MSA NEWS

MULTIPLE SYSTEM ATROPHY TRUST MEMBERSHIP MAGAZINE |

► ISSUE 32, 2011 | WWW.MSATRUST.ORG.UK

THE WORLD MEETS MSA
MSA communities around the world
raise global awareness

A pledge from the NEW CHAIRMAN
Michael Evans sets the scene

OUR FRIEND "LOO"
A guide to helping the relationship!

...AND FINALLY, CHRISTMAS IS COMING
TRUST CHRISTMAS CARDS AVAILABLE NOW!

Follow us on Twitter & Facebook and help raise awareness of MSA.
See our website, www.msatrust.org.uk

EXECUTIVE DIRECTOR AND MSA NEWS EDITOR:
Nickie Roberts

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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Registered Charity Number 1137652.
Company Number 7302036.

MEMBERSHIP AT OCTOBER 2011

Current MSA members	844
Carers, relatives & friends	1024
Healthcare professionals	1466
Total	**3334**
New MSA Members since 1 June 2011	48

MSA NEWS CONTENTS

Multiple System Atrophy Trust

Information, support, education and research. Free services for people with MSA, carers, family, health and social care professionals.

A pledge from THE CHAIRMAN

BY MICHAEL EVANS

I was thrilled and a little surprised when Eileen Strathnaver called to tell me that my fellow Trustees had voted for me to succeed her in becoming the new Chair of the Trust. It's a huge honour.

My own involvement with the Trust started when my mum was diagnosed with MSA in 1997. I remember the emotion and relief when I first spoke to the Trust's specialist nurse at that time, to finally discover someone who understood everything that my mum and the family were going through.

After my mum passed away in 2001, I really wanted to get involved. I ran the London Marathon in 2002, in 2004 I became a Trustee and in 2007 took part in Cycle to Cannes, which annually raises significant funds for our work. As a Trustee, I've witnessed the transformation of the charity under Eileen's leadership.

When the Trust started there were no staff, no support groups, nothing - the original Trustees, including Eileen and Val Fleming, had to do everything themselves.

Things have come a long way:

- 18 UK-wide support groups and more in the pipeline, plus an active online community.
- Two specialist nurses who run our telephone helpline, answer your email questions, support the online community and work hard to improve health professionals' knowledge of MSA.
- Seven research projects.
- We have invested in staff to develop the Trust and its services.

One thing that has always struck me about the Trust is its sense of belonging and connection, both in my dealing as a member but also as a Trustee and I feel sure this is something very important to members. We are here to serve and help you, and we need to know how we're doing - when we've done things well or where we could do things better. It was for this reason that last year we undertook our first extensive membership survey, and there were some clear messages.

You want us to lobby for change and improvements in your healthcare, to focus on research and to continue to provide information and support. We've taken your views on board:

- The first ever MSA Research Day is taking place in November, organised by Trustee Professor Clare Fowler, with over 30 leading researchers and medics involved in MSA taking part.
- We've committed funds to support new research grants.
- We've published our first research strategy.
- We've announced our £1 m Research Appeal.
- Support groups continue to grow as does our online community, helping to spread the word about MSA as well as helping to connect people.
- Our range of materials continues to grow, MSA News has been updated and expanded, and we have a more responsive and modern website.
- Through our work with Rare Disease UK and the Neurological Alliance, we've joined forces with other similarly minded organisations to get better recognition of the needs of people who not only have a neurological condition, but a rare one.
- We have contributed to updating health professional standards relevant to MSA through the clinical standards body, the National Institute for Clinical Excellence.

So now we embark on an exciting new chapter, and I'm delighted to be Chair at this stage in the Trust's development. Along with my fellow Trustees and staff, I am committed to supporting you. MSA

MSA & THE "LOO"

It's a fact that many people with MSA become well acquainted with the demands of their bladder and bowel - from what food to eat, the amount of fluids to have, to planning trips and the location of toilets. Here we give you some tips on how to meet those demands, and we'll be following up in our next issue with more information.

ACCESSIBLE PUBLIC TOILETS AND THE NATIONAL KEY SCHEME

If you're planning a trip out for the day you might be wondering where to find a public toilet, particularly if you're going on a long journey or to a place you're not familiar with.

There are thousands of public toilets accessible to people with disabilities and wheelchair users in particular. Accessible toilets can be found in places such as tourist information centres, supermarkets, fast food restaurants, train and bus stations, ferry terminals and many visitor attractions. Motorway service stations are generally 30-45 minutes apart and each one should have facilities for disabled travellers.

Many accessible public toilets need a special key produced by The Royal Association for Disability and Rehabilitation (RADAR) as part of the national key scheme. Though there is a small charge for the key, it's then yours to keep for future visits. RADAR also publish the National Key Scheme Guide which lists public toilets across the UK (£16.99).

For more information on the scheme, or to purchase the key and or guide, please contact RADAR on 020 7250 4119 or visit their website www.radar.org.uk. Special offers and discounts are sometimes available through their website.

CONSTIPATION IN MSA

The digestive system runs from your mouth to your back passage, ie, your rectum, and serves two functions: it breaks down food into small parts that the body can use and it also gets rid of unusable food. The muscles in the digestive system walls contract and squeeze the food through the system. The stomach acts as a reservoir for the food, mixing it with acids and enzymes to start its breakdown. The food then moves into the bowel which has two distinct parts: the small intestine (the duodenum) and the large intestine (colon). The small intestine absorbs the useful parts of the food into the blood stream, and the remaining food waste passes through into the large intestine where water is reabsorbed and the faeces are stored until they pass out of the body through the back passage.

The movement of food through the digestive system is controlled mainly by the autonomic nervous system and normally you are unaware of this process.

Having MSA means the autonomic nerves are impaired. This means the movement of food through the digestive system becomes disrupted resulting in the whole process becoming slower, uncomfortable and may be unpredictable. Constipation is the most common disruption, although you might also have episodes of diarrhoea.

Constipation can make you feel unwell, but it might also affect how well your medication works as well as possibly affecting your blood pressure by causing it to lower (postural hypertension) by straining too much. So how best to try and avoid constipation? Here are a few facts and tips:

- Constipation in autonomic conditions such as MSA is a common problem.
- Prevention is better than cure.
- Drink plenty, at least 2 litres (3.5 pints) of fluids a day and discuss management with the Trust's or Parkinson's specialist nurses. If you're worried about drinking because of bladder control problems, a continence advisor will be able to offer advice.
- Increase the fibre content in your diet and try to eat some of these at every meal; a dietician can offer advice on a variety of ways to do this, and guide you on the type of food to help your digestive system to be more efficient. However, please note that increasing your fibre intake without maintaining a good fluid intake may make things worse.
- You're likely to require a daily laxative, but it's important to choose the right one to help your particular constipation problems which may change over time. Laxatives should be used with the guidance of your GP or the Trust's nurses.
- Some medication, eg, pain killers, can cause constipation so read the information leaflet before starting any new medication, and discuss alternatives with the doctor who prescribes them, or your GP.
- Being active and moving around helps to move food through the system; gentle massage can also help move food along and can ease discomfort - try a 10 minute a day abdomen massage in a clockwise direction.
- Establish a toilet routine and allow sufficient time; being comfortable in your bathroom is important - if you need a raised toilet seat or handrail, your occupational therapist should be able to help organise this. They can also give you advice on clothing to make using the toilet easier.
- Please note that severe or persistent diarrhoea needs medical attention.

If you'd like a copy of our Managing Constipation in MSA and Continence in MSA factsheets, please email Lyn Shaw at lyn.shaw@msatrust.org.uk or call the office on 020 7940 4666. **MSA**

Sharing EXPERIENCES

In our last magazine, we invited readers to share their personal experiences of life with MSA. Trust member, Michael Siddle, would like to share his.

My wife died eight years ago after having MSA for about four years. In that time memories of particular things - once vivid - begin to fade.

However, one thing still remains in my memory which I am sure others may well have to face.

I am a retired Vicar, and in spite of years of dealing with people in end of life situations, I still remember Rita saying to me one day, “Am I going to die?”

The pat answer (for a Vicar) was, “We are all going to die one day”.

That wasn’t what she wanted to hear, and neither did I. But facing it and saying, “Yes, but I do not know when” took us quite a bit further along our way and the realisation, put into words, helped us both greatly to face the fear.

Another memory is that in those final years we laughed together a lot more than for a long time. Laughter helped us much more than tears (although there were plenty of those).

An example is of our experience, before we got a stair-lift, of getting stuck on the stairs when Rita could go no further without a long rest. I remarked on the fact that in about three months someone would find two bodies stuck half way up the stairs. We laughed and laughed and laughed until the tears flowed and the strength came back.

I hope this might help someone who is following the same track as we did. **MSA**

If you’d like to share your experiences of living with MSA, tips and ideas, please email nickie.roberts@msatrust.org.uk.

Support GROUPS

Have you tried out your local support group? Have you been thinking of going along but haven't got round to it yet - or perhaps you're not sure which one to try!

Thanks to our volunteer group leaders, the Trust's network of support groups has been growing steadily and we have others in the pipeline to complement those already up-and-running. This means much greater choice for you, as not only are there many more around the UK to choose from, but you are also very welcome to attend as many groups as you like. We haven't set group boundaries as you are best placed to decide which group - or groups - are the most convenient for you to get to.

Support group leaders organise each meeting, and to help them prepare we need to make sure our records here at the Trust's office are up-to-date. A plea from the office follows!

The Trust's Administrator, Lyn Shaw, would love to hear from you - please let her know which support group(s) you'd like to be invited to. You can contact her on 020 7940 4666, write to her at the Trust's office, or email her at office@msatrust.org.uk and she will make sure your support group preferences are recorded on our database……. and you might also want to pop a few of the group meeting dates into your diary!

If you haven't been to a support group yet, you might like to get a sense of what it's all about. Neil Hunter, the Trust's Information and Support Manager, describes his recent visit to the Surrey Support Group, run by group leader Peter Turvey.

> “The Surrey Support Group is held in the picturesque village of Shalford. It's an incredibly friendly and welcoming group - I'm sure like all our groups - and the informal 1pm lunchtime start provided the perfect opportunity to talk to people and perhaps start new friendships, which forms the heart of this successful group.
>
> After lunch, we heard from Sue Ball, a speech and language therapist (SaLT), who looked at a variety of things including eating, drinking and communication difficulties that can occur with MSA. She offered some great tips such as how to ease swallowing when drinking by using “thickeners” available on prescription, to thinking about your environment to improve communication, such as closing windows if loud noises are coming in, or turning the radio off. As Gill said, simple and sometimes obvious solutions are often overlooked! Perhaps her most important message, though, was that speech and language therapists have a great deal of support to offer, so if you're having difficulty with eating, drinking or communication then get a referral to a SaLT.
>
> The day was perfectly hosted by Peter Turvey, ably supported by Susan and Mary, Surrey-based information and support workers from Parkinson's UK, and by Lisi, an occupational therapist from the Phyllis Tuckwell Hospice.
>
> The meeting was a great blend of friendship and support, backed up by expert information of practical benefit to people with MSA and their carers. **MSA**”

BERKSHIRE
Karen Jenkins
(contact via the Trust)
Time & venue TBC

BLACKPOOL
Jo Hans
hansjj@talktalk.net
01253 821693

CORNWALL
Jane Hardy/Jan Pearce
moonbeams@ymail.com
01726 74792/01726 861361

DERBYSHIRE
Karen White/Kulwant Sehmbi
karen@karenwhite7.wanadoo.co.uk
01283 735847
16/02/12 (2 - 4pm)
Dovenside Social Club, Hatton, Derby, DE65 5DT

DEVON
Dennis Westrip
denniswestrip@btinternet.com
01271 378273
Baptist Church, High St, Cullompton, Devon, EX15 1AJ

EAST MIDLANDS
Elizabeth Brackenbury
Ian Jones
holmepierrepont@aol.com
i.jones5@ntlworld.com
0115 9333083 / 0115 9199294
Holme Pierrepont Hall, Holme Pierrepont, NG12 2LD

ESSEX
Lady Laurelie Laurie
Sir Bay Laurie
baylaurie331@btinternet.com
01206 210410
Great Tey Village Hall, Great Tey, Essex

GREATER MANCHESTER
Katie Rigg
nurses@msatrust.org.uk
01434 382931
Mayo Building, Salford Royal Hospital, Manchester, M6 8HD

KENT
Linda Nicolaides
marlin.michris@virgin.net
27/10/11 (2 - 4pm)
Medway Camps, University of Greenwich, Central Avenue, Chatham Maritime, Kent, ME4 4TB

NORTHERN IRELAND
Rosemary Arbuthnott
roseyart@gmail.com
Time & venue TBC

NORTH LONDON
Penny Stokes
07956 312168
28/11/11 (2 - 4pm)
Southgate Hockey Centre, Snakes Lane, Oakwood, London, EN4 0PS

SCOTLAND - FIFE
Kim Carr
(contact via the Trust)
Time & venue TBC

SCOTLAND - INVERURIE
Gill Campbell
(contact via the Trust)

SHROPSHIRE
Cathy Hopkins
(contact via the Trust)
Time & venue TBC

SOUTHERN IRELAND
George Hunter
george@georgehunter.biz
00353 872525252

SOUTHPORT
Fraser Gordon
frasergordon@live.co.uk
01704 894129
01/12/11
St James' Church Hall, Southport

SURREY
Peter Turvey
peterturvey@waitrose.com
01483 827395
01/12/11
Shalford Village Hall, Kings Road, Shalford, Guildford, GU4 8JU

WARRINGTON
Linda Moss
linda.moss@warrington-pct.nhs.uk
01925 867710
10/11/11 (3 - 5pm)
Fairfield & Howley Neighbour Project, Fairfield Street, Warrington, WA1 3AJ

KEY:
Group leader
Contact
Date/Time
Venue

Our £1 MILLION RESEARCH APPEAL!

We announced in the last issue of MSA News that plans are underway to launch the Remember MSA Research Appeal in 2012, in recognition of our 15th anniversary and the many people who have been affected by MSA.

This is the last magazine before 2012, so now's your chance to really get behind our push to get MSA research properly funded, by helping us to get more and more people involved in our fundraising activities.

Hopefully, you'll feel so inspired by our ambition that you'll want to get directly involved in fundraising yourself! To reach the million, we need to motivate hundreds of people to take part, so please try and persuade colleagues, friends, family and neighbours to get involved too.

To help you, we've pulled together some facts you may like to share with others so they too can see why researching to find the cause of MSA, with the hope of finding a cure, is of importance to us all.

Please photocopy or remove these pages, positioned in the magazine so you can pull out easily, and hand to whoever you feel could help us raise the million... or to somebody who simply loves a good challenge. As they say, every little helps!

WHAT IS MSA?

- Multiple system atrophy (MSA) is a devastating, progressive neurological disease.
- Its impact on the person who has it, and members of their family, is profound.
- It is totally indiscriminate, which means it could strike any one of us, male or female.
- MSA is not known to most people, which means those living with it often feel isolated.
- Not being able to talk to work colleagues, neighbours, friends without having to repeatedly explain what MSA is, adds to this sense of isolation.
- MSA simply doesn't have the public profile of many other diseases, such as cancer, heart disease, diabetes.
- MSA was only recognised in its own right 40 years ago, and the medical understanding and agreement of how the disease can present has only come about in the last 20 years.
- It is not a new disease, it's just that modern medicine is better at recognising it.
- However, diagnosis of MSA remains difficult.
- With diagnosis comes the devastating news that the condition is currently incurable.

WHAT CAN BE DONE?

Research into MSA has been poorly funded worldwide, and particularly so in the UK. Now, because of advances on several fronts in neuroscience, there is the opportunity for a concerted international effort to make progress towards finding the cause and a cure for this disease.

The Trust's ambition is to raise £1 million to fund an academic post, the **first** UK MSA senior research fellow.

This would fund essential costs over a substantial period, and for the appointment of a well-established neuroscientist with a keen interest in the molecular biology of neurodegenerative disease to direct a programme of work towards finding the cause and, one day, a cure for MSA.

WILL YOU HELP?

We could raise a staggering £250,000 – a quarter of our target – if 50 amazing people set themselves their own target of £5,000!

There are so many ways to do this and, of course, it doesn't need to be raised in one go……. perhaps think about spreading different fundraising activities across the year. Perhaps a coffee morning with friends, a session on Ebay or, for those of you who can't think of anything for your Christmas list to Santa, a gift of a donation!

We've got lots of ideas to help get you – or somebody you could persuade to help – started, as well as Appeal materials and the vital ingredient, lots of encouragement. Mike Coffey at the Trust would love to hear from you, and you can contact him by email at mike.coffey@msatrust.org.uk or by calling 020 7940 4666.

For those of you who prefer something more physically challenging, we can help you find events to take part in, or you might want to consider registering for one of the Appeal challenges the Trust is organising. Mike Coffey, our fundraiser, can tell you more about challenge fundraising and our own Appeal activities. Please email him on mike.coffey@msatrust.org.uk or call him on 020 7940 4666.

For more details of MSA, the work of the Trust and, of course, the Remember MSA Appeal, please visit our website, www.msatrust.org.uk, or call Mike Coffey on 020 7940 4666.

Getting involved is easy!

THE APPEAL CLUB

Our fundraising isn't all about challenges, it's also about the Appeal club. To help us reach our target of £1 million, we've formed the Remember MSA 2012 Club. The club is open to everyone to join and by becoming a member you are directly supporting the Appeal and moving us ever closer to the magical £1 million. Club members receive a member's badge, updates on Appeal progress and information about Appeal events. Membership is..... £20.12! Please complete the form and return to Mike Coffey: Multiple System Atrophy Trust, Southbank House, Black Prince Road, London SE1 7SJ. Thank you!

REMEMBER MSA 2012 CLUB MEMBERSHIP FORM

Name:..

Address:..

.... Postcode:..............................

Email:.. Telephone:..

STANDING ORDER MANDATE: To The Manager:.............................. Bank/Building Society

Address of your Bank or Building Society:..

....

Branch sort code: ☐☐-☐☐-☐☐ Account Number: ☐☐☐☐☐☐☐☐

Starting on: .... I would like to set up a standing order, to be paid monthly/

annually (please delete as appropriate), of £.............................. to the account below:

Bank: CAF Bank Charitable banking | **Account Name:** Multiple System Atrophy Trust
Sort Code: 40-52-40 | **Account Number:** 00096281
Address: 25 Kings Hill Avenue, Kings Hill, West Malling, Kent, ME19 4JQ

Are you a UK taxpayer? If you pay tax on UK wages, savings or pensions, you can make your gift worth 25% more by signing a Gift Aid declaration. Would you like to Gift Aid your donation? Yes ○

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

The Multiple System Atrophy Trust is registered in England as charity number 1137652 and registered as company number 7302036.

If you'd like to support our call to raise funds for MSA research and register your interest in any of our activities, please email Mike Coffey at mike.coffey@msatrust.org.uk or call him on 020 7940 4666. MSA

TRUST CHRISTMAS CARDS 2011
NOW AVAILABLE TO ORDER!

Yes, we're planning for Christmas already - it really does seem to get earlier and earlier! We're now taking orders for our Christmas cards, and here's this year's selection.

We have two designs - Merry Christmas Tree and By the Fireside. The greeting inside reads: "With Best Wishes for Christmas and the New Year". Each design is available in packs of 10 and cost £3.50 plus postage. Please see "Cost" which shows how much the packs are with postage.

The cards are a simple way to raise funds for the Trust and, importantly, to help raise awareness of MSA as our name is printed on the inside cover.

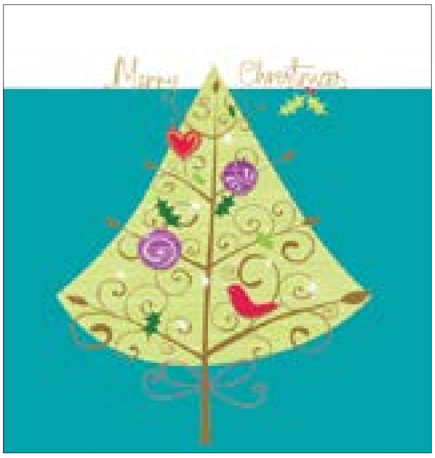
To order, please send us the slip below indicating which pack(s) you would like, enclosing a cheque made payable to "Multiple System Atrophy Trust" and post to:

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

COST

1 (pk)	£4.99
2 (pk)	£8.59
3 (pk)	£12.42
4 (pk)	£16.31
5 (pk)	£21.48
6 (pk)	£25.68
7 (pk)	£29.87
8 (pk)	£33.99
9 (pk)	£39.33

Thank you for your support!



MULTIPLE SYSTEM ATROPHY TRUST CHRISTMAS CARD ORDER

Name:..

Address:..

Postcode:... Telephone:...

Merry Christmas Tree (Qty):.. By The Fireside (Qty):..

Total payment enclosed £..

Please either cut here or photocopy and return to us by **5 December**. Thank you!

A PRICELESS LEGACY

BY LYN SHAW

Probably like many of those whose lives are affected by MSA, Graham (my husband) and I had never heard of a brain bank before he was diagnosed. But then Graham saw an article in the Trust's magazine about an MSA research project at London's Queen Square Brain Bank (QSBB) and he immediately made up his mind that he wanted to register as a brain donor.

At Graham's request, I contacted Susan Stoneham, the QSBB Administrator, for more information. Susan provided a helpful information pack explaining the importance of brain donation for research into, and treatment of, neurological disorders, including MSA. Together, Graham and I went through all the guidance notes and consent forms and Graham took on board that he could change his mind at any time. Within a few weeks of posting off the completed forms, Graham received his brain donor card which he always kept with him, while I made sure I carried a copy of it in my purse.

Sadly, Graham's condition suddenly deteriorated in the spring of 2011 and his life came to an end late on the morning of Thursday, 21 April, Maundy Thursday. This may sound strange to some, but in the immediate aftermath of Graham's death it helped me a great deal to be able to focus on making the practical arrangements for his donation.


Graham Shaw

I got straight on the 'phone to Susan at QSBB who very calmly talked me through the post mortem consent process. Susan also flagged up potential practical difficulties as the long Easter holiday weekend was about to start (I hadn't factored that into my contingency plans). However, thanks to Susan's swift action and the wonderful co-operation of Graham's GP, the funeral director and the local hospital, we were able to get Graham to the relevant facilities with minimal delay.

Shortly after Graham's funeral, I received a lovely letter from Susan on behalf of the QSBB directors. The final paragraph of that letter read:

"Your help in supporting this donation to the Queen Square Brain Bank is of major importance to the success of our research. I hope that it will be of some consolation to you and your family that many people with neurological disorders may be offered help as a result of your husband's priceless legacy."

It is indeed a great consolation. Brain donation is a personal choice and may not be for everyone. But for Graham it was absolutely the right decision. I know that he drew enormous comfort from the knowledge that the gift of his brain might help bring researchers one small step closer to finding the cause of - and ultimately a cure for - MSA.

If you would like more information, please contact the Trust on 020 7940 4666, or email office@msatrust.org.uk.

RADIO WITH A PURPOSE WORLD RADIO FOR CARERS

Ten years ago a small team of presenters, producers and technical staff started the Carers' World Radio to provide a platform for carers to learn about developments in policy and services available to them in their own country, as well as to provide an opportunity to debate issues with policy makers. Their last two programmes transmitted in July and August looked at the Government's independent commission which is considering funding of carer support, and an e-learning package for GPs to help general practices become more carer aware.

The programme makers are keen to hear from you too.

"We don't only want you to listen to our programmes, we also want you to take part in them as well. Who knows the issues carers face on a day-to-day basis, but carers."

If you'd like to share your story, they'd love to hear from you; it doesn't matter where you live as their technology can connect you to their team.

If you'd like to know about their planned programmes, to suggest ideas for future programmes or, perhaps, to find out how to take part, contact them at:

WEBSITE:
www.carersworldradio.com
EMAIL:
production@carersworldradio.com
TELEPHONE:
020 8123 0652

IN MEMORY

Members passed away during 2011

Dennis Jones
Keith Dixon
Martin Brookes
Betty Griffiths
Jackie Willbourne
Ivor Zietman
Owen Laugharne
Ian Richardson
Bill Forrest
Wendy Reid
Jenny Plank
Teresa Donovan
Keith Wilson
Hazel Leafe
Marion Inman

Patricia Reynolds
Gerald Maume
Malcolm Willis
Nigel Rubie
Ernest Freemantle
Philip Bawden
Maureen Hawyes
William Cope
Alan Gould
Pam Rodger
Barry Wigmore
Ralph Somerville
Lionel (Lee) Wright
Thomas Melling
Chris Masters

Ronald Bodell
Bob Hobbs
Ernest Crowe
Keith Denham
Jas Hans

Richard Wood
Gillian Smith
Matt Lloyd
George Skipper

FUNDRAISING
OUR INCREDIBLE MEMBERS IN ACTION

Fundraising weekend

The friends of Richard Harrison of Wallingford, organised an entire weekend of fundraising events on his behalf in Oxfordshire. On Friday, 26th August they held a fundraising quiz followed on Saturday afternoon with live music courtesy of two local bands. Completing the weekend, Sunday saw a wide range of events including more live music, a raffle, tombola, BBQ and a rowing machine competition. Children enjoyed a bouncy castle and face painting, and activities ended on Monday with an Aunt Sally competition. An amazing fundraising weekend raised a total of £4,350.

Walking Southend's Colourthon

Jane Taylor, Anna Smith, Jenny Packer and Hannah Stuart took part in the Essex Colourthon 13.5 mile walk on a beautiful summer's evening in Southend. The friends work for the local speech and language therapy team and were raising money for various communication charities as part of their Hello Campaign - the National Year of Communication. Thanks to their efforts a total of £500 was raised on behalf of the Trust.

Photo: Anna, Jenny, Jane (in the grey hooded top) and Hannah

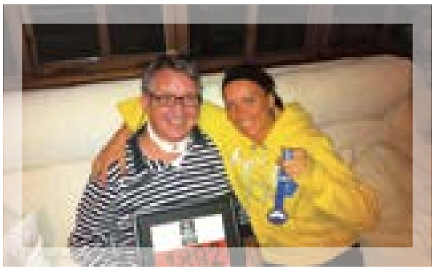
Lancashire walks & head massage raise funds for the Trust!

Friends of Eric Armitage, Oldham, held a fundraising walk for him in late July. The walk started from Castleton and went into Rochdale town centre through to Littleborough and on to Hollingworth. The walk raised a total of £500 for the Trust, and Eric's wife head massage/Reiki fundraising added a further £110.

The Mayor and Strawberry Tea

Diane Bettley's friends organized an afternoon's fundraising at the local Highwoods Farm in Halstead, Essex. The afternoon comprised live music, a strawberry tea and stalls, all of which raised £1,820 on the day. The Mayor of Halstead, David Hume, along with Sir Bay and Laurelie Laurie who run the Trust's local Essex Support Group which Diane attends, were all delighted to lend their support to the day.

Belfast Marathon



Keira Davidson's father, Joe, was diagnosed with MSA in 2003. Since then Keira's family have been regular fundraisers for the Trust. In May 2009, Kiera took part in the Belfast half marathon as part of a relay team with her colleagues, and this year she decided to run the full marathon. Despite a setback to her training due to a stress fracture in her foot, Keira completed the 26.2 miles in just over 4.5 hours. Next year she plans to take part again, and has set herself a target of completing the course in 4 hours. Thanks to Keira's efforts, £1,450 was raised for the Trust.

Three Peaks Challenge

After raising £4,000 for the Trust by running in the 2010 London Marathon, intrepid Sadie Geoghagen conquered the Three Peaks Challenge in an astonishing 24 hours. The challenge consisted of climbing Ben Nevis in Western Scotland (4,409 ft), Snowdon in North Wales (3,560 ft) and Scafell Pike in North-Western England (3,209 ft). The climb involves 26 miles of ascent and descent, and a 475-mile journey between the three mountains. To help her fundraising, Sadie posted regular Tweets on Twitter and created a JustGiving page entitled "Make Sadie Climb" - harnessing modern technology to help her fundraise. Sadie undertook the challenge in memory of her mum, Margaret.

A bake sale and rounders matches

Kirsty Smith from Tenbury in Worcester and friends organised two separate fundraising events for the Trust. Kirsty's dad, Brian, has MSA and Kirsty is determined to help raise both funds and awareness for the illness. The first was a bake sale in July which took place outside the local Regal Cinema, and the second was a series of weekly rounders matches which started in June and finished in early September. Together the two events raised £690 for the Trust, with more funds to come. Kirsty is shortly off to university to start her teacher training, and all at the Trust wish her the very best.

Birthday gift

John Ledwith's father-in-law, John Calderwood, was recently diagnosed with MSA. John was a long-time coach with Greenhills' Dynamo, a local amateur football team. Under John's management, the team enjoyed an extremely successful six years winning the league and several cup competitions. Eventually, John went on to become club chairman and now holds an honorary post. Such has been the affection that John has inspired that one of the club's former players, Paul Connelly, decided to raise money for the Trust rather than receive gifts at his 40th birthday party. A total of £483 was raised on the night of Paul's party, which he subsequently increased to £500.

An app a day FOR THE HEALTH SECRETARY

Health Secretary, Andrew Lansley, has set up a panel to judge the potential of health apps (software applications) and information maps that could help people make more informed choices about their care and create a more modern and personalised NHS.

He is looking at a number of areas, including improving long-term care and support and personalisation and choice of care and support.

Dr Shaibal Roy, panel member and an investigator at the National Institute for Health Research, champions the use of digital technology in healthcare and says, “Useful and easy to use smartphone apps and information maps will surely support both patients and clinicians in their shared decisions.”

The Department of Health will be showcasing the apps and maps chosen by the panel, which received nearly 500 entries, 900 comments and over 7,000 votes. If you’d like to follow the panel’s progress, sign on to Twitter@dhgovuk.

Calling ALL iPAD USERS

If you have experience of using an iPad to help you with MSA, Neil Hunter at the Trust would love to hear how they help you. Please email your thoughts to neil.hunter@msatrust.org.uk or call him on 020 7940 4664. **MSA**

CAMPAIGNING FOR BETTER SERVICES

As a member of the Neurological Alliance, the Trust is aiming to improve the services you receive - the primary purpose of the umbrella group is to campaign for better services for people with neurological conditions and their carers. It represents neurological charities in England to present a united voice. We’re looking at how we can become more involved in Scotland and Ireland too.

WHY DOES THE ALLIANCE NEED TO CAMPAIGN FOR BETTER SERVICES?

People with neurological conditions which, of course, includes MSA, often have complex needs. Those needs will almost certainly vary over time, so people need high quality, joined up services - unfortunately this doesn’t always happen, and services can be fragmented and patchy.

The Alliance estimates there are only around 350 whole time equivalent neurologists in the UK - one neurologist for every 170,000 people living in the UK. They say the European comparison is an average of one neurologist for every 18,000 to 35,000 members of the population. Their Taking Control campaign revealed that useful information is not getting into the hands of the people who need it most, and that 70% of people with a neurological condition were given no advice at diagnosis about where to seek further information on their condition.

Clearly there’s a lot to do, and the Alliance is pushing for change. We’ll keep you up-to-date with progress.

THE WORLD MEETS **MSA**

"Hello and welcome to World MSA Day!", the message greeting people as they visited the Trust's Facebook page on 3 October - a day set aside from the rest of the year by worldwide MSA communities to focus attention on MSA.

The common uniting purpose throughout the world was to have a chance to talk about MSA and to share stories and experiences, through traditional and virtual media, culminating at the end of the day with people being encouraged to light a candle for MSA.

Using the Trust's Facebook page and Twitter, we took part in World MSA Day by sharing one family's story of multiple system atrophy. Amanda Woodhall told the world how her dad, "Shorty", her brothers and sister and her mum, got to know MSA.

She said, "I'm here today to support MSA awareness because sadly, on 25 July this year, just three weeks after I moved here from Australia, my dad passed away from MSA. Today, 3 October, he would have turned 61. I want to share part of his story in the hope that it can bring some comfort to others affected by MSA. Also, I want to help raise awareness for others who perhaps search for answers to their loved one's symptoms, but have not yet connected it to MSA. When someone dies, you feel so helpless, and I feel that maybe this is one small thing I can do in memory of him. Today I really wish that I could ring him and wish him a happy birthday and so, in his memory, I will share a part of his story, and my family's story, in the hope it will help others."

Throughout the day and evening, Amanda told us of Shorty, what he was like, how hard he worked and what a family man he was. She talked of the struggle to discover what was causing the problems he was having.

"My dad was diagnosed with MSA in March 2010. I remember it distinctly as it was three weeks before my wedding. In the August before that he had been diagnosed with either Parkinson's or MSA and then trialled on Parkinson's medication for six months to nil effect. We knew when the medication was having no effect that it was likely it was MSA. I went with mum and dad to the neurologists when they delivered the news. By this stage though it wasn't a shock, as not a lot of information had been provided about MSA, so they didn't really know what they were dealing with. Also, in some ways, it was a relief to have a name to something after eight years plus of searching for an answer."


Shorty & Amanda

Visitors to our Facebook page began to "talk" to Amanda about her family's experience and to each other about their own, creating a fantastic sense of unity. We asked Amanda what her hope for the future would be. Her reply will surely resonate with many.

"My hope for MSA is they find a cure, or at least a treatment to give those with MSA hope. I hope others don't have to go through years of being made to look foolish, or being told there is nothing wrong with them when actually they know themselves that something is not right. I hope health professionals and the general public gain more knowledge, so that more understanding can develop and diagnosis can happen earlier allowing people to make important life choices given the information they have. I hope that people with MSA and carers get the empathy and support they deserve as they tackle this difficult and challenging disease."

Many, many thanks to Amanda for sharing her story with the world. Thanks also to Facebook users who changed their profile pictures to the Trust's logo, helping in a different way to raise awareness.

Since the day, the combined efforts of everybody, including people Tweeting for us, has increased "likes" to our Facebook page from 377 to 532… and rising!

FOOTBALLER WES BROWN AND HIS FAMILY SUPPORT WORLD MSA DAY

At a fantastic fundraiser for the Trust, Sunderland footballer, Wes Brown, and his brothers Reece and Clive, remembered their dad, Bancroft, who had MSA by showing their support for World MSA Day. Guests at the glittering event were asked to Tweet for MSA and to encourage their Followers to do the same. They willingly obliged, including betting shop owner, Paddy Power, who tweeted about the Trust and the "great cause". **MSA**


Nickie Roberts, Trust Director, and the Brown brothers

Multiple System Atrophy Trust
Founded by Sarah Matheson

WAYS TO SUPPORT THE TRUST & HELP IT GROW

BECOME A FUNDRAISER

Events such as coffee mornings, car boot sales and a wide variety of sponsorship opportunities bring the Trust valuable income every year. New ideas are always welcome! Email mike.coffey@msatrust.org.uk or call 020 7940 4666.

USE OUR ONLINE FUNDRAISING/ DONATION FACILITY

We have the facility for you to use an online fundraising package on www.justgiving.com. This facility can be used for anything from a personal occasion to an *in memorium* for a person's life.

MAKING A REGULAR DONATION

If you would like to make a regular donation to support our work, please complete the form below and send to the Trust office. If you are a UK taxpayer we can increase the value of your donation by 25% by reclaiming the tax as Gift Aid. Regardless of size, all donations help us to maintain and improve our services.

CONTRIBUTE TO MSA NEWS

Sharing your experiences and tips with other members helps keep it *your* magazine. Email nickie.roberts@msatrust.org.uk or call 020 7940 4666.

FORM A LOCAL SUPPORT GROUP

We can offer guidance and encouragement to run a group to provide local support for people affected by MSA. Email neil.hunter@msatrust.org.uk or call 020 7940 4666.

RAISE AWARENESS ABOUT MSA

Share our information with family, friends and the health professionals you meet. Follow us on Twitter and Facebook by visiting www.msatrust.org.uk.

Thank you for your support.

Name:..

Address:..

.... Postcode:.......................................

Signed:... Date:..

☐ I would like to make a regular donation. Please send me a form.

☐ I would like to make a donation of £............................. and enclose a cheque.

☐ I am a UK taxpayer and wish all gifts of money that I have made in the past six years and all future gifts of money that I make from the date of this declaration, until I notify you otherwise, to be treated as Gift Aid donations.

PLEASE MAKE ALL CHEQUES PAYABLE TO 'MULTIPLE SYSTEM ATROPHY TRUST'

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