Film Night

University student Sam Wheeler accomplished "50 Dry Days" without alcohol and raised **£775** in the process.

We kicked off MSA Awareness Month with "Where are you Wearing Your Orange". We received great photos from all around the UK and even Australia and New Zealand.



#MSA Orange in Oz

The month of marathons! We had three runners battle the Brighton Marathon raising over **£5,000**. The London Marathon also took place with 9 runners smashing our **£20,000** target.

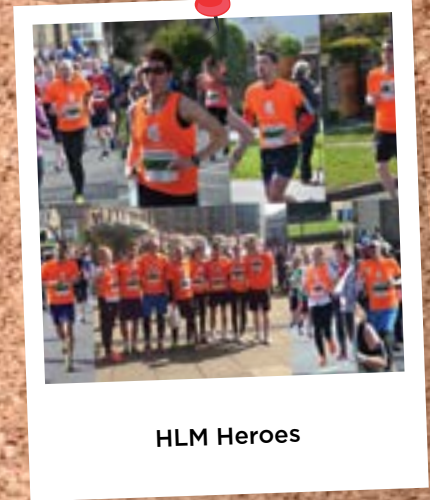
Laura Lipinski held a Craft & Gift Fair raising **£500**.

Two beautiful Service of Light events were held in London and Manchester in memory of our loved ones who we have lost to MSA.



Service of Light

The HLM Heroes, also known as the HLM Architects raised **£1,425** after completing the Sheffield Half Marathon. Nicky Shaw said "We all enjoyed the run and I'm bowled over with the amount of support we've had and the amount of money we raised for the MSA Trust".



HLM Heroes



Steph Wilkes, family & Nan

Steph Wilkes and family took part in the ever popular Color Obstacle Dash raising **£416** in support of their Nan who has MSA.

Repeat fundraiser Ali Bisson cycled from Whitehaven to Whitley Bay raising nearly **£2,000**.



MILK, SUGAR AND TEA PARTY IS BACK!

3rd October 2016 is World MSA Day and we'd love for you to join us in hosting a **Milk, Sugar And Tea Party** to raise vital funds in aid of the MSA Trust. Whether it's you and a few friends at a family gathering or at your work or school, it's a great excuse to get together. Get started and order your pack today! Email us at fundraising@msatrust.org.uk or complete this tear-off and send back to us.

I would like to host a Milk, Sugar And Tea Party and order my pack

Name:.....

Address:.....

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

Email:.....

Where will you host your tea party: Home Work

School/University Other.....

When will you host your tea party: World MSA Day

Other.....

(Please complete and return to MSA Trust, 51 St Olav's Place, Lower Road, London SE16 2XB)



20TH ANNIVERSARY CELEBRATIONS 2017

We're gearing up for our 20th anniversary celebrations. Karen Walker explains why you should too!

It hardly seems possible that the MSA Trust has been in existence for nearly 20 years. We are so proud of the work we have been able to achieve with your invaluable support including:

- developing a growing community that supports people living with MSA, their carers and families, increasing knowledge and reducing isolation
- a research network that shares understanding and information on how MSA progresses and factors that could influence it's development
- the implementation of an awareness strategy that helps to educate, inform and equip health and care professionals so that they can better help people affected by MSA

So we are planning to celebrate the long road we have come along together since Sarah Matheson, our founder, and her closest friends established the charity in the her sister's front room in London all those years ago. But because there is so much more to be done, we also want to use this opportunity as a springboard to re-double our efforts to develop our work for those affected by MSA.

Whilst we are in the planning stages of our celebrations, we would love to hear any ideas you may have on how you think we can make our 20th anniversary truly special. **MSA**



CELEBRATE & GIVE

In celebration fundraising is a simple, personal way to celebrate a special occasion and it is the perfect alternative to receiving a gift. Whether it's a birthday, wedding, or a new baby, your special event could help raise money for MSA. Let us know when you are celebrating and we will send you our fundraising materials. Email us at fundraising@msatrust.org.uk or complete this tear-off and send back to us.

Name:.....

Address:.....

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

Email:.....

- I will be celebrating my:**
- Birthday Wedding Milestone Anniversary
- Retirement Other.....

(Please complete and return to MSA Trust, 51 St Olav's Place, Lower Road, London SE16 2XB)

MEMBERS STORIES

A lighted hearted take on living with MSA written by our Cambridgeshire Support Group Leader Elizabeth Koe...

Just Out Of Reach

My husband brings me a welcome cup of coffee, made just how I like it. He puts it down carefully on the table next to me. It smells lovely, but there is a problem, the handle faces away from me - just out of reach!

One of our dogs comes to say hello, and promptly rolls on her back for a tummy tickle. You guessed it, just out of reach. I try a tummy rub with my foot. This does not go down well. Ah well, I try again but...

Modern living requires 'walk about' telephones. These are a nightmare since ours have developed legs, and...

Bother, I've dropped the stylus I was using to write this but I think I can just get it with my foot. Clumsy me, I've pushed it Just-Out-Of-Reach!

SUPPORTING & HELPING EACH OTHER

With 36 Support Groups across the UK and Ireland, members continue to share a wealth of information. Emma Rushton, the Trust's Information and Services Manager has been keeping her ears open and shares a taste of what's been going on...

With a record number of Support Group meetings held already during the first half of this year you can find out about plans for the next six months by visiting our website www.msatrust.org.uk. A map will locate the Support Group closest to you and also a calendar with all the events planned. As ever, please call us in the office on 0333 323 4591 and we can give you further details.

Our Cornwall Support Group recently visited the Mobility Centre in Truro to find out what was on offer to people with MSA. Mobility Centres give advice on many different types of equipment ranging from items such as foam handled cutlery and non-slip mats, to larger items including wheelchairs, titling chairs and bath aids. Staff can give demonstrations and also run workshops to help with any adaptations needed. To find your local mobility centre visit www.mobility-centres.org.uk.

A member at the Inverurie Support Group explained at their last meeting that they had bought suction fix grab rails and a portable fold down bed rail to take on holidays and breaks away. These had come in helpful when staying new accommodation, which although accessible had needed specific personal tweaks. You can buy both these pieces of equipment from various outlets with many options online from web-

sites such as www.amazon.co.uk.

The Cambridge Support Group arranged for a speaker from the Carers Trust to talk about the services available. Key advice was to find out if your County Council provides any emergency planning schemes for caring. In Cambridgeshire they have an option of signing up to a scheme where 48 hour emergency replacement care for the person you are caring for can be provided if you become unwell. To find out more about this please visit www.carerstrust.org.

At both West Sussex and County Durham Support Groups there were discussions around difficulties applying for NHS Continuing Healthcare. This is an important but complex area. Our MSA Nurse Specialists are happy to support applications and there is a brief guide to Continuing Healthcare in issue 45 of MSA News.

For more information on anything mentioned here or about invites to Support Groups please contact Emma in the Trust office. **MSA**

Emma Rushton - Information & Services Manager
0333 323 4691 or
emma.rushton@msatrust.org.uk

MSA SUPPORT GROUP DIRECTORY

Local support groups are a great way to meet other people affected by MSA and healthcare professionals that can support you.

Please contact Emma Rushton at the Trust's Office on **0333 323 4691** 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.

DATE	VENUE	DATE & TIME
Oxfordshire	The Girl Guide Hall, Southern Road, Thame OX9 2EE	Mon, 20 June - 2.00pm
South Yorkshire	St Peter and St Paul Church, Todwick, Sheffield S26 1HN	Wed, 22 June - 1.30pm
Greater Manchester	St Andrews Church, Hope Centre, 27 Tattersall Avenue, Bolton BL1 5TE	Thur, 23 June - 1.30pm
Cornwall	Echo Centre, Barras Place, Liskeard PL14 6AY	Mon, 27 June - 1.00pm
Dundee	Day Hospice, Roxburghe House, Jedburgh Road, Dundee DD2 1SP	Mon, 27 June - 4.00pm
Gloucestershire	Whitminster Village Hall, School Lane, Gloucester GL2 7NT	Wed, 29 June - 1.30pm
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Fri, 1 July - 2.00pm
Aberdeenshire	Community Room, Tesco Store, Harlew Road, Inverurie AB51 4SR	Fri, 1 July - 1.30pm
County Durham	Chester Le Street Hospital, Day Room, Front Street, Chester Le Street DH3 3AT	Mon, 4 July - 1.30pm
Worcestershire	Droitwich Spa Community Hall, Heritage Way, Droitwich Spa WR9 8YB	Mon, 4 July - 11.00am
East Yorkshire	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wed, 6 July - 1.30pm
Cardiff	Ty George Thomas Hospice, Whitchurch Hospital Grounds, Cardiff CF14 7BF	Wed, 13 July - 11.00am
Kent	Room B028, University of Greenwich, Central Avenue, Chatham Maritime, ME4 4TB	Thur, 14 July - 2.00pm
Surrey Carer's lunch	Please contact the Trust office for more details	Thur, 14 July - 12.30pm
Dorset	Trinity Methodist Church Hall, Southbourne Road, Bournemouth BH6 5AQ	Mon, 18 July - 11.00am
Lancashire	Neuro Drop in Centre, Stone Row Head, Lancaster Farm Estate, Lancaster LA1 3QZ	Fri, 12 Aug - 1.30pm
West Sussex	Worthing Quaker Meeting House, 34 Mill Road, Worthing BN11 5DR	Tue, 23 Aug - 2.00pm
Northumberland	TORCH Centre, Corbridge Road, Hexham NE46 1QS	Thur, 1 Sept - 11.00am
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Mon, 5 Sept - 1.30pm
Leicestershire	Village Hall, Main Street, Swannington, Coalville LE67 8QL	Tue, 6 Sept - 11.00am
Surrey	Shalford Village Hall, Kings Road, Shalford GU4 8JU	Thur, 8 Sept - 2.00pm
Surrey Carer's Lunch	Please contact the Trust office for more details	Thur, 15 Sept - 12.30pm
Southport	St James Church Hall, Lulworth Road, Birkdale PR8 2BQ	Thur, 15 Sept - 2.00pm
Wiltshire	St Paul's Church Hall, Malmesbury Road, Chippenham SN15 1PS	Mon, 19 Sept - 2.00pm
South Yorkshire	St Peter and St Paul Church, Todwick, Sheffield S26 1HN	Wed, 21 Sept - 1.30pm
Worcestershire	Droitwich Spa Community Hall, Heritage Way, Droitwich Spa WR9 8YB	Mon, 3 Oct - 11.00am
North London	Southgate Hockey Centre, Snakes Lane, London EN4 0PS	Tue, 4 Oct - 2.00pm

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