Issue 29 Autumn 2010

Multiple System Atrophy Trust
Founded by Sarah Matheson

MSA News

The official magazine of the Multiple System Atrophy Trust

Contents

The Multiple System Atrophy Trust provides a support and information service to people with MSA, their families and carers, healthcare professionals and social care teams. We also sponsor and support research into MSA.

It's been a very busy few months at the Trust.Our volunteer-led support groups, researchers and nurses have been working hard in their respective roles and some of their activities are covered here: Dr Anna Sailer describes how her work investigating the genetics of MSA could lead to a better understanding of the disorder; specialist nurse Samantha Pavey warns of the risks of being tempted by "miracle" treatments, and new Surrey support group leader, Peter Turvey, shares his experience of the group's first meeting.

At head office we've been analysing the amazing response to our membership survey – and thank you to everybody who replied. Your feedback will help us form our services for the future, and I'd like to share some of the results with you now.

You told us that encouraging the government to improve NHS services should be a key priority for the Trust. We've already started to identify ways in which we can get MSA higher up the healthcare agenda, and will keep you posted. Increasing awareness about MSA in the general population was also considered to be a key priority, and 93% of respondents said they had never heard of MSA before you, or the person you care for, was diagnosed so there really is a need to make MSA more visible.

Funding MSA research and expanding the nurse network, not surprisingly, were considered essential areas for the Trust and we are looking at ways to develop both areas, as well as the possibility of securing significant funds through the launch of an appeal in our anniversary year of 2012.

Our range of literature was shown to be our most important service, and it's encouraging to learn that 80% of respondents share our leaflets with family and friends. Many of you said you are keen to get more information and support through the internet, and we're currently working on updating our website to make it easier to use and to include "virtual support groups" in the form of Blogs and Forums.

We've learned a lot from the survey and will share more of its results and what we're doing to develop services in future issues.

Lastly, you'll have noticed we now have this publication's new title, *MSA News*. Not, perhaps, the most exciting name but it does show our determination to make MSA more visible at every opportunity. We've upgraded its status too, from newsletter to magazine as we try to broaden the range of articles we cover and to make a statement about how important news on MSA is!

Nickie Roberts, Executive Director

Carers miss out on pension protection

According to Carers UK, a quarter of a million people caring for an ill or disabled friend or relative could be missing out on a top-up that protects their basic and second State Pensions.

An estimated one milliion people have given up work to care for someone. Pensions Minister, Steve Webb, wants "hidden" carers who could be eligible for Carer's Credit to benefit and is encouraging people to check their personal situation by visiting the Directgov website (www.direct.gov.uk/carers) or by calling the Carer's Allowance Unit (0845 604 5312).

People giving up their time for 20 hours or more a week to provide unpaid care for a loved one, who are not already claiming Carer's Allowance, could qualify.

Carer's Credit is not a cash sum but means that a carer's financial future can be protected. It credits a person's National Insurance record for the time they are caring, helping them to build up their State Pension. The Department of Work and Pensions estimates suggest that around 160,000 more people could start to gain Carer's Credit for the basic State Pension in 2010. New weekly National Insurance and earnings factor credits for carers have been available since April of this year.

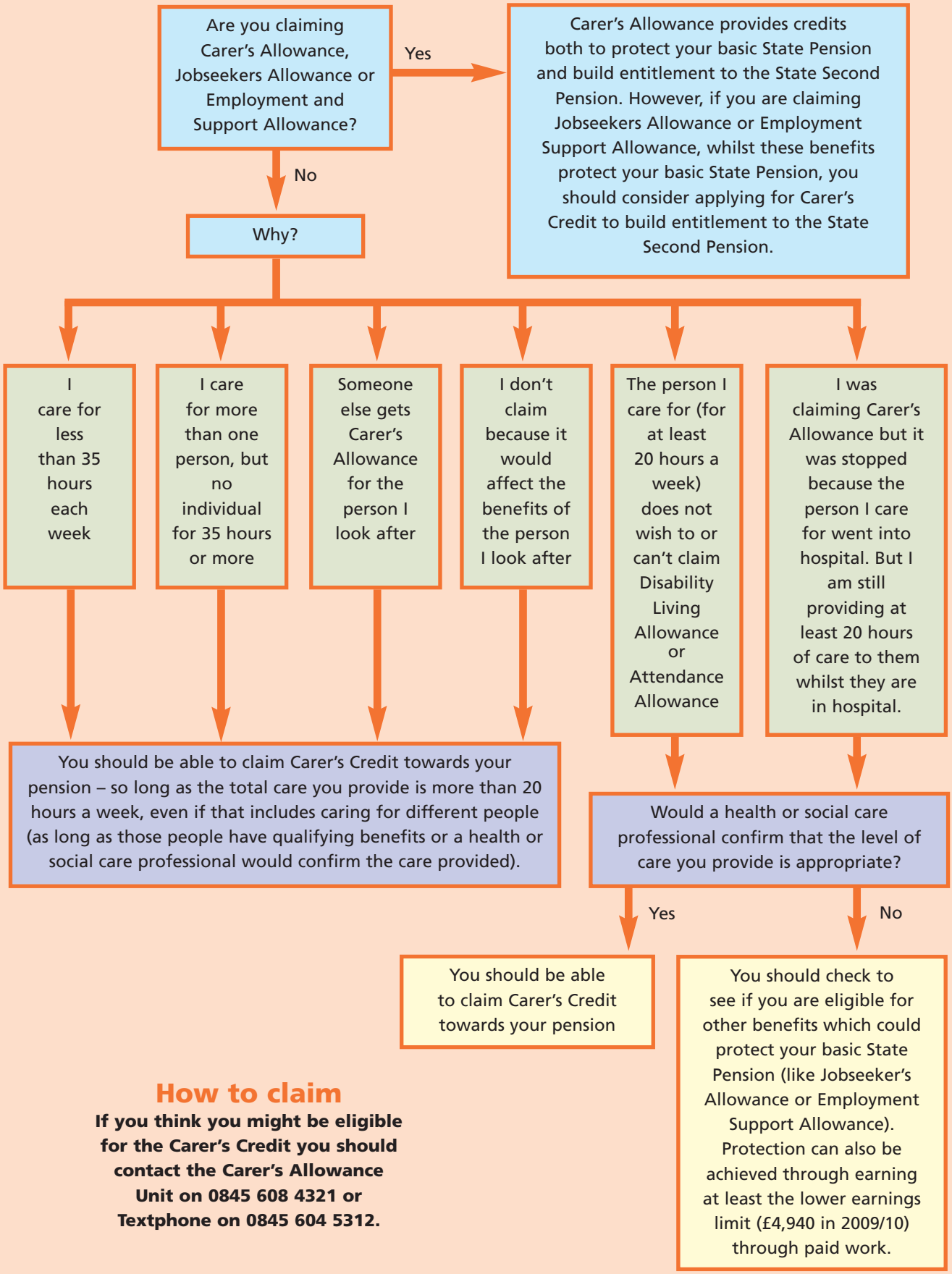
Could you benefit from changes to pension rules?

There are new rules to help carers who are missing out on National Insurance Contributions. You could if you are in one of these situations:

- You care for 20 hours or more a week but miss out on Carer's Allowance because you don't care for 35 hours or more
- You care for someone who can't or refuses to claim disability benefits
- Where there is more than one of you caring for a disabled or ill person and someone else is getting the Carer's Allowance for that person
- You look after several people but cannot claim Carer's Allowance because you do not care for any one of them for 35 hours
- You are still providing a lot of care for someone who has gone into hospital or a care home, but cannot get Carer's Allowance because they don't get disability benefits because they have been in hospital or a care home

The Trust is an affiliate member of Carer's UK, and information in this article has been reproduced from their material.

How can carers get National Insurance Contributions?



How to claim

If you think you might be eligible for the Carer's Credit you should contact the Carer's Allowance Unit on 0845 608 4321 or Textphone on 0845 604 5312.

Six things carers can do to make the most of their pension

1. Find out how much State Pension you have built up by getting your own State Pension forecast and checking your National Insurance (NI) Contributions record.
2. Find out if it is worth paying additional Contributions for any years of NI Contributions you have missed. This could give you a bigger State Pension.
3. Carers can get help to get a full basic State Pension From April 2010 carers who care for a total of 20 hours per week or more but do not get Carer's Allowance may be able to apply for a Carer's Credit which will help more carers get a full basic State Pension.
4. From April 2010 it will be easier to qualify for a full basic State Pension as you will need only 30 years of NI Contributions to get a full basic State Pension (instead of the current 39 years for women and 44 years for men) which will help carers who have gaps in their NI record.
5. Don't forget you can get credited with NI Contributions if you meet certain conditions or receive certain benefits including Carer's Allowance, Jobseeker's Allowance, Employment and Support Allowance and Working Tax Credit.
6. Track down any lost private or work pension pots through the Pension Tracing Service. It's simple and free to use.

If you are already getting a State Pension check if you could get other benefits including Pension Credit Housing Benefit or Council Tax Benefit.

Useful Contacts

- www.direct.gov.uk/pensions
- www.direct.gov.uk/carers
- State Pension forecast: 0845 3000 1668 and online at https://secure.thepensionservice.gov.uk/ statepensionforecast
- State Pension claimline (you should automatically be sent claim forms four months before you reach pension age. If you have not received the forms you can contact the claimline): 0800 731 7898
- Pension Tracing Service (if you've lost touch with your occupational or personal pension scheme, this service may be able to help): 0845 600 2537, or www.direct.gov.uk/en/ Pensionsandretirement planning
- The Pensions Advisory Service: 0845 601 2923, or www.thepensionadvisoryservice.org.uk
- Carers UK's adviceline: 0808 808 7777
- Carer's Allowance Unit: 0845 608 4321
- Pension Credit Hotline: 0800 99 1234
- Benefit Enquiry Line: 0800 88 22 00

Nominations for our Carer Awards is now open!

There are two types of awards. The first is the Personal Carer Award which is for a spouse, friend, partner, family member or neighbour. We'd like to know who helps you get through the day or week, who keeps you smiling, who makes a difference by doing or saying the things that matter.

Our second award is the Professional Award and is for any professional that helps you. This could be a therapist, nurse or doctor – it could also be a shopkeeper who puts a chair out especially for you, or the librarian who tracks down that talking book you want to listen to.

To nominate somebody, please write or telephone us with the person's name and the reason why you would like to nominate them. You can nominate one person for each category.

Each person nominated will receive a certificate, small gift and a mention in a future edition of *MSA News*.

Your nominations will need to be with us by the end of **December 2010**. We look forward to hearing from you!

Help raise awareness on Rare Disease Day 2011

Rare Disease Day is an annual event that takes place on 29 February (ie, a rare day!). As 2011 is not a leap year, the event will be marked on Monday, 28 February. This will be the fourth Rare Disease Day. What initially began as a European initiative has grown and is now marked in countries all over the world.

The purpose of Rare Disease Day is to raise awareness of rare diseases and to emphasise their importance as a health priority. In the past, policy makers have tended to overlook rare diseases. This is partly due to the mistaken belief that rare diseases affect a small number of people; that there is little that can be done to help patients and families with rare diseases or that what can be done would be unfeasibly expensive. Rare Disease Day provides the opportunity to highlight that there are over 6000 rare diseases that will affect approximately 3.5 million people across the UK (or 1 in 17 people). Collectively rare diseases are not rare! As a result they need to be viewed as a priority.

Rare Disease Day provides the opportunity to bring all the stakeholders involved in rare diseases together. This includes patients, families, carers, policy makers, healthcare providers, clinicians, researchers, health-workers, the pharmaceutical industry and patient organisations. By acting simultaneously and collaboratively, nationally and internationally, the voice of rare disease patients can be heard by more people.

"Rare Disease Day provides the opportunity to bring all the stakeholders involved in rare diseases together."

Rare Disease UK is coordinating Rare Disease Day 2011 in the UK. Rare Disease UK (RDUK) is the national alliance for people with rare diseases and all who support them. RDUK is leading the campaign for a strategy for rare diseases in the UK with the support from a range of stakeholders and organisations, including the Trust.

The Government committed to implement a strategy to encourage research into rare diseases and to improve care and support for patients when it signed the European Council Recommendation on an action in the field of rare diseases in June 2009. RDUK is campaigning to ensure that the Government does in fact act on this commitment and develop an effective strategy in the UK.

RDUK has been conducting an investigation over the past 18 months into why a strategy for rare diseases is needed and what an effective strategy should include. The final report from this work will be launched to coincide with Rare Disease Day 2011 at four parliamentary receptions at Westminster, the Scottish Parliament, the Welsh Assembly and the Northern Ireland Assembly.

How you can get involved

There are a number of ways in which you can help raise awareness of rare diseases on Rare Disease Day 2011, including holding your own event or participating in media work. One of the most effective ways to raise awareness is by writing to your MP to let them know about the day, your condition and the Trust. RDUK will be providing a template letter for you to send to your MP and details of other ways you can get involved. The Trust's website will provide further information about how you can get involved, but if you would like to sign up to the RDUK newsletter to get information directly and to show your support for a strategy for rare diseases you can sign up for free at: www.rarediseases.org.uk.

For more information on Rare Disease Day please visit www.rarediseaseday.org.

Please help make Rare Disease Day 2011 the most successful yet!

Trust researchers investigate the genetics of multiple system atrophy

Dr Anna Sailer is working at the Institute of Neurology in the Department of Molecular Neuroscience in London. Funded by a Trust grant, she works with Professor Henry Houlden investigating genetic risk factors for MSA. We asked Anna to tell us about her research.

Could you give a summary of the project's objectives

Multiple system atrophy (MSA) occurs in adults and presents with a combination of parkinsonism, cerebellar signs and autonomic failure. Why and how people develop MSA is still largely unknown. We want to identify genetic risk factors that contribute to the development of the disease. Identifying such genetic causes and understanding how they contribute to disease development is very important for future research into treatment possibilities of MSA.

Does this mean MSA is a genetic disease?

MSA is certainly not inherited in the classical monogenetic fashion where one gene is mutated and passed on from parents to offspring. MSA does not run in families and was therefore always considered as a "sporadic" or non-genetic disease. However, in the last few years science has shown that also sporadic diseases have some genetic component. The genetic predisposition is thought to be complex and is likely to be made up of a number of risk factor genes that contribute to the development of the disease. The effect of each genetic risk factor is probably very small and other non-genetic factors certainly play a role in disease development. In other words, genetic risk in MSA is not black and white like in classical genetic diseases but rather different shades of light grey. Which shade of grey we don't know yet, and it may be different for every MSA patient.

What have been the main areas you have concentrated on since starting the project in October 2008?

Our approach has been two-fold. A lot of genetic research has already been done in similar more common diseases like Parkinson's disease. So, firstly, we looked at risk factors for these diseases to see if they also play a role in MSA. In doing this, a genetic association between MSA and the alpha-synuclein gene was found by a collaboration of our team and American researchers last year. This gene was already known to play a role in Parkinson's, but it is a very exciting finding in MSA as it is the very first genetic risk factor that could be identified.

On the other hand MSA is a distinct disease of its own, and we want to find the genetic risk factors that are specific to it. This is my main focus at the moment. We do this with a Genome Wide Association Study (GWAS). In this study we analyze more than 600,000 markers that are scattered all over the genome of MSA patients and compare the results to data from healthy controls. If we find that some markers are more frequent in MSA patients than in controls, that may lead us to believe that the gene in that area plays a role in MSA disease risk. In the past year we placed great effort into collecting enough MSA patients for this part of the project.

Collaborators for genetic studies in MSA

Why has this been important to the progress of the project?

The genetic differences between MSA patients and controls can be very subtle. We therefore need large numbers of MSA patients and controls to be able to detect them. So collecting a large study group has been our biggest hurdle so far. It is not easy in MSA. First of all, the disease is very rare. Secondly, as probably some members of the Trust have experienced, it is not easy for doctors to diagnose.

Our resources here at the Institute of Neurology are very good; its Queen's Square Brain Bank has the largest tissue collection of MSA patients in the world. In addition MSA patients are frequently seen at the National Hospital of Neurology and Neurosurgery. However, for a GWAS this is not enough. We therefore set up collaborations all over Europe and the US. Convincing other researchers to contribute DNA samples to our study was not easy in the beginning. Many were in doubt whether we would collect enough MSA patients. However, with the help of many collaborators inside and outside this Institute (see map) we have managed to collect nearly 1000 DNA samples.

What will your focus be for the next 6-12 months and why?

Now that we have collected nearly 1000 samples we will begin to process them and analyze the data. While collecting samples we performed a preliminary study and we are hoping for results soon.

So will the project be completed soon?

Unfortunately science never works that fast! Although we hope to get informative data in the next few months we still need to do follow-up work. Before we can be sure that a gene really plays a role in MSA we have to confirm and validate the finding. Therefore collecting DNA from MSA patients will continue so that we can replicate our results in a second group.

What will happen next?

The GWAS will certainly not give answers to all our questions. It will not identify all genetic risk factors and it will not tell us why a genetic risk factor contributes to disease development. We are already establishing a new project that will look at all the genes in greater detail by using a method called exome sequencing.

This is very new technology. When I started less than two years ago we didn't even think this would be possible as part of my project. But technology has developed very fast. It is still very expensive and at the moment we can only do this in a small number of MSA patients. However, as costs come down and as we get more funding we will extend and hopefully identify further MSA genetic risk factors.

What are you anticipating from your studies?

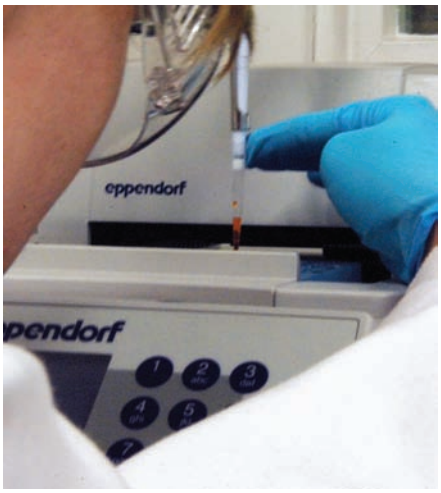
We expect to discover new genes that specifically contribute to MSA risk and that play a role in disease development. Finding these MSA specific mechanisms is also very important for future therapeutic research. As an example, there is a lot of overlap between MSA and Parkinson's disease. Nevertheless the response to Parkinson's drugs like L-Dopa in MSA is generally very low. We will therefore have to find new MSA-specific targets. However, these are unfortunately long-term goals.

Do you want to get involved in MSA research?

The National Hospital for Neurology and Neurosurgery and the Institute of Neurology, Queen Square, London are looking to recruit patients with MSA for a study on genetic risk factors in MSA. The aim of the study will be to improve medical knowledge and understanding of MSA (see article).

Participation is entirely voluntary. All we need is a blood sample and we may ask for your permission to contact your GP or neurologist for details on your disease. We will need approximately 3 to 4 teaspoons of blood (15-20ml) from which we isolate genetic material (DNA) for our study. Taking the blood sample can be arranged locally through your GP.

For further details please contact Dr Anna Sailer or Professor Henry Houlden (asailer@ion.ucl.ac.uk; Institute of Neurology, Queen Square, London WC1N 3BG).



How do you feel the project will contribute to the understanding of MSA?

To-date the causes and disease mechanism in MSA are largely unknown. In other neuro-degenerative diseases like Parkinson's or Alzheimer's disease huge progress in understanding the basic mechanisms was made by identifying genetic factors. This project aims to identify similar causes for MSA that will hopefully lead to a better understanding of the disease.

Glossary

DNA (deoxyribonucleic acid): The molecule holding the code in which genetic information is stored in cells

Gene: A stretch of DNA that encodes a specific information

Genome: The entirety of all genes that an organism contains. The human genome consists of about 20,000 different genes

Mutation: A change in the genetic code of a gene that alters the function of the gene and can lead to disease

Monogenetic disease: A disease that is caused by a mutation in one single gene

Complex genetic disease: A disease that is caused by subtle changes in several different risk genes. Other factors (eg, environmental) contribute to disease risk

Genetic predisposition: This is the inherited risk of developing a disease. A genetic predisposition for a disease does not mean that the person will get that disease, but the person's risk may be higher than that of the general population

Meeting people locally

Close contact with others affected by MSA can provide a supportive environment for people with MSA and carers. Many people who have attended the Trust's support groups have frequently told us how informative and beneficial the meetings are. These sentiments came through loud and clear in the results of our first Members' Survey. Jackie Davis, the Trust's Information and Support Officer reports.

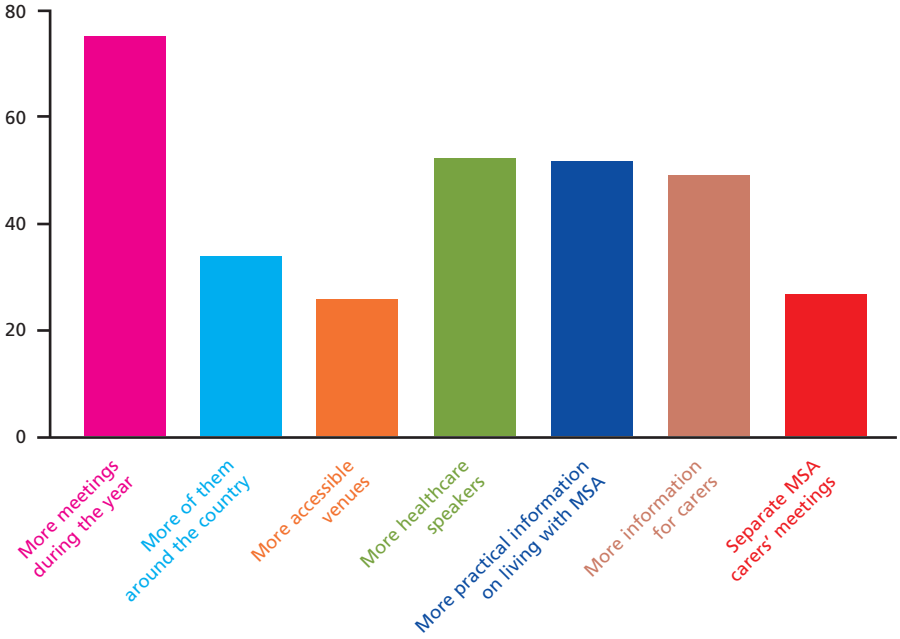
The results of the Trust's first Members' Survey (2010) clearly indicate that, for those who have attended support group meetings, a third found it a good opportunity to meet people in a similar situation. Of people who have attended a meeting, 69% found them helpful and 67% found them informative.

The survey suggests that a major concern among Trust members is the lack of local groups: 66% of respondents would like more regional groups throughout the UK, 30% would like more frequent meetings and 46% would like more healthcare professionals to talk at meetings. The bar chart shows how you answered.

This feedback is important and reinforces the Trust's commitment to developing and supporting more regional groups. Since April 2010 the number of groups either running or proposed has increased from 10 to 16 and now include Scotland and Ireland (Northern and Southern). The Trust is also very keen to help group leaders build the content of meetings, and will be working with them to invite guest speakers to meetings, such as local healthcare professionals or local authority representatives, to talk about local services, resources and to answer questions.

To grow the support group network the Trust needs volunteer group leaders who, in turn, are supported by volunteers who help them at each meeting. Assistance ranges from sending out leaflets to making cups of tea, but it is all invaluable support.

If you have been to a support group meeting, in what way do you think they could be improved?



Meeting people across the UK

The survey also indicated that over half of all respondents (56%) are interested in joining a 'virtual' support group, partly to overcome travel problems faced by so many people with MSA. We're currently reviewing our website and will be looking at the best way to set up a virtual form of support group, which may include Blogs and Forums.

One respondent commented, an online virtual group "would be helpful because I feel poorly somedays and would not be able to attend a group but could catch up online whenever I felt well."

Another added, "Chatting with other carers could be helpful. I wish that an online network was available as I would like to be able to contact other carers for sharing knowledge, advice, empathy, etc."

Some people commented in the survey that, although interested in accessing online support, they're unfamiliar with the use of computers and the internet. As part of our website review, we will look at how we can help people become comfortable with computer use.

Watch this space!

If you are interested in setting up your own support group, if you can assist in the running of a group, or you simply want to attend one, please contact Jackie Davis at the Trust on 0207 4960 4666 or email jackie@msaweb.co.uk. You can also speak to your local support group leader.

One of the Trust's key aims is to offer support and information to people whose lives are affected by MSA, and the work of the support groups and their volunteer leaders has always played a significant role in reaching people across the UK. The magazine has always carried brief reports from group meetings. With the support network growing, we thought we would take a more in-depth look at some groups each month on a rotational basis.

Surrey group meeting 14th August 2010

The first meeting of any support group often sets the tone for forthcoming events, and it was fantastic to see such enthusiasm from the Support Group Leader, Peter Turvey, his family and all the new attendees.

Over 40 people went along to the meeting. This included Samantha Pavey, MSA Specialist Nurse, a Parkinson's nurse specialist and a Parkinson's support and information officer. Clare Powell one of our Trustees who is Surrey-based, also attended.

Peter Turvey and his wife, Louise

Samantha talked to the group about the wide-ranging symptoms that individuals might experience and different ways of addressing these. She also discussed the importance of regular consultation with different health care professionals such as speech and language therapists and Parkinson's nurses. Samantha explained that engaging the services of a hospice should be a top priority as most offer family support, day centres and symptom management.

After hearing from Samantha, the group was canvassed on the set-up of future meetings and it was agreed to meet four times a year and to invite along specialist speakers. There is also interest in hearing different people's stories.

Jackie Davis

Devon group meeting – 2nd July 2010

Our last meeting was held at the Baptist Church Hall in Cullompton on Friday, 2nd July. We had another very good attendance with 18 people, including carers. Unfortunately, four people were unable to attend due to illness and we all wish them well. It was a pleasure to welcome two new members from Plymouth and I hope they found the meeting helpful.

Everyone was pleased to see Samantha Pavey, the Trust's Specialist Nurse for the Southern Region, who was asked many questions during the afternoon. Her answers and useful tips were very welcome. Devon has been allocated three new Parkinson's nurses, and I will being doing my best to see if they can attend a future meeting.

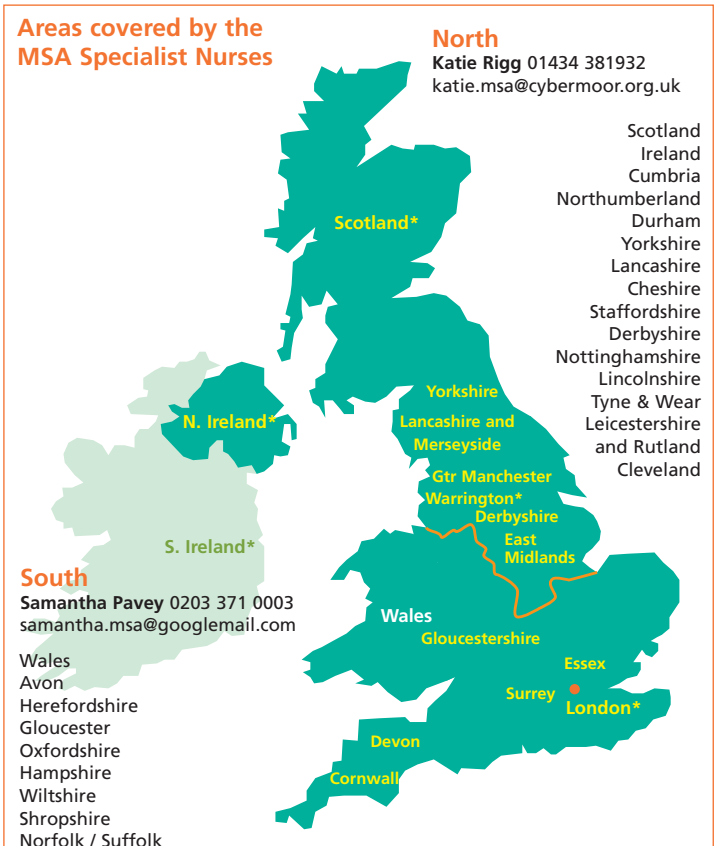
The group discussed the charity's change of name to Multiple System Atrophy Trust and everyone was supportive of this.

Refreshments were served during the afternoon and thank you to Brenda Nan and all the carers for their help. The next group meeting will be held at the same venue on Friday, 5th November from 2.00-4.00pm.

Ian and his wife, two of our members, are planning to move before our next meeting so we wish them well for the future. Thank you to everyone for their support at these meetings and we look forward to seeing you next time.

Dennis Westrip

Areas covered by the MSA Specialist Nurses



Regional support groups

The following is a list of current and new regional MSA Support Groups. If you are interested in attending a Group, please either contact the Support Group Leader directly or register your interest with the Trust Head Office (020 7940 4666).

Region	Group leader/ Coordinators	Email	Phone	Next meeting	Venue
Blackpool	Jo Hans	hansjj@talktalk.net	01253 821693	Wed, 27th Oct 2010 2.00-4.00pm	Thornton Cleveys Blackpool
Cornwall	Jane Handy Jan Pearce	moonbeams@ymail.com	01726 74792 01726 861361	No meetings currently scheduled for 2010	
Derbyshire	Kulwant Sehmbi Karen White	karen@karenwhite7.wanadoo.co.uk	01283 735847	Thurs, 30th Sept 2.00-4.30pm	Skills Centre, 50 Swallowdale Road, Sinfin, Derby, DE24 9NT
Devon	Dennis Westrip	denniswestrip@btinternet.com	01271 378273	Fri, 5th Nov 2010 2.00-4.00pm	Baptist Church, High St Cullompton, Devon EX15 1AJ
East Midlands	Elizabeth Brackenbury (Trustee) Ian Jones	holmepierrepont@aol.com i.jones5@ntlworld.com	0115 9333083 0115 9199294	Wed, 6th Oct 2010 2.00-4.00pm	Holme Pierrepont Hall Holme Pierepont NG12 2LD
Essex	Lady Laurelie Laurie Sir Bay Laurie	baylaurie331@btinternet.com	01206 210410	Mon, 25th Oct 2010 From 12.00pm	Great Tey Village Hall Great Tey, Essex
Gloucester	Janice Davies	janicedavies147@hotmail.com	01242 224617	Thurs, 21st Oct 2010 3.00-5.00pm	The Hewlitt Arms, Hart Hill, Cheltenham GL52
Greater Manchester	Katie Rigg	katie.msa@cybermoor.org.uk	01434 382931	Fri, 22nd Oct 2010 1.00-3.00pm	Mayo Building, Hope Hospital, Eccles Manchester
Northern Ireland*	Rosemary Arbuthnott	roseyart@gmail.com			Venue to be confirmed
North London*	Samantha Owen	samanthaowen@gogglemail.com			Venue to be confirmed
Scotland*	To be confirmed				Venue to be confirmed
Southern Ireland*	George Hunter	george@georgehunter.biz	00353 872525252	First meeting to be held beginning Oct	Venue to be confirmed
Southport	Jo Hans Fraser Gordon	hansjj@talktalk.net frasergordon@live.co.uk	01253 821693 01704 894129	Meeting held in Sept	St James Church Hall Lulworth Road, Berkdale Southport
Surrey	Peter Turvey	peterturvey@waitrose.com	01483 827395	Thurs, 2 Dec 2010 2.00pm	Shalford Village Hall Kings Road, Shalford Guildford GU4 8JU
Warrington*	Linda Moss, Parkinson's Nurse	linda.moss@warrington-pct.nhs.uk	01925 867710		Venue to be confirmed
Yorkshire & Humber	Karen Walker (Trustee)	karenwalker@BH-CC.co.uk	01274 861947	Meeting held in Sept	The Nerve Centre 2nd Floor, Standard House, Half Moon Street, Huddersfield HD1 2JF

Support groups are open to people with MSA, their carers and family members. The groups provide an invaluable opportunity to share concerns in an informal setting, to find out about local resources and to make contact with people in a similar situation. Once you have registered your interest, you are welcome to attend whenever you can and whenever you are feeling up to it. The group leader will keep you informed of forthcoming meetings and local information.

**** New groups - details and dates to be confirmed***

Beware 'alternative' health solutions

Do you sometimes feel tempted by 'miracle' treatments or cures? Well you might want to think carefully before you follow up any of these. As MSA Nurse Specialist, Samantha Pavey explains, these claims may be made by organisations promoting a product that is not recognised by the scientific and medical community and may not have been properly evaluated.

As with much in life, generally if something appears to be too good to be true then it probably is, but selling drugs and treatments that have not been proven effective is known as health fraud.

At best such treatments may not work, at worst they can be dangerous. Importantly, they may interfere with prescribed medications you are already taking as well as potentially wasting your money.

These types of claim are often referred to as "alternative" health solutions or remedies and can often be spotted by the use of testimonials from "satisfied users" who have experienced a miracle cure, anecdotes and subjective judgment. However, they will usually not have been subjected to peer review or critical evaluation.

A treatment that is not part of the recognised mainstream could be genuine but is more likely to be experimental, unproven, questionable or perhaps even a hoax. For a treatment to be considered genuine it has to have been scientifically proven for safety and effectiveness.

Any treatment will come under one of three possible categories:

- It may be genuine
- It may be experimental: it seems credible and is undergoing investigation
- It may questionable: the claims made for it are unproven and implausible

Sometimes a solution fits into more than one category, for example a treatment generally recognised as being genuine for another illness may, in fact, not be effective – or may even be worthless – in treating MSA.

If you hear about a treatment for MSA from a source other than your GP, consultant, the Trust or other recognised authority, try posing the following questions:

- Is online purchasing of the treatment available?
- Are 'patient testimonials' available?
- Is the treatment described as a 'cure'?
- Is the treatment described as 'having no side effects'?
- Does the treatment have 'limited availability' and is 'advanced payment' required?
- Are there promises of 'money-back guarantees'?

If one or more of these questions can be answered 'Yes' then treat this as a warning that the product may not be a genuine treatment. If claims are made of proven clinical trials for the product, find out if the trial results are available and ask to see them. If you are refused for any reason, treat the product with suspicion.

Before agreeing to take a treatment for which you have seen promising advertisements or articles in the press, please first contact your GP, consultant or the Trust to check if it is known to be effective or proven.

Your chance to have a piece of football history!

If football's your thing, or you know somebody who loves the game, now's your chance to grab a piece of football memorabilia.

The Trust has been given this fantastic Southampton football shirt (size: small adult) and ball, signed by players, as a "fundraiser" for our work. The shirt and/or ball will be sent to their new homes (in time for Christmas?!) to the lucky people who get in touch with Lyn Shaw at the office by 5pm, Thursday, 25 November 2010. The highest pledge secures the shirt or the ball (please say which you would prefer).

Thanks and good luck!

Researchers need help now from people with MSA

Are you happy with the service you receive from health and social care? Well this is your opportunity to share your thoughts with researchers at the University of Birmingham who are keen to hear about your experiences of what works well and what you would like to improve. They feel there is insufficient information about the services people with rare neurological conditions receive, and need your help to fill this gap.

You can take part in the RESULT survey (Review of Epidemiology and Service in Rare Long Term Neurological Conditions) in a number of ways:

- Complete the survey online at www.result-survey.bham.ac.uk, or
- Call researcher Sonal Shah on 0121 414 8585

REVIEW OF EPIDEMIOLOGY AND SERVICE USE
RESULT
IN RARE LONG TERM NEUROLOGICAL CONDITIONS

There is an October deadline, so if you would like to take part in the survey, don't delay – the researchers are waiting to hear from you!

In Memory

If you have informed the Trust of a loved one's death and their name does not appear below, please accept our apologies. Let us know and we will rectify this in the next edition. Some members passed away earlier than 2010 and the corresponding year is shown in brackets next to their name.

- Vera Drew (2009)
- Ellen Moffett (2009)
- Janet Bunt
- Jacqueline Cawthorne
- Paul Couture
- John Dilks
- Rosemary Fordham
- Lalitha Fraser
- Mary Fraser
- Keith Gordon
- Donald Johnson
- Beryl Kirkham
- Pamela Kovacs
- Charlotte Lawson
- Sylvia McCredie
- Elizabeth Milburn
- Eric Mobbs
- Jean Molyneux
- Derek Ormerod
- Alan Ross
- Douglas Sinclair
- Basil Smith
- Jeanne Smith
- John Strachan

muchloved.com

muchloved.com is a website dedicated to offering personalised website tributes in memory of a loved one. MuchLoved is a UK registered charity set up to help with grieving and healing. The website can be used without charge or obligation. To visit the website go to www.muchloved.com

So many people help the Trust by raising funds for our work. Their amazing efforts make it possible for us to provide our services and fund research into MSA. Here are a few of their stories, and a big thank you to **everyone** who works so hard to support us.

Coast to coast by bike

Richard Dodds of Stockton-on-Tees travelled from coast-to-coast in style on his motorbike riding from Scarborough to Grange-over-Sands. The trek took 13 hours and Richard raised £105 for MSA research. His friend, Peter Scott, was diagnosed with MSA in 2005. Peter and his wife Helena would like to say a big thank you to Richard.

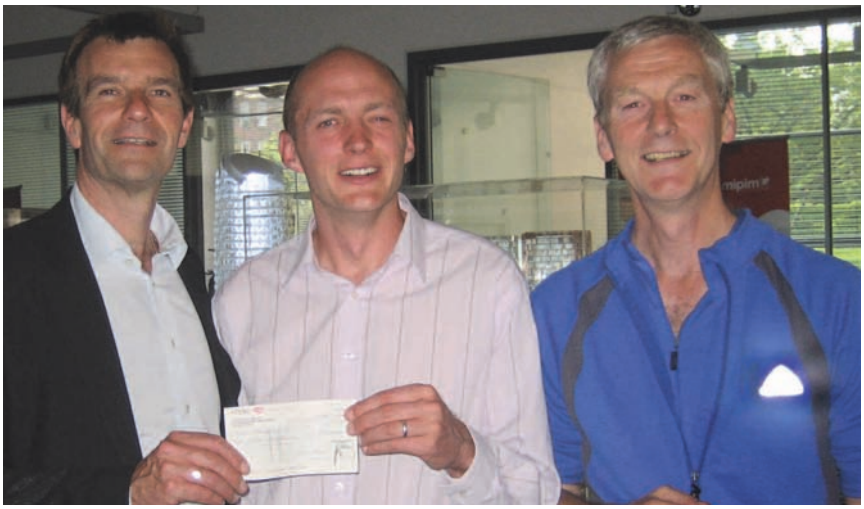
The boys on their bikes

British 10K Run

Talya Gordon of London completed the British 10k run in July. Talya had amazing support from friends and family and (with gift aid) raised over £2,800 for the Trust. Talya completed the race in 59 minutes and was accompanied by her friend Caryn Abrams (also pictured). Talya says, "I'm so pleased to have been able to raise money for the Trust. I'm very aware of the condition as my mum was diagnosed with MSA in 2002".

Tayla Gordon and Caryn Abrams

Aedas Cycle to Cannes charity challenge



Left to right: Michael Evans (Trustee and 2008 rider to Cannes), C2C's Nick Hanmer and Terry Pawson (of Terry Pawson Architects)

The Trust has again been regularly generously supported by the Aedas Cycle to Cannes charity challenge and in June, Nick Hanmer, Chief Executive of The Aedas Cycle to Cannes, presented the Trust with a cheque for £26,000. The annual event draws riders from the real estate industry and this year raised an amazing £172,000 for core charities. Plans are already underway for the 2011 ride and Nick says they're keen to reach the £1 million mark for total money raised for their chosen charities. If you'd like to know more about getting involved as a cyclist or a sponsor, Nick would love to hear from you! Contact him on info@cycle2cannes.org.

BUPA 10K Run

Wendy and Les Robertson of the HASSRA Fylde Rambling Club in Blackpool travelled to London for the Bupa London 10k run in May. HASSRA is the Sports and Social Club of the Department for Work and Pensions and the club has chosen the Trust as their charity of the year. Wendy says, "It was a glorious day and a great way to see some of the sights of London. The crowds were very supportive, with lots of clapping, cheering and encouraging of runners." They both agreed the hard training before the event was worth it, especially as they raised £150 in sponsorship for the Trust.

Musical evening

Anna Ramsden's concert group put on a musical event in Northallerton's Town Hall earlier this year in memory of her husband, Alan. They raised over £1,700 and managed to raise the profile of the Trust and MSA in their local press.

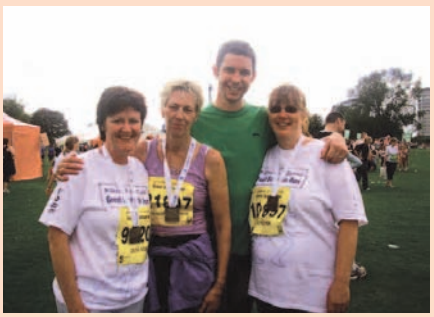
Trust Support Group Leader and Trustee, Karen Walker, receives the cheque

Coniston swim

Hannah Young of Wargrave braved rain and freezing water to swim Cumbria's Lake Coniston in memory of her father-in-law, Alistair Young. Hannah says, "As we stripped off and greased up, swimmers were telling themselves and each other that it would be warmer in the water than out (it was 14 degrees out and very wet and windy). I got counted into the water. It was freezing. Screams went out, 'IT'S NOT WARMER IN THAN OUT!'." Just over three hours later, Hannah finished the race seventh out of 12 women from a total of 39 swimmers. As well as her race certificate, she was awarded the Arthur Ayres Trophy for endeavour and says, "I'm thrilled with the amount raised for the Trust which has topped £1,600, taking our efforts to well over £5,000".

Great Scottish Run

Anne Troy of Dunblane sent in these photos from a race held in memory of Molly, a mother and grandmother. Anne says, "The girls did their 3k run on Saturday, 4th September. It was the first 3k event for Lucy and Sophie, but Holly and Kelly are now veterans at this event. Scott had run his 10k in 56 minutes before I had even started my half marathon, which took 2hrs 39 mins." She reports that the weather was lovely for the supporters but extremely warm for the runners "Hence I had to walk most of the way instead of jog/run but I did manage to run across the finishing line." The group raised around £180 for the Trust. Anne says, "Well, that's our races done at the moment until the women's 10k next May. Now it's back to training. Arrrrrrrgh!"



Left to right: Sophie, Holly, Kelly and Lucy. The adults (left to right) are Jacqui (Anne's daughter-in-law) first time 10k runner, Anne Troy, Scott Christie (her new son-in-law) and Susan (her cousin) second time 10k runner.

Paris Marathon

Debbie Kingston from Twickenham, Middlesex, says, "Unbelievable – I was in Paris for the whole weekend, with no children, and meeting my Norwegian friend, Maiken, who I hadn't seen for four years. I was also running the Paris marathon!" Debbie, who finished in 4hrs 32 minutes, chose the Trust as her cause in support of a friend who has MSA. Debbie raised £1,200, and says "It felt so good to finish, and our meal out that night was especially enjoyable with the glow of a job well done."

We are very grateful for all your fundraising activities.
We would be grateful if any future cheques be made payable to 'Multiple System Atrophy Trust'

Trust Christmas Cards 2010

Now Available to Order!

Twelve Days

T'was the Night Before Christmas

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 new designs – Twelve Days and T'was the night before Christmas - and 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. The table below shows how much the pack (or packs if buying more than one) cost with postage.

Number of packs	Total cost including postage
1	£4.80
2	£8.50
3	£12.00
4	£15.85
5	£19.70
6	£23.20
7	£28.30
8	£32.45
9	£35.95
10	£40.00

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

To order, please send us the slip below indicating which packs 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.

Thank you for your support!

Either cut here or photocopy

Multiple System Atrophy Trust Christmas Card Order

Name .....

Address .....

.....**Postcode**.....

Telephone no.....

Total payment enclosed £ .....

	No. of packs
Twelve Days	
T'was the Night Before Christmas	

Multiple System Atrophy Trust
Founded by Sarah Matheson

Information, Support, Education and Research in Multiple System Atrophy.

Providing services to people with MSA, families, carers and professionals.

- Information leaflets and magazine
- Specialist nurses
- Telephone help line
- Regional support meetings
- Training and education sessions
- MSA research
- Communication aid loans
- Welfare gift scheme

All correspondence and enquiries to:
Multiple System Atrophy Trust
Southbank House
Black Prince Road
London SE1 7SJ
Tel: 020 7940 4666
www.msaweb.co.uk

The Trust is financed entirely by voluntary donations.
Registered Charity Number 1137652
Company Number 7302036

Membership Numbers
as of August 2010

Current MSA members	812
Other patient members	34
Relatives and carers	516
Professionals	1422
Others	190
Total	**2974**

Ways to support the Trust and help it grow

Become a regular donor
Donations can be made to the Trust by setting up a monthly or annual direct debit. Regardless of size, all donations help us maintain and improve upon our services. Don't forget to Gift Aid any donations to increase the value of the donation generously given.

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.

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.

Contribute to *MSA News*
Sharing your experiences and tips with other members helps keep it *your* magazine.

Form a local support group
Link with the Trust office and independently run a group to provide local group support.

Raise awareness about MSA
Share our information with family, friends and the health professionals you meet.

Gift Aid It!
Did you know that if you are a UK tax payer, we can increase the value of any donations made to the Trust. This Gift Aid could raise the Trust's income by as much as £20,000 extra per year. We have Gift Aid forms available at the office.

Donate now!
If you would like to make a donation to the Multiple System Atrophy Trust (formerly the Sarah Matheson Trust) please complete the form below and send to the office. If you are a UK taxpayer we can increase the value of your donation by 28% by reclaiming the tax as Gift Aid.

Name _____

Address _____

_____ Post code _____

Signature _____ Date _____

❑ I would like to make a regular donation by standing order. Please send me the appropriate form.

❑ I would like to make a donation of £ _____ and enclose a cheque made payable to 'Multiple System Atrophy Trust'.

❑ 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'

Next issue All articles to be received by the office by 31st November 2010

The Trust endeavours to ensure the accuracy of articles in *MSA News*. Please note, however, that personal views and opinions expressed are not necessarily endorsed by the Trust.

Designed, laid out and printed by INQ Design. Call Martin on 020 7737 5775