MSA NEWS

MULTIPLE SYSTEM ATROPHY TRUST | MEMBERSHIP MAGAZINE

▸ ISSUE 40, 2014 | WWW.MSATRUST.ORG.UK

VOLUNTEER COORDINATOR APPOINTED

Building an army of support

Carer's Guide

Hints, tips & practical advice

2ND MSA RESEARCH SYMPOSIUM

~ Optimism grows ~

MSA NEWS EDITOR:
Neil Hunter

ALL CORRESPONDENCE AND ENQUIRIES TO:
Multiple System Atrophy Trust
Southbank House, Black Prince Road
London, SE1 7SJ
Tel: 020 7940 4666
www.msatrust.org.uk

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MEMBERSHIP AT JUNE 2014

Current MSA members	1,065
Carers, relatives & friends	1,771
Healthcare professionals	2,071
Total	**4,907**
New MSA Members since 1 February 2014	71

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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

There's been a lot happening in the world of MSA since the last magazine hit your doorsteps.

An international group has formed with the purpose of developing a global roadmap for MSA related research that will hopefully provide a framework to find new therapies for people with the disease. In Europe, researchers from neighbouring countries have secured significant, five year funding from the EC to look at the development of imaging technologies for therapeutic interventions in rare diseases. Closer to home, the Trust has just launched its 2014 grant round having increased our annual commitment to a minimum of £150,000 and on pages 9-11 you can read our report of the second UK MSA research symposium.

There's also been a fair bit happening at the Trust too. After three years as Trustee Board Chairman Mike Evans is standing down and will be handing over the role to fellow Trustee Professor Clare Fowler. Mike has been a Trustee for over ten years and will, I'm pleased to report, be remaining on the Board in that capacity for a few more yet. He has worked closely with myself and our small staff team in helping to shape the charity so that it is well placed to continue supporting you now and in the future. Clare, who is Emeritus Professor of Uro-Neurology and practised at the National Hospital for Neurology and Neurosurgery in London, has been a Trustee for the past three years and has vast experience of both research and caring for people with MSA. The Trust continues to grow and for this reason we have created the new role of Vice Chair, this time round with the portfolio of our new committee responsible for many things, including finance and HR. Past Support Group Leader and Chair of our Services Committee, Karen Walker, will be taking on this role having been a Trustee for four years. I'm also delighted to report one final change to our Trustee Board, the addition of Professor David Burn from Newcastle who is also the Chairman of our Scientific Advisory Board who advise the Trust on research grant applications.

Sadly we've said goodbye to Lyn Shaw who will, I'm sure, be known to many members. Lyn, whose husband Graham had MSA, was a long-time supporter of the Trust and Essex Support Group, and had volunteered her services before taking up her role as Information and Support Officer. We wish her well for the future. Finally, and by no means least, we welcome on board our latest additions to our staff team, Jill Lyons our new MSA Specialist Nurse covering Wales and the West of England and Emma Myers who takes on a brand new position of Volunteer Coordinator. Based in the East Midlands, Emma will be working hard to increase our community presence to build funds and awareness.

Exciting times ahead!

Nickie Roberts
Executive Director - Mission

VOLUNTEER PROJECT

We are delighted to announce that Emma Myers will be joining us at the Trust as Volunteer Coordinator to help build an army of support. This is a key step in bringing closer community involvement. Head of Services, Neil Hunter reports:

Emma will be responsible for developing regional volunteer groups to raise awareness, fundraise and to provide local service knowledge. Each region, probably a county or half a county, will have a team of volunteers overseen by a lead volunteer. Emma's role will be to recruit, train and support these lead volunteers in developing regional teams.

As a small but national charity one of our main challenges is to deliver strong local support and to raise awareness about MSA in local communities. It is a big task to recruit and mobilise a "volunteer army" and this year we are starting with eight areas.

We hope to signpost members to appropriate local services and maximise local fundraising to help us deliver more support and raise awareness of MSA throughout each county and country within the UK. This will help increase knowledge of the health and social care professionals and reduce the isolation of those living with MSA.

Executive Director, Nickie Roberts, said "our move towards building a large volunteer network represents an exciting new era for the Trust. I know there are many people keen to help by offering their time. It is through engagement at a local level that we hope to make a real difference to people living with MSA".

More details of the volunteer roles, and the scheme in general, will appear on the Trust's website in the coming weeks. If you are interested in finding out more please get in touch with Emma. You can contact her by emailing: office@msatrust.org.uk or by calling 020 7940 4666. **MSA**

> "I've been working in the voluntary sector for over 10 years delivering support services to young people. A great deal of this time has been spent working with volunteers supporting fundraising, operations and delivery for The Prince's Trust, a national youth charity. I am passionate about the impact volunteering can have on a community and very excited by the opportunity to work for the MSA Trust."

Emma Myers

NEWS ROUND-UP

TRUST'S 2014 MSA RESEARCH GRANT ROUND GOES LIVE

The next round of MSA Trust funding for research grants opens in July. This year we have increased the research pot by 50% to £150k affirming our commitment to finding the cause and ultimately the cure for MSA. Full details are available on the Trust's website, along with a copy of the charity's updated Research Strategy. **MSA**

WALES FAMILY & FRIENDS DAYS

A family and friends day will be held in Wales on 23 October 2014 at the Future Inn hotel in Cardiff. The day, organised by the Trust, is open to people living with MSA, their family and friends. It will offer a chance to hear from various health professionals about managing MSA and provide an opportunity to meet other people living with the condition. The day runs from 10.00 am to 3.30 pm, is free and includes a buffet lunch. If you would like to book a place, or would like to know more, please get in touch with the Trust on 020 7940 4666 or visit our website www.msatrust.org.uk. Places are limited so please book early to avoid disappointment. **MSA**

TRUST RESEARCH GRANT RECIPIENT AWARDED PROFESSORSHIP

Janice Holton has become Professor in Neuropathology and Director of London's Queen Square Brain Bank. Professor Holton's Trust funded research has been looking at the underlying mechanisms of disease in MSA for the past five years. She is currently looking at the role of the CoQ2 gene in MSA. **MSA**

FIRST NEUROLOGICAL PATIENT EXPERIENCE SURVEY AIMS TO IMPACT ON CARE

The Neurological Alliance, of which the Trust is a member, has produced a patient experience survey - the first of its kind for neurological conditions. A report on the survey's findings will be published at the end of the year to provide a comprehensive picture of what is happening in relation to neurological services nationally. It will be a vital tool for the Alliance and the wider neurological community for raising awareness of neurological conditions, and providing a baseline for measuring progress in services. The survey will be open from the end of June to around mid-September. More information will be available through the Neurological Alliance website: www.neural.org.uk. **MSA**

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

FATIGUE IN **MSA**

Very little has been written about fatigue in multiple system atrophy (MSA) but we do know that it is a symptom that affects many people living with the condition.

Fatigue is more than just tiredness after a hard day; it is more an overwhelming sense of exhaustion and lack of energy. It can have a significant effect on your ability to deal with day-to-day activities and can also affect your cognitive ability, speech, psychological wellbeing, relationships and mood. It is really important to look at ways of managing fatigue in MSA.

RECOGNISING FATIGUE

If you feel you may be affected by fatigue a useful way to check is to see if you have six or more of the following symptoms:

- Diminished energy or increased need to rest, disproportionate to any recent change in activity level
- Complaints of general weakness or limb heaviness
- Diminished concentration or attention
- Decreased motivation or interest in engaging in usual activity
- Insomnia or hypersomnia (excessive sleep)
- Experience of sleep is unrefreshing or un-restorative
- It feels like a real to get moving or get on with a task
- Overwhelming emotions around feeling fatigued
- The feeling of difficulty with short-term memory
- Post-exertion malaise (feeling out-of-sorts) lasting several hours

WHAT CAUSES FATIGUE

The causes of fatigue can be endless and it is quite often listed as a symptom for most diseases and conditions. We don't yet know what causes it in MSA but it is likely to be a number of factors related to your other symptoms. These symptoms fall into four general areas: physical, emotional, environmental and biological.

PHYSICAL ASPECTS – WHICH MAY INCLUDE:

Deconditioning: Having MSA means a greater effort is needed to be mobile, this can lead to deconditioning of the muscles and the cardiovascular system which in turn can lead to fatigue. It is important you talk to your physiotherapist about this.

Lower blood pressure: May well cause fatigue and should be checked and treated where possible. The Trust has factsheets advising about blood pressure and dealing with postural hypotension.

Sleep disturbance: Sleep problems are common in MSA due to pain, anxiety or urinary difficulties and sleep disturbance is another factor in fatigue. Talk to your GP or specialist about managing these symptoms.

Extra effort: Having MSA will impact on your energy levels and this will make everyday tasks such as washing, dressing, and getting out of a chair a little more difficult than you are used to. This in turn could contribute to fatigue.

EMOTIONAL ASPECTS – WHICH MAY INCLUDE:

Low Mood /Depression: This should be assessed and treated. Low mood can lead to less motivation to be active, which can in turn lead to fatigue. It is important that you talk to your GP or specialist about this.

ENVIRONMENT ASPECTS - WHICH MAY INCLUDE:

Environmental causes may include:

Lighting: Poor lighting causes increased visual effort which can cause fatigue.

Temperature: Extreme temperatures can cause fatigue

Noise: Too much auditory stimulation can cause fatigue

BIOLOGICAL ASPECTS – WHICH MAY INCLUDE:

Medications: It is important to monitor if any changes to medication make fatigue worse. Make a note of any medication changes and any changes in fatigue and discuss these with your GP or specialist.

Infection: Any infection can make MSA symptoms worse and so it is important to be aware of the risk of infection and treat promptly. It is important to note that a lack of a high temperature does not rule out the possibility of infection.

MANAGING FATIGUE

If you think you are suffering fatigue ask your occupational therapist to assess this and help you develop a management plan. They will also need to liaise with other members of the care team.

You might also want to consider the following lifestyle changes to help ease your fatigue:

Exercise and nutrition: A good balanced diet and as much exercise as you are able may help combat fatigue. You should speak to a dietician about your diet and a physiotherapist about what safe beneficial exercises. And remember to drink plenty of water, this is so important for many aspects of MSA and is known to help fight fatigue.

Planning and delegating: It is important that you pace activities and allow plenty of time for rest. Don't be afraid to accept help or delegate things to others, either family and friends or outside agencies. It is difficult to ask for help but the people around you will be happy to support you.

Mood and anxiety: Easier said than done but try avoiding stress, identify the things that cause stress and work out ways to reduce the problem; an occupational therapist will help you here. If the fatigue is caused by low mood then it might be worth considering therapy or even medication, you should talk to your GP about this.

The key message here is that lots of people will be able to help you with your fatigue. It isn't something you have to battle alone and it is something that may be managed. Sometimes the smallest of changes can have a big impact, so consider the above and talk to your care team or speak to our Specialist Nurses. MSA

The Trust has a fact sheet with more information on Fatigue in MSA, it can be downloaded from the website or contact us for a copy: 020 7940 4666 or office@msatrust.org.uk.

FUNDRAISING IN MEMORY

Many people have told us that making a donation in memory of a loved one has been a positive way to commemorate their life, while at the same time helping the Trust to support other people with MSA.

Often families decide to have a collection at a memorial service or funeral, asking friends to make a donation instead of sending flowers. Should you wish to do this, the Trust can provide special envelopes to make this as simple as possible.

Katie Heyward, the Trust's Head of Fundraising says: "Making a gift to the Trust in memory of your loved one may be a way to celebrate their life, and at the same time bring much needed hope and support to all those affected by this awful disease, both now and in the future. Your donation will be gratefully received and used wisely."

Should you wish to discuss your wishes with us, please call Katie on 020 7940 4134 or email her at katie.heyward@msatrust.org.uk. **MSA**

In Memory

Peter White
Michael Stammers
Arthur Berry
Brian Woodward
Jennifer Brett
Graham Revill
Allan Walling
Stan Clarke
Doreen Blakeman
Alan Milner
Peter Parnell
Pascal Betto
Sue Sullivan
Margaret Crabbe
Philip Chadwick
Mike Lawrence
Keith Dyson
Elmarie O'Reilly
Elfriede Bailey
Kenneth Storry
Geoffrey Giddings
Keith Walkley
June Brown
Carol Wells
Pietro Viale
Mary Hepworth
Alison Carnall
George Murphy
David Childerley
Katherine Smith
Phil Lipinski
Kay Farley
Michael Mills
Maureen Dutton
John Mawer
Christopher Edgley
Barry Denham

2ND MSA RESEARCH SYMPOSIUM

MSA RESEARCH AND CLINICAL INTEREST - 27 FEBRUARY 2014

Clinical Neuroscience Centre, Queen Square, London.

On February 27th researchers gathered for the second MSA research symposium. It built on the optimism generated from the first meeting in November 2011 and revealed that research is much more closely relevant to those who are living and coping with MSA on a daily basis than you might think. John Telford reports:

The meeting heard talks from 14 of the leading experts in MSA from around Europe. There was a lot covered from MSA essential characteristics to its management, and from the measurement of its progression to treatments that could target its underlying causes.

SHORT HISTORY OF MSA

Professor Niall Quinn started by giving an historical run down of the development of understanding of MSA. Dr Janice Holton described what has been discovered to date about the pathology and how it relates to clinical symptoms while Dr Helen Ling went through the 'life history' of the condition. As well as the two main forms of MSA known as MSA-P (because it has symptoms in common with Parkinson's disease) and MSA-C (because it involves the cerebellum and other structures at the top of the brain stem), recent studies have revealed a long duration, less aggressive form.

MSA is a notoriously difficult disease to diagnose with only a 75% diagnostic accuracy, often being confused with Parkinson's, PSP, and various ataxias. The progressive nature of the disease means treatment has to be constantly revised. This was highlighted in a talk by Dr Janesh Panicker on urogenital dysfunction. In short, the problems start with overactivity in the muscles which empty the bladder causing urge incontinence but progress to incomplete voiding and retention and finally affect the sphincter muscles. The drugs which are initially useful to control the earlier symptoms need to be replaced by different ones for the later symptoms.

BENEFITS OF EARLY INTERVENTION

The management of MSA in all its other aspects was the theme of Professor Huw Morris's presentation and he stressed the need for an accurate diagnosis as early as possible so that the right treat-

ment can be given. Anxiety is often caused when health professionals struggle to diagnose in the early stages of symptoms. Without a specific diagnosis the best treatment cannot be prescribed. Hence the need, said Professor Morris, for improved identification of MSA and its differentiation from other atypical parkinsonisms. Progress has been made in recent years but the resulting diagnostic techniques are still to work their way down to all clinics.

This touches on another theme which emerged in the meeting which was the importance of information. The patient has a role not only in receiving it but also providing it. For example, systematically capturing symptomatic information right from the start enables the constantly progressing condition to be monitored allowing treatment to be given as soon as it becomes necessary. Conversely improvement is needed in the availability of information in the surgery and clinic relating to MSA, the MSA Trust and MSA nurses.

GREATER PATIENT INVOLVEMENT

But there is another vital aspect to information. MSA is a comparatively uncommon disease but progress in understanding it, treating it and eventually preventing and curing it requires the study of as many patients as possible drawn from the relatively small number affected. Valid conclusions can only be drawn from a sufficiently large number of cases. This is to do with statistical significance and is especially true for genetic studies. As Professors Henry Houlden and John Hardy told us, techniques such as Genome Wide Association Studies rely on large numbers of cases to identify genetic variations which may be linked to a predisposition to a disease. Patients and families often express a wish to help others who come after them and encouraging and facilitating them to participate in research studies, and for researchers to provide the opportunities to participate, is certainly something that could beneficially be stepped up. Better pre-diagnosis, diagnosis, maintenance care, palliative care, optimised care planning and development of disease-modifying treatment all require people to put themselves forward to participate in research studies. This includes seriously considering bequeathing tissue to brain banks that have research interests in MSA.

There were three presentations on gathering biological information from people with MSA. Dr Alex Gerhard spoke about advances in neuroimaging in MSA that will help with finding out what is going on in the living brain. Neuroimaging has limitations with regard to diagnosis but has significant power in monitoring changes and correlating the structural and metabolic changes with symptoms. It can also be used to image the inflammation in the brain associated with MSA which may help determine whether reducing this inflammation by medication could slow disease progression.

BIOMARKERS TO AID UNDERSTANDING

Biochemical changes in people with MSA are reflected in changes in substances in the cerebrospinal fluid (CSF), which is the fluid that surrounds the brain and spinal cord. Like imaging, accurate ways of measuring the levels of such substances and changes in them could potentially enable disease stage and progress to be accurately monitored. This is particularly important when new treatments are developed in order to know how effective they are in slowing down or stopping the disease. Observable and measurable substances or physical states are known as biomarkers and the identification of good ones is currently an important objective in all areas of neurological disease. Dr Nadia Magdalinou spoke about recent CSF studies and went through the various substances that were present in CSF that could be good biomarkers for MSA either singly or in combinations. Good progress was being made in discovering which biomarkers enabled MSA to be distinguished from other conditions and in determining their patterns of change as the disease progresses.

In parallel with the efforts in the imaging and biomarker fields, repositories for information and biological samples are being actively set up.

> “a database and biobanks in seven centres are being planned under the new, MSA Trust-funded UK-MSA Network. These would be built up as expanding resources with open access for all who are conducting research into MSA. This will benefit investigations into the development of better and earlier diagnosis, identification of markers of disease progression, and the discovery of effective treatments.”
>
> **Professor David Burn**

It is a promising framework through which all patients can be offered the opportunity to make a tangible contribution for the benefit of others to come.

FUTURE DIRECTIONS

With a sound infrastructure for MSA research through such collaborative, patient-involved networks we can be forgiven for having a good measure of optimism. More is known about the disease now than ever before and there is greater collaborative effort and knowledge-sharing. This is good news for future advances in understanding MSA. Professor Gregor Wenning presented details of how he has been able to reproduce the mechanics behind the misfolding of the alpha-synuclein protein responsible for MSA. This advance may help target research into treatments at some point. This optimism was echoed by Professor Maria Spillantini whose team are investigating how existing drugs for similar conditions may bring effective treatments for MSA to the clinic faster owing to safety testing for them already having taken place.

COLLABORATION THE KEY

Professor Clare Fowler, member of the Trust’s Board, brought the symposium to a close by highlighting the amount of money the MSA Trust puts into research. But the charity is comparatively small and so Professor Fowler emphasised the theme of collaboration. The meeting had demonstrated the spirit of enthusiastic collaboration amongst the researchers. But since it was becoming more apparent than ever that there was a common biopathology amongst neurodegenerative diseases we should encourage and look toward a greater number of joint research projects with larger, and better funded, charities like Parkinson’s UK so that the limited financial pot can achieve optimal benefit for the whole neurodegenerative disease community. **MSA**

For a full write up of the symposium, visit the MSA Trust website or contact the office on 020 7940 4666 or by email at office@msatrust.org.uk.

CARERS CORNER

CARER'S GUIDE

We are delighted to announce the launch of our new Carer's Guide designed to help you get the right information about caring for someone with MSA. It offers practical tips, advice and signposting on where to get further support. Here, author Kathryn Gilbert, provides a brief glimpse of what is contained in the Guide:

LOOKING AFTER YOURSELF AND THE PERSON YOU CARE FOR

If you look after someone with MSA, you'll know that caring is often physically and emotionally demanding. It's only natural to want to put the needs of the person with MSA first, but it's really important that you think of yourself too. After all, if you don't look after your own health and wellbeing, you won't be able to provide the best possible care and support.

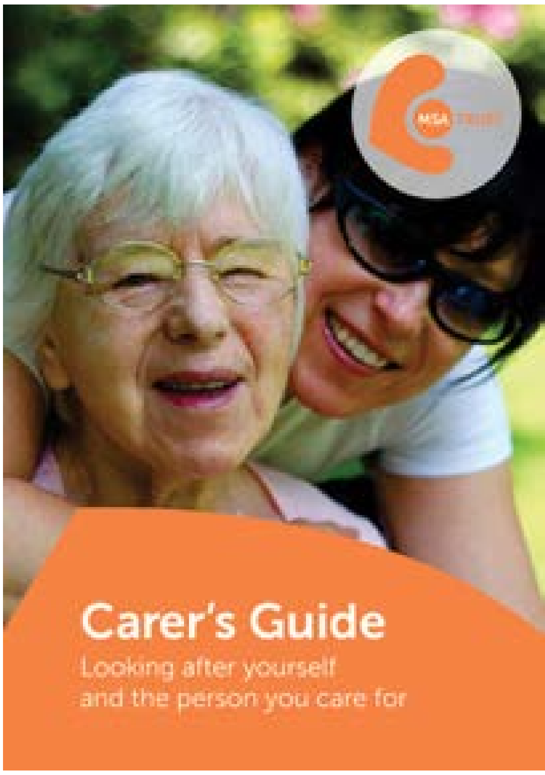
This is why we've developed a new Carer's Guide especially for individuals who look after someone with MSA. It covers some of the worries or problems you might face if you're a carer. Perhaps most importantly, it also tells you about the different types of support that are available to you and how to access them, including contact details for different organisations.

> "Lots of carers carry on as if it's their duty, or feel guilty if they have to ask for help. But you have a right to ask for that support."
>
> **Samantha Pavey, MSA Trust Nurse Specialist**

Generally speaking, the guide is divided into three sections:

GETTING HELP WITH PRACTICAL THINGS

This section covers topics such as respite care (including how hospices can help), the carer's assessment and employment. It also offers an overview of the benefits and allowances you may be entitled to – statistics show that 49% of carers struggle financially because of their caring role*.



Carer's Guide

Looking after yourself
and the person you care for

STAYING HEALTHY AND STRESS-FREE

Looking after someone close to you when they need care can be very rewarding, but it can also be stressful and exhausting at times. This section looks at how important it is

> "Our journey of looking after mum has brought guilt, anger and despair at times. But spending time with her is now more precious than ever, and the best advice we can give is just to cherish it as much as possible."
>
> **Andrew, cares for his mum**

that you eat well, stay active and get enough sleep, with tips to help you.

LOOKING AFTER YOURSELF

Recent figures have shown that 61% of carers have faced depression because of their caring role*. Looking after the way you feel is just as important as looking after your health, and this section offers advice on how to do that – whether it's by attending support groups or simply taking breaks every now and again.

> "I wish we had something like this when mum was diagnosed as there was little information given to us"

Each section includes first-hand accounts and advice from other carers and professionals. Additionally, each section ends with a summary of the main points – providing everything you need to know at a glance. Here are a few tips to give you an idea of what's included:

Register as a carer with your GP – Most practices offer priority appointments for carers.

Keep doing something you enjoy – This might be going to work, or something as simple as reading, gardening or walking. Do anything that makes you happy, even if it's just for a few hours a week.

Don't forget to drink – Dehydration can lead to headaches and irritability, but it's easy to forget to have a drink when you're busy looking after someone else. Try to drink eight glasses of water a day.

Offload everyday tasks – If you aren't keen on the idea of getting someone else in to provide care, think about which everyday tasks you could pay someone else to do – such as the housework or DIY, or mowing the lawn. Or you may have family, friends or neighbours who are willing to help out for free.

TO ORDER YOUR COPY

If you care for someone with MSA, or if you know someone who does, and would like a copy of the new Carer's Guide please contact us on 020 7940 4666 or at office@msatrust.org.uk. The Guide is also be available for download from our website at www.msatrust.org.uk. **MSA**

* Carers UK statistics - State of Caring 2014, www.carersuk.org

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

Katie Rigg
(North of England, Scotland & Ireland):
01434 381 932

Samantha Pavey
(East of England):
0203 371 0003

Jill Lyons
(West of England & Wales):
01934 316 119

FUNDRAISING ROUND-UP

The Trust's first Service of Light event was held during MSA Awareness Month in March and we are delighted to report that it was a huge success, raising in excess of **£11,000** towards MSA research. Our fundraising team, Katie Heyward and Louise Trott report:

Although an occasion to remember those we have lost to MSA, the event in London's Covent Garden provided a lovely opportunity for people who have been through the same journey to come together and celebrate the lives of those lost. "I want to thank you for Saturday – it was a lovely service. It was very emotional, as I expected it would be but it was really good. The young lady who spoke so eloquently about her mum, echoed all our feelings. The music was wonderful and well performed. I am so glad that we came. It was tremendous. Well Done." Based on your feedback, we will be holding two services next year; in London on Saturday 21 March 2015 and in Manchester at St Ann's Church on Saturday 7 March 2015.

A TRIATHLON WITH A TWIST...

After losing her dad to MSA on Christmas Day, Anna Gardner has decided to undertake a huge challenge for the Trust. First up is a non-stop 100km walk from London to Brighton; she will follow this with a 100km cycle ride; and will end her adventure with a 100km swim. Anna has already raised over £2,000 for the Trust, and you can follow her progress at: www.justgiving.com/AnnaPGardner.

MARATHON FUNDRAISING

This year saw six supporters take on the Brighton Marathon, raising an amazing £10,943 between them. Just one week later, another 10 brave souls took on the London Marathon and smashed all previous Trust records, raising an astonishing £25,847 in total! Special mention to Becky and Emma Knowles who raised almost £6,000 in the Brighton Marathon, Dave Findlay for raising £4,248 in the London Marathon and Andy Humphrey who raised £6,300 by running the London Marathon in a mankini. Well done to you all.

STREET COLLECTIONS

Jill Roberts of Bournemouth has booked four street collections throughout the year to raise funds and awareness for the Trust. Could you do the same? All you have to do is contact your local council and arrange some convenient dates and we will provide you with collection tins and all you need to get started.

OPEN WATER SWIM

The idea of swimming 3km in open water is not a usual goal for a lady of nearly 70 years of age. That is, unless you are Jen Dale, who did just that to raise money for MSA research. Setting herself a target of £1,000, Jen has managed to surpass it with donations to date of almost £1,400. A tremendous achievement, congratulations.

Rochdale Ball

Jen Dale & Family

Anna Gardner

Dave Findlay

Service of Light

GROWING SUPPORT AT GRASSROOTS

Our official corporate partner Klondyke Garden Centres did us proud during MSA Awareness Month in March. All 24 stores raised valuable funds and awareness through selling our wristbands, custom MSA Trust poppy seed packets, and orange cakes in their on-site cafes. We are grateful to staff and customers who helped raise £3,063. Thank you.

MASQUERADE SUCCESS

April saw a new event in our calendar, a Mandarin Masquerade Ball organised by Beverly Wrigley from Rochdale, whose brother Eric Armitage has MSA. The inaugural event was a huge success, attended by almost 100 guests consisting of representatives from the Trust, friends, family and professionals involved in Eric's day-to-day care. The event raised in excess of £2,700, and it is hoped that the theme of the evening will be adopted and replicated by other supporters throughout the country. We are pleased to say that Beverley is already working on her plans for the 2015 Ball in Rochdale. MSA

GET INVOLVED

If you, your friends or your family would like to get involved in fundraising for the Trust, we would love to hear from you. Please call the fundraising team on 020 7940 4666 or email fundraising@msatrust.org.uk. **Thank you.**

MSA SUPPORT GROUP DIRECTORY

Local support groups are a great way to meet other people who understand life with MSA. Please contact the Trust's office on 020 7940 4666 or email office@msatrust.org.uk for more details.

GROUP	VENUE	DATE AND TIME
Oxfordshire	The Girl Guide Hall, Southern Road, Thame, Oxfordshire OX9 2EE	Mon, 14 Jul - 1.00pm
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Fri, 4 Jul - 2.00pm
Cambridgeshire	St Mary's Church, Church Street, Buckden, St Neot's PE19 5TL	Wed, 9 Jul - 2.30pm
Kent	Room B028, University of Greenwich, Chatham Maritime ME4 4TB	Thur, 10 Jul - 2.00pm
Cornwall	The Old Cattle Market, Porthleven Road, Helston, TR13 0SR	Thur, 24 Jul - 2.00pm
Yorkshire (East)	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wed, 30 Jul - 1.30pm
Fife	Burnside Hall, Balmullo KY16 0AW	Wed, 6 Aug - 2.00pm
Gloucestershire	Whitminster Village Hall, School Lane Gloucester GL2 7NT	Wed, 6 Aug - 1.30pm
Inverurie	The St Mary's Centre, St Mary's Place, Inverurie AB51 3NW	Fri, 8 Aug - 2.00pm
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Mon, 1 Sep - 1.30pm
Southport	St James Church Hall, Lulworth Road, Birkdale PR8 2BQ	Thur, 11 Sep - 2.00pm
Warrington	Fairfield and Howley Neighbourhood Project, WA1 3AJ	Fri, 12 Sep - 2.00pm
Oxfordshire	The Girl Guide Hall, Southern Road, Thame, Oxfordshire OX9 2EE	TBC
Lincolnshire	TBC	Sep: TBC
London (North)	Southgate Hockey Centre, Snakes Lane, London EN4 0PS	Mon, 15 Sep - 2.00pm
West Midlands	Moxley People's Centre, 3 Queen Street, Moxley WS10 8TA	Wed, 17 Sep - 1.00pm
Surrey	Shalford Village Hall, Kings Road, Shalford GU4 8JU	Thu, 18 Sep - 2.00pm
Wiltshire	St Paul's Church Hall, Malmesbury Road, Chippenham SN15 1PS	Mon, 22 Sep - 2.00pm
Northumberland	TBC	Wed, 24 Sep
Yorkshire (South)	St Peter and St Paul Church Hall, Todwick, Sheffield S26 1HN	Wed, 24 Sep - 1.30pm
West Sussex	Field Place - Pavilion Room, The Boulevard, Worthing BN13 1NP	Tue, 30 Sep - 2.00pm
East Midlands	Holme Pierrepont Hall, Holme Pierrepont NH12 2LD	Wed, 15 Oct - 2.00pm
Kent	Room B028, University of Greenwich, Chatham Maritime ME4 4TB	TBC
Greater Manchester	TBC	Tue, 21 Oct - 1.30pm
Essex	Great Tey Village Hall, Great Tey, Essex CO6 1JQ	Mon, 27 Oct - 2.00pm
Norfolk/Suffolk	Roydon Village Hall, High Road, Roydon IP22 5RB	Wed, 29 Oct - 2.00pm
Yorkshire (East)	Etton Village Hall, 37 Main Street, Beverley HU17 7PG	Wed, 29 Oct - 1.30pm

EMAIL ADDRESSES NEEDED
FOR SUPPORT GROUP INVITATIONS

Neil Hunter, Head of Services, needs your help to make sending support group meeting invitations more efficient and less costly. He explains the new system which will come into effect from 1 August of this year:

The success of our MSA Trust support groups continues and recent additions to the network has taken our total groups to 33. This is an amazing achievement, by the Support Group Leaders, and reflects the views of many Trust members in our 2014 survey who emphasised how supportive and beneficial support group attendance is.

We're looking at how to maintain this success by addressing the rising administration and postage costs of sending invitations to group meetings, enabling us to save these funds to support our other activities such as research and specialist nurse services.

So what we would like to do is send out all, or as many as possible, meeting invitations by email. Doing this would save us around £5,000 per year, which would be an incredible saving.

To do this we need your email address. We appreciate that not everyone will have one or be on the internet, but you might have family members who are who could let you know when meetings are taking place.

We will continue to publish the dates of upcoming meetings in MSA News, which is delivered to you three times per year, and we have a full listing of support groups and upcoming meetings on the Trust's website. You can also call us at the office to find out when your next meeting is. Please don't hesitate to call us.

We intend to start using an email invite system from 1 August this year instead of postal invitations.

I know this is a big ask, but I hope you will agree that the money saved makes this worth trying.

You can let us have your email address by simply emailing office@msatrust.org.uk with your name and postcode. Thank you for your support in this, and please get in touch if you'd like to talk through the new process. **MSA**

SUPPORT GROUP ROUND-UP

Congratulations to Support Group Leaders Sir Bay and Lady Laurelie Laurie and to the Essex Support Group for reaching their ten year anniversary in April. It is a fantastic achievement and our thanks go to all who have supported the Essex group over the last decade.

Thank you also to the new support group leaders who started meetings in recent months: Linda and John Hewitt in South Yorkshire, Ron Ingamells in Cambridgeshire and Dawn Tocco and Michelle Formosa in Peterborough. That brings our total to 33 groups.

And finally thank you to Vanisha and Vinny Rana, who are back and running the West Midlands support group following the birth of their son, Dhilan. Dhilan got first-hand experience of running a group at the recent meeting - perhaps a volunteer of the future! **MSA**

MSA AWARENESS

While it can sometimes take years to get a diagnosis, people whose lives are affected by MSA soon end up becoming ‘experts’. This is often from personal research, being referred to specialists or linking with the Trust and our specialist MSA nurses. Head of Communications, Franca Tranza, reports on the importance of raising awareness amongst health professionals.

The Trust’s 2014 membership survey highlighted the need to prioritise raising awareness among health professionals, as loneliness and isolation often experienced by people who have MSA can be compounded when health professionals have little knowledge about the disease.

We have taken this on board and have some positive news to report.

Over the last eight months, 235 health professionals have registered with the Trust. This is a sharp increase on the 134 who had registered in the previous eight months.

Neil Hunter, Head of Services at the Trust said, “We write to each of our members’ GP’s with a comprehensive information pack on MSA. These receive a lot of positive feedback so we decided to roll the packs out to all health professionals our members come into contact with. The results speak for themselves, and hopefully this will translate into better care for people living with MSA.”

The Trust has also been successful in directly targeting doctors with stories about MSA. Earlier this year the doctors’ professional association, the British Medical Association, published a blog by one of our members, GP Dr Aysha Kemp. The blog gave a poignant account of when West Yorkshire based Dr Kemp found out about her father’s MSA diagnosis. Her father was living in France at the time:

> “I honestly thought he’d got it wrong, that something had got lost in translation, especially given my father and step-mother didn’t speak French very well. I turned to the internet and found out that it was a bona fide condition.”

About 50,000 doctors access the BMA website every week and coverage like this is invaluable for raising awareness of MSA. It also appears to have struck a cord - the BMA have told us it was one of the most commented upon blogs they have published.

While GPs cannot be expected to know about every disease, the Trust is committed to helping doctors find out more about MSA.

We’re always trying to raise the profile of MSA and stories based on GPs and other health professionals can be a useful tool for generating greater awareness. If you feel your GP, or other member of the healthcare team, should share their MSA story, please ask them if they would be happy to be involved in awareness raising. If they are, I can be contacted at the Trust on 020 7940 4666 or by email at franca.tranza@msatrust.org.uk.

MSA

MEET YOUR CARE TEAM

Continuing our series of interviews with members of your health and care team, in this issue of MSA News we meet Lorna Raggett, an Occupational Therapist (OT) in Ireland.

1. How do you help people with MSA?

Occupational therapy services vary depending on the person's stage of MSA. Occupational therapy is usually required when a person with MSA experiences limitations in the areas of personal care, functional mobility, accessing their home environment, work, and leisure activities. Typically, an OT would make environmental and daily living task modifications to help promote and maintain independence. We would also offer education to a person living with MSA, and their family, and use our knowledge and expertise in collaboration with the client to identify problems and develop and try solutions in their daily activities.

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

I have had a specialist interest in MSA for a number of years through my work as a primary care OT working in southern Ireland.

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

Positives I would say are facilitating a person's independence in their daily activities that are truly meaningful to them, and helping to maintain their life roles.

Negatives would be that sometimes it can be frustrating with the amount of work the primary care OT has in the community we are limited on the time we can spend with our clients.

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

There is definitely a greater awareness of MSA in the south of Ireland with more accurate, and earlier, diagnosis taking place. This has led to better education and understanding of MSA among the health and care professionals and therefore our patients. It empowers the client and their family and those caring for them, and they feel more confident in the support offered and received.

5. What difference do you think the Trust has made?

The MSA Trust has been a great support and resource to me and my other colleagues in our contact with MSA in the community. It's supported me in helping to raise awareness amongst the multi-disciplinary team and has been a great source of comfort and information to my clients.

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

Earlier diagnosis. It would be great to see clients being linked earlier with a more specialised in-depth service, allowing improved management of their condition. MSA

NEW TRUST MERCHANDISE AVAILABLE ONLINE

The Trust's online shop has new stock!

BAG

£5
50p P&P

Our cotton tote bags are a must for the summer months – 100% cotton, crafted to a high specification and with the Trust's logo on both sides, you can be proud to be a supporter of the Trust with this unique bag. The bag measures 38x42cm.

MUG

£5.60
£4.40 P&P

Partial to the odd cup of tea? Our lovely new ceramic mugs are perfect for tea and a biscuit, and feature our logo to ensure that all your family and friends are made aware of our work.

BEAR

£10
£2.50 P&P

We have also received new stock of Bertie bear! A beautifully crafted Guernsey bear, Bertie comes with his very own embroidered Trust sweater. He remains the ideal mascot for all your fundraising events, as well as being a wonderful gift for children – or perhaps for particularly generous event sponsors. He is 19cm high when sitting.

For more information and to order any of our items, please visit:

www.msatrust.org.uk/our-shop

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