



Multiple System Atrophy Trust
Founded by Sarah Matheson

MSA News

The official magazine of the Multiple System Atrophy Trust

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**Wanted –
Honorary Treasurer!**
Please see page 15 for details

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.

You can tell Spring is upon us – there's a sense of change in the air, including here at the Trust. Two of our longstanding Trustees have stood down from the Board – Lady Harriot Tennant and Elizabeth Brackenbury. Both have been staunch supporters of the Trust and its work for many years, and our heartfelt thanks go to both for their commitment over the years. We are fortunate that Elizabeth will be staying with us as East Midlands Support Group Leader. On page 11 of the magazine she describes how she has watched the Trust grow from an idea amongst friends and her sister, Sarah Matheson, to a still growing charity supporting hundreds of families living with MSA.

We also look at some of the practical issues of interest to carers, particularly the juggling act of caring and working, and just before we went to print the Government published its Welfare Reform Bill and we will follow up on this on our website and in future issues of the magazine. However, it appears that, for carers who are currently means-tested, the Carer's Allowance will remain a non means-tested benefit and will be outside the new Universal Credit. Carers currently in receipt of the Carer Premium means-tested benefits will be moved onto the Universal Credit. Experts in this field, Carers UK, say they do not oppose this in principle, as these carers are already means-tested and could be better off if they are able to juggle work and care. They should be able to keep more of their benefit as they earn. We will update you as we learn more about the Bill.



Lady Harriot Tennant

Spring change has also come to our website, as at the end of February we went "live" with a new and more informative version. Please check out www.msatrust.org.uk to have a look and also to find ways of getting involved, including helping us to raise awareness of MSA and the Trust.

And on the theme of awareness-building – thank you so much to all the members who helped draw attention to Rare Disease Day on 28th February, from talking to local journalists, linking to our new Facebook page and fundraising. As the saying goes, "Every little helps!" – and together we *will* get MSA on the map!

Nickie Roberts
Executive Director

Working and caring

Carers UK have compiled a guide, *Looking After Someone*, which covers a range of areas of interest to carers. Here's their advice on carers in the workplace.

Juggling work and looking after someone can be difficult. Having an understanding and knowledgeable employer or manager can make this easier. It is helpful to have access to information and advice in your workplace. Ask your employer if they have a carers' policy. There may be a range of ways they could help you, eg, by providing access to a telephone. Companies sometimes operate counselling services and have advice packs for carers. Trade unions can also be a good source of information and support. You have certain legal rights as a carer in the workplace.

Flexible working

Most working carers now have the legal right to request a flexible working pattern from their employer to help them to balance their work and caring responsibilities. There is a set procedure that employers must use to consider such requests. As a carer, you have this right if:

- you are an employee, and
- you have worked for your employer for at least 26 weeks, and
- you are a parent with a child(ren) under 17 or a disabled child(ren) under 18, or
- you are caring for an adult (over 18) who lives at the same address as you. If the person doesn't live with you, then he or she must be a relative

Flexible working could include:

- flexible starting and finishing times
- compressed working hours (eg, working 35 hours over a 4 day period)
- annualised working hours



- job sharing, term-time or part-time working
- home-working or tele-working

To apply, write to your employer asking for the changes you would like and why they will help. You will also need to explain the effect, if any, you think the change might have on your job and how you think this could be dealt with. For example, could a colleague be trained to take on additional tasks? You can only make one request per year and, if accepted, the changes will mean a permanent change to your employment

contract, unless agreed otherwise, so it is important that you think carefully about any financial and practical implications before you apply. If your employer refuses your request, which they can on certain business grounds, you can appeal their decision.

Time off in emergencies

You have the right to take a "reasonable" amount of time off work to deal with an emergency involving a dependant. This right also includes some protection from victimisation and dismissal. It is at the employer's

discretion whether the leave is paid or unpaid. Situations where this leave might be taken include:

- a disruption or breakdown in care arrangements
- if a dependant falls ill, has been assaulted or has an accident, including when the victim is hurt or upset rather than physically injured
- to make longer term arrangements for a dependant who is ill or injured
- to deal with the death of a dependant

Jobcentre Plus support for going back to work

If you want to balance work with caring responsibilities, Jobcentre Plus may be able to help you now or later if your caring responsibilities change. For example, you could go on a course to help you get a job or improve your skills. Jobcentre Plus contact details can be found in your telephone directory.

Giving up work

Many people feel forced to give up work when faced with intensive caring responsibilities. It is very important that you think of all the options before taking this step. It can have implications on your income and

“You have the right to take a ‘reasonable’ amount of time off work to deal with an emergency involving a dependant.”

quality of life, but also your future pension entitlements.

A carer’s assessment must look at how you are managing to balance your caring responsibilities with your employment. If you are thinking of giving up work to care full-time, ask for a carer’s assessment (or reassessment if you’ve already had one). The fact that

your job is at risk means that social services must treat you as a priority and consider what help they can provide to enable you to continue working, if that is your wish.

Protection from discrimination

The new Equality Act came into force in October 2010. It brings together various pieces of legislation on equality into one single act, and extends some rights to groups not previously covered. For the first time, carers have protection from direct discrimination. This means that employers and providers of goods and services must not treat carers less favourably than those without caring responsibilities.

This information has been reproduced from the Carers UK guide, Looking After Someone 2010/11

Further information

For more information, visit www.carersuk.org, your local Citizens Advice Bureau, the Government Equalities office (www.equalities.gov.uk) or contact the Equality and Human Rights Commission:

- England 0845 604 6610 (Textphone: 0845 604 6620);
- Scotland 0845 604 5510 (Textphone 0845 604 5520);
- Wales 0845 604 8810 (Textphone 0845 604 8820).

To find out the current position in Northern Ireland, contact the Equality Commission there on 028 90 890 890.

Getting help with continence and laundry services

If you are dealing with incontinence problems then your GP should be your first port of call who, along with your local Primary Care Trust, can provide support, advice and information. Members of the primary care team include continence advisors or specialists, as well as occupational therapists, physiotherapists and dieticians.

The continence advisor may be able to provide small items and other equipment which can help, including plastic or PVC covers to protect beds, disposable or washable continence pads and waterproof pants.

Your social services department should be able to provide small aids and adaptations for the home, including hand rails, commodes and raised toilet seats. Some departments provide a laundry service for people who have incontinence, and you should contact your local department for more information and, possibly, an assessment of your personal situation.

You can also buy your own continence products ranging from pads and pants to more specialised items. The Bladder and Bowel Foundation (www.bladderandbowelfoundation.org – Specialist Continence Nurse helpline: 0845 345 0165. General enquiries: 01536 533255. Fax: 01536 533240. Email: info@bladderandbowelfoundation.org) provides an independent directory of incontinence products.



Medical research and the Trust

When you give money for medical research, do you know what happens next? How does a medical charity decide which scientists to fund, and to do what? And, very importantly, who ensures their projects are worthwhile? Trutsee and chair of our research advisory panel, Clare Fowler, explains



Professor Clare Fowler

Securing funding is a major pre-occupation for anyone running a research laboratory. It is something which is done by obtaining grants. The laboratory director needs to have a well thought out plan of what, in the context of current scientific understanding, their team of research workers can usefully do and then apply for grants. It is through awarding grants that donations get to those who are doing research. Each grant will only last for a finite time, perhaps three years, but to maintain momentum based on a discovery, a laboratory needs to have a continuous supply of funding to keep staff in post and so avoid loss of technical expertise which may have taken many years to build up. Money must be found to pay laboratory staff, buy equipment, pay laboratory expenses and support the infrastructure of the organisation (usually a uni-

versity) within which they work. It's a tough job!

Funds are in very short supply, perhaps worse now in "Austerity Britain" than ever before, and things may get worse: donations to charities are down all round and as people struggle to make ends meet with rising costs and perhaps precarious incomes, giving money to a charity to fund research may be a low priority.

Are donations being well spent?

Donors to medical charities must feel confident that their gifts are being properly spent, and there are several well-defined processes which have to be followed for that to be the case. A charity making research funding available must advertise this widely in appropriate journals where all potential researchers will see the "call for funding" in good time. A deadline is set and applicants complete a form describing the research work they intend to carry out, the scientific rationale for that work, a detailed costing and the justification for their costs. These applications are then collected in, and assessed by, chosen experts in the field who will evaluate the proposed projects against the background of known science. They take into account the likelihood of the project producing "deliverables" based

on the feasibility of the proposals and the track record of the applicants. The experts must declare any conflict of interest they might have with the applicant, and must never be in a position of awarding money to themselves. The experts' opinions are then reviewed by the charity's research advisory panel (as is the case with the Trust) or its equivalent, which prioritises the applications for funding based on the expert evaluations. Recommendations are given to trustees of the charity, who offer funds according to money available.

Competitive process

There are some variations on this general scheme outlined above, but that is now established as being the fairest method of funding for what are considered to be the most worthwhile projects. However the number of grant applicants and the sums of money requested greatly exceeds funding available, be it either from a government funded source such as the Medical Research Council or a small

"The number of grant applicants and the sums of money requested greatly exceeds funding available."

charity such as the Multiple System Atrophy Trust. This means that researchers spend a lot of their time writing grant applications which are unsuccessful – a few years ago it was generally reckoned that only one in 10 applications was successful and the situation is probably worsening. It will be obvious from the description of the process that it is essentially competitive, and although the success or otherwise may be affected by the ability of the applicant, it may be difficult for that applicant if the answer to the question – “is it medically important and are a lot of people affected?” – is not “yes”. So, if we want to undertake research specifically into MSA, the Trust must make funds available. That is not to say that MSA will only be researched by money that was specifically so given because that is not the case, and there have been recent instances of discoveries being made about MSA when researchers were investigating other neurodegenerative diseases, but money restricted to MSA funding certainly helps a lot.

Trust grants

In 2005 the then Sarah Matheson Trust identified the need to establish a Research Advisory Panel (RAP) which



Box 1. Research Advisory Panel (RAP) members

From 2005

- Prof David Burn (Newcastle)
- Prof Clare J Fowler (London)
- Prof John Newsom-Davis (Oxford) (died 2007)
- Prof Martin Rossor (London)

From 2007

- Prof Nick Wood (London)
- Prof Gregor Wenning (Innsbruck)

could develop the Trust’s support for research and oversee the allocation of its grant money. A RAP was appointed (see Box 1 for list of members) and their first task was to decide what the central aim of research should be. The unanimous view was that we should try and attract “proposals for research aimed at discovering the cause of MSA”, rather than spending the money on a number of smaller patient-orientated projects.

The Sarah Matheson Trust nominated Ms Darcy Hare as the Trustee appointed to liaise with the RAP and assistance from the Sara Koe PSP Research Centre was gratefully received, allowing us to modify their grant application forms. Subsequently we received assistance from Parkinson’s UK with the grant assessment process.

The grants which have been awarded by the RAP since 2005 are summarised in Box 2 and although it is not the purpose of this article to detail what has been discovered through those projects, it is enough to say that their progress has been impressive and they are contributing in a significant way to worldwide efforts to discover more about MSA, its cause, how its progression might be halted and a possible cure.

1st UK MSA researchers meeting

Although most of the funding has so far been given to researchers in London and the Institute of Neurology specifically, there has been great added value

Box 2. Grants awarded by RAP

Jan 2008

- Prof Tamas Revesz and Dr Janice Holton (London) were awarded a one year grant

June 2008

- Prof Henry Houlden (London) was awarded a 3 year grant
- Dr Janice Holton (London) was awarded a 3 year grant

Jan 2010

- Dr Shahin Zibae (Cambridge) was awarded a 1 year grant

from this. Under the chairmanship of Dr Janice Holton an “MSA Research Group” was formed which has monthly meetings in the Department of Neuro-pathology. Results are reviewed and discussed, but from these meetings came the idea of arranging the first UK MSA researchers meeting. The intention of this is to bring together all those in the UK engaged in MSA research. It is perhaps surprising that this meeting can claim to be the first UK MSA researchers’ meeting and although this really is the case, it is not to say that researchers in this field have not met before. They almost certainly have and they know of each other’s work but, to-date, meetings dedicated to MSA research have been abroad rather than here in the UK. It is hoped that from this meeting people will be able to establish collaborations and plan to share resources as well as discuss their ideas. This meeting is being planned for 4 November 2011 at Queens Square in London and preliminary soundings have produced a very positive response from the research community. Certainly any researcher reading this who would like to attend would be most welcome and should send me an email (c.fowler@ion.ucl.ac.uk).

Reports about this meeting will be covered in future issues of MSA News – so please watch this space!

Going into hospital

Going into hospital can be an anxious time for anyone and people with medical conditions like MSA have additional considerations. Being prepared can make things much easier for you.

If you have a planned admission you may have some time to get prepared but it is worth preparing in case you have an unplanned admission.

Take all the relevant information about your condition and current medication whenever you go to hospital, including out-patient appointments. Use a folder to store all this information in one place. Many professionals you meet may not be familiar with your condition.

Know your medication

Ask your doctor or pharmacist to give you a printed list of all your current medication as this will help the hospital doctors looking after you. Let them know if you are on any trial drugs, unlicensed medication or herbal/homeopathic remedies. It is worth taking a supply of your usual medications with you.

Making life easier

Decide which equipment you need to take into hospital with you (eg, walking frame, wheelchair, lightwriter) and label these. You may want to consider adding valuable pieces of equipment to your household insurance.

GP involvement

Some emergency admissions can be arranged through your GP who can arrange for the relevant hospital doctor to see you in the Accident and Emergency department. This will save



you having to see the Accident & Emergency department doctors first and may reduce waiting time.

Investigations and surgery

These can have an effect on your symptoms. Find out as much as you can about the procedure, what preparation is involved, how long the procedure will be and what the planned aftercare is. You may be asked to attend a pre-assessment clinic as part of preparing for surgery or investigation. This is the ideal opportunity to get the information you need and to let the staff have more detail about your condition.

The following are important:

- **Nil-by-mouth** This is the term that describes the period of fasting (usually 6-8 hours) before an anaesthetic or procedure. Being nil-by-mouth can mean that you become dehydrated which can worsen your symptoms. To avoid dehydration you may need replacement fluids by intravenous infusion: 'a drip'. Even though you may be nil-by-mouth, you may still be able to take medication that will help your mobility or blood pressure in preparation for the procedure. The anaesthetist or doctor can discuss this with you.

- **Blood pressure** People who have postural hypotension (a fall in blood pressure when sitting or standing) often have higher blood pressure

recordings when laid flat. This is something the anaesthetist needs to be made aware of. Continue to keep your bed in the same position (head up tilt), although this may not be possible for some procedures or surgery. You may feel dizzy when you try to sit up after you have been lying flat. Your blood pressure control can also be affected by lack of activity or exercise. Doing leg exercises before you attempt to get out of bed is advisable, as well as sitting up slowly. Inform the ward staff if you have blood pressure problems.

- **Mobilising** One of the priorities of nursing staff and physiotherapists is getting people up and about after surgery. This is to reduce possible complications and to help your recovery. However, you may find that your progress is slower than other patients because of your existing condition. If you tire easily plan short periods of exercise and activity frequently, ie, little but often. Avoid being in the same position for several hours. Try to be active whilst in bed or sitting in a chair by doing gentle leg exercises. Advise the physiotherapist if you have “good” and “bad” days or your best time of day to carry out your exercises.

- **Breathing** It is important while you are less active to keep up the breathing exercises that the

physiotherapists and nurses will show you. You may have your breathing and oxygen levels monitored, especially if you have any breathing problems when laid flat or if you snore loudly. You will need to continue using any equipment that helps you breath at night.

- **Infection** Staff should be made aware that you are prone to infection (urine or chest) because of your condition. They will need to monitor this and may need to use preventative antibiotics. People with MSA may not experience a high temperature when they have an infection.

- **Recovery times** Being in hospital and having surgery are major events for anybody. If you consider

the additional factors related to your condition, don't be alarmed if you need some time to recover. Convalescence will be an important part of your recovery.

- **Discharge planning** Making preparations for going home should start on admission to ensure that everything is in place to get you home safely. Have with you details, including telephone numbers, of the people who help you at home. It's advisable to avoid discharge over a weekend if you rely on home care services. You will need a supply of medication to take home. Follow-up care may include visits from community nurses and therapists, as well as a hospital appointment.

See page 8 for a useful template to help prepare for your hospital stay

Top tips round-up for going into hospital

Before you go:

- Ask your GP to arrange hospital transport if you are unable to get there yourself (some hospitals will arrange this with you directly but check with your GP first)
- If you need help with communication or require an interpreter, let the hospital know beforehand
- Make a list of questions you would like to ask the consultant/specialist
- Take a copy of all your current medications with you (and/or take your medications)
- Ask a family member or friend to accompany you if you would like them to
- Take a spare MSA guide (available from the Trust) with you in case there are people at the clinic who are not familiar with MSA

When you see the consultant/specialist:

- Ask questions if there is anything you don't understand, particularly medical terminology
- Make notes if you feel that would be helpful, or ask someone to do this on your behalf
- Ask if you can have a copy of any letters written about you - most hospitals offer this service
- If you are prescribed medication, ask what benefits you might expect to see and what the potential side effects are
- Ask what happens next – eg, dates of further appointments
- Ask who should you contact if you have any further questions/concerns
- Ask when you can expect the results of any tests carried out and who can explain these to you

After your appointment:

- Keep a folder with any letters relating to your appointment. This is helpful for future appointments, sometimes medical notes are lost!
- Your GP can explain the contents of any letters you receive if you are unsure what they mean
- Book any tests and put the dates in your diary. Arrange transport as above
- If there is anything you are still unsure of, call the Trust specialist MSA nurses for advice

You may find it helpful to give the following information to hospital ward staff (eg, copy and complete) so they can help to maintain your usual routine and include in your “care plan”

	Things to think about	Describe your usual routine
Communication	Do you ... <ul style="list-style-type: none"> • have a quiet voice? • need a nurse call bell? • use any communication equipment? 	
Sleeping	<ul style="list-style-type: none"> • What time do you go to bed and get up? • How many pillows? • Head up tilt? • Do you need help turning? • How do you get to the bathroom? 	
Moving around	<ul style="list-style-type: none"> • What equipment do you use? • Do you need help? • How far can you walk? • Do you have a best time of day? • Does your blood pressure or medication affect your mobility? 	
Eating	Do you ... <ul style="list-style-type: none"> • have a special diet? • need special cutlery? • need help cutting food? • need help eating? • need to eat snacks? 	
Drinking	<ul style="list-style-type: none"> • What do you like to drink? • Do you need a special cup or straw? • Can you pour drinks? • Do you need help to drink? • Do you need your drinks thickened? 	
Bathrooms	<ul style="list-style-type: none"> • Where are they? • Can you get there alone? • Do you need help undressing? • How often do you go to the toilet? 	
Anything else?		
Current medication		
Allergies		
Equipment		

Useful telephone numbers

Multiple System Atrophy Trust 020 7940 4666	GP <input type="text"/>	Specialist <input type="text"/>	Social Worker/Care Manager <input type="text"/>	MSA Nurse Specialists Samantha Pavey – 0203 371 0003 Katie Rigg – 01434 381932
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Using herbal remedies in health care

Herbal remedies are made from plant materials used to treat disease and maintain good health, mostly as a complementary treatment (one given alongside conventional treatments). Because herbal remedies come from plants, and thus are naturally occurring, they are often mistakenly believed to be harmless. MSA specialist nurse, Samantha Pavey, explains.



Samantha Pavey

It is worth remembering that some of the most powerful medicines used today in the pharmaceutical industry have been derived from plant sources. A herbal remedy can have serious side effects and interact unhelpfully with other medication being taken at the same time, so if you are taking any medicines it's important to speak to your GP or pharmacist **before** taking any herbal remedies.

There are different types of therapies that use plants as remedies including:

- Ayurveda, which affects your mind and body together with herbal remedies, yoga, massage, diet and meditation
- Kampo, which uses similar techniques to Chinese medicine and involves the study of herbs to help illness
- Traditional Chinese medicine, which works on the same principles as Ayurveda and uses herbs to boost or disperse qi (energy)
- Traditional Tibetan medicine, which uses herbal remedies as well as diet changes and therapies such as acupuncture to help illness
- Unani-tibb, which has an emphasis on restoring balance by encouraging healing from within
- Western herbal medicine

Examples of specific herbs and the conditions they are used to treat include the following:

- St John's Wort can be used to treat depression
- Echinacea may be useful in treating the early stages of a cold in adults
- Serenoa repens can provide some improvement in symptoms of an enlarged prostate gland
- An extract of hawthorn, used in addition to conventional treatments, may be of benefit to people with chronic heart failure
- Ginger may relieve the sensation of feeling sick and vomiting
- Melissa officinalis (lemon balm) and salvia officinalis (sage) may improve mental ability in people with Alzheimer's disease
- Horse chestnut seed extract can be effective in treating circulatory problems
- Certain herbs including petasites hybridus (butterbur) may be an effective treatment for hay fever, although more research is needed to confirm this.



Risks associated with herbal remedies

Herbal remedies may interact with other medicines. For example, St John's Wort can interact with medicines that thin your blood, such as Warfarin and immunosuppressant medicines.

Like any medicine, herbal remedies can have side-effects. For example, kava, used for lifting the mood, is suspected to cause severe liver poisoning. Some Chinese herbal remedies have also been shown to cause serious kidney problems.

The scientific evidence for the

claims of herbal remedies is of variable quality. Research is often conflicting and while symptoms of some illnesses improve, the best evidence generally fails to prove that herbal remedies cure illnesses. Herbal remedies have been widely used for many years and may be useful for self-treating minor illnesses. However, natural doesn't mean harmless and it's important not to exceed the recommended doses.

There is no statutory regulation of herbal practitioners at present. However, the UK government is in the process of introducing a system to regulate both

herbal remedies and herbal practitioners. Herbal practitioners who are members of the National Institute of Medical Herbalists will have trained for at least three years, are insured and follow the Institute's code of conduct.

Some herbal practitioners work alongside doctors and your GP may be able to refer you, but this is likely to be to a private practitioner.

It's important to be aware that the active ingredients in herbal remedies and conventional medicines can interact, so ALWAYS ask your GP for advice.

Virtual support

New website unveiled

Our new website went “live” at the end of February – we hope you’ll find it informative and easy to navigate. It covers a wide range of topics and information, with specific areas on the treatment and management of MSA, different aspects of living with MSA including a section for carers.

We have an area on support groups. This includes a map showing where local support groups are held with contact details of support group leaders, venues and dates of meetings.

The results of our membership survey (undertaken last year) showed that over half of respondents were interested in joining a virtual support group – partly to overcome travel problems and for general convenience. As a



result of this feedback, we have set up a virtual support group – an online community – in the form of Blogs and Forums. We’re also aware from the survey that some people would like to access online support but are not very

familiar with computers. Please do call the office (020 7940 4666) if you would like to talk through how to get the best from our online support.

Raising awareness of MSA was a key priority of respondents to the survey. Our new website includes a section on how you can get involved with this. If you’d like to help the Trust increase knowledge of MSA amongst the general population, then please visit our Getting Involved section on the website and look for “Awareness”. We’ve provided

a few ideas plus facts on MSA which you might like to share amongst your Facebook friends, Twitter followers and local media.

We hope you like the site, which you can find by visiting www.msatrust.org.uk.

Farewell but not goodbye from Founder Trustee

Founder Trustee and Support Group Leader, Elizabeth Brackenbury, recalls the Trust's early days as she steps down from our Trustee Board.

I am retiring as a Trustee and decided to put some of my thoughts down. Sarah Matheson was my sister. She was diagnosed with MSA in 1993 by Professor Clare Fowler and Professor Christopher Mathias, London specialists. At that time, there was absolutely no support system whatsoever in place for MSA sufferers. Sarah did receive great support from Professor Mathias himself, and also from her friends and relations who rallied round and helped her. Sarah never married and had a great many friends, both through her work at the Royal College of Art and at the Architectural Association. She also had many social contacts both in Scotland, where she was brought up, and in England where she lived and worked for many years.

Val Fleming (still a Trustee) formed a committee of some of these friends and relations, to which Professor Mathias was invited. We met in our sister Margaret's house, where Sarah was then living. This was the birth of The Sarah Matheson Trust for Multiple System Atrophy. Very soon Catherine Best, the neurological nurse from the National Hospital for Neurology and Neurosurgery in London, became our nurse specialist. She was absolutely brilliant and was soon joined by a second nurse specialist. Between them they did everything from a very small office in St Mary's Hospital in Paddington, London. They started the newsletter, brought out leaflets about MSA, started the lightwriter loan scheme, in addition to coping with the



Elizabeth Brackenbury

dozens of 'phone calls and much else. The Trust was formed in 1997 and grew at a very fast rate, from 13 people with MSA on the books to over 800 today.

Catherine did marvellous work with her information days in hospitals all over the country, with teaching sessions for professionals in the mornings, and MSA patients and their carers in the afternoons. MSA was such a rare disease and unknown to most health-care professionals.

By 2009 we had completely outgrown the small office in St Mary's. Catherine had left to work full-time for Professor Mathias. The Trustees decided to move into a bigger office in South-

bank House. We appointed a part-time Executive Director and a part-time Administrator, which was very necessary to cope with the heavy workload and to support our two nurse specialists. I feel very proud to have been involved with this fantastic project from the start. I am very thrilled that the Trust has grown and has been able to fund some very good research projects in the hope that we can eventually conquer this horrible disease.

In 2002 I thought I would try and do something in the East Midlands, where I live. I was given a list of all the MSA patients in my area and asked them to lunch. After lunch I said, "Perhaps we should do this again next year". "Oh no" was the reply. "We want four meetings a year". We actually have two. I had vaguely thought I was fundraising but found instead that I was running a support group. It is really very heartening that after this tentative start, there are now so many support groups dotted round the country. I really do think people are very reassured to find they are not the only ones coping with a strange and relatively unknown disease. We try to make our meetings lighthearted and fun, as well as a chance for everyone to talk and compare notes, if they want to.

I am retiring as a Trustee but am continuing with the East Midlands Support Group, ably supported by Ian Jones and Margaret Palfreyman Biddulph.

Our next meeting will be held on 27 April 2011 from 2.00 pm to 4.30 pm at Holme Pierrepont Hall, Nottingham.

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	Thurs 14th April 2011 2.00pm-4.00pm	Venue to be confirmed
Cornwall	Jane Handy Jan Pearce	moonbeams@ymail.com	01726 74792 01726 861361	No meetings currently scheduled for 2011	
Derbyshire	Karen White Kulwant Sehmbi	karen@karenwhite7. wanadoo.co.uk	01283 735847	Late February 2011	Doveside Social Club, Hatton, Derby DE65 5DT
Devon	Dennis Westrip	denniswestrip @btinternet.com	01271 378273	Fri 4th March 2011 2.00-4.00pm	Baptist Church, High St Cullompton, Devon EX15 1AJ
East Midlands	Elizabeth Brackenbury (Trustee) Ian Jones	holmepierrepoint@aol.com i.jones5@ntlworld.com	0115 9333083 0115 9199294	Weds 27th April 2011 2.00-4.00pm	Holme Pierrepont Hall Holme Pierrepont NG12 2LD
Essex	Lady Laurelie Laurie Sir Bay Laurie	baylaurie331 @btinternet.com	01206 210410	Mon, 11th April 2011 From 12.30pm	Great Tey Village Hall Great Tey, Essex
Gloucester	Janice Davies	janicedavies147 @hotmail.com	01242 224617	To be confirmed	Venue to be confirmed
Greater Manchester	Katie Rigg	katie.msa@cybermoor.org.uk	01434 382931	Fri 25th March 2011 1.00-3.00pm	Mayo Building, Salford Royal Hospital, Manchester M6 8HD
Northern Ireland	Rosemary Arbuthnott	roseart@gmail.com		To be confirmed	Venue to be confirmed
North London*	To be confirmed			To be confirmed	Venue to be confirmed
Scotland*	To be confirmed			To be confirmed	Venue to be confirmed
Southern Ireland	George Hunter	george@georgehunter.biz	00353 872525252	To be confirmed	Venue to be confirmed
Southport	Ann McLennan Fraser Gordon	annandon@btinternet.com frasergordon@live.co.uk	01704 568353 01704 894129	Thurs 3rd March 2011 Thurs 2nd June 2011 Thurs 1 Sept 2011 Thurs 1 Dec 2011	Venue to be confirmed
Surrey	Peter Turvey	peterturvey@waitrose.com	01483 827395	Thurs 3rd March 2011 2.00pm Thurs 2nd June 2011 Thurs 1 Sept 2011 Thurs 1 Dec 2011	Shalford Village Hall Kings Road, Shalford Guildford GU4 8JU
Warrington*	Linda Moss, Parkinson's Nurse	linda.moss@ warrington-pct.nhs.uk	01925 867710	To be confirmed	Venue to be confirmed
Yorkshire & Humber	Karen Walker (Trustee)	karenwalker@BH-CC.co.uk	07710 312552	To be confirmed	Venue to be confirmed

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

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.

Student nurse takes on the Birmingham half marathon

Before I joined the Army my weekly exercise consisted of dancing at the weekend in my hometown, Bristol. I'd never even thought of running a half marathon but here I was, two years into my new career as a student nurse, on the starting line of my SECOND Birmingham Half Marathon!

As a military student nurse, I was lucky enough to spend one of my clinical placements at the Queen Alexandra Hospital Home which was just as fantastic as I had been told. During the placement I met Graham Shaw, a resident who has MSA. I had never heard of MSA before but, having learned more about the disease, I knew that raising money for the Trust would be a great reason to run those 13.2 miles a second time around!

I first ran the Birmingham Half Marathon in 2009 and I remember thinking that I would have to have a very good reason to run it again! Raising £220 for the Trust was such a small contribution in comparison

to the work that staff, trustees and volunteers do year round, but it was great to be part of it and I hope I can contribute again this year - maybe by running the Birmingham Half Marathon for a third time!

Kelly Lupton



Riding from Land's End to John O'Groats

Philip East of Ongar, Essex raised over £300 in memory of his wife, Celia, when he cycled from Land's End to John O'Groats from 15 May to 1 June

A relaxed looking Philip



last year. Phil rode with a group of 22 other cyclists, and they were blessed with good weather for almost the entire two weeks. Phil says that although the journey was sometimes arduous, it was great fun too, especially after he and a fellow cyclist adopted the habit of riding their bikes straight into hotel receptions on arrival at their daily destination. On one occasion, and much to the amusement of the hotel staff, they were unable to resist the temptation to ride their bikes along the red carpet that had been rolled out for a wedding party! Phil and Celia regularly attended Essex Support Group meetings over the years, and fellow members are delighted that Phil continues his involvement in the group.

Wetherby man takes on the Bolton Iron Man challenge

Steve Catterick of Wetherby, West Yorkshire took part in the Bolton Iron Man Challenge in August last year in memory of his father-in-law, who had MSA. Steve trained incredibly hard for the event which involved a 2.5 mile swim, a 112 mile bike ride and a marathon. He completed all this in a very impressive 13.5 hours. An amazing achievement, made all the more significant by the fact that Steve raised £900 in support of the Trust.



The perfect mix – cakes and golf

Susan Parnell of Bicester, Oxfordshire, decided that the 'Family Fun Day' at their local golf club (The Bicester Golf & Country Club) would be the perfect opportunity to try and raise funds for the Trust. The picture shows Sue on the left (in red fleece) with her helpers, including her grand-daughters, running their fundraising cake stall. Sue's husband, Pete, has MSA and says it was a shame that all their hard work was slightly ruined by bad weather – but that didn't stop people parting with their money in support of the Trust!

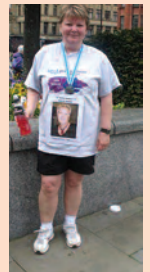


Swapping uniforms for festive gear!

Pupils and staff at Killicomaine Junior High School in Portadown, Co. Armagh, kicked a December week last year off to a good start by taking part in a non-uniform day with a twist to raise money for charity. They were given the chance to try out their festive creativity by coming to school wearing clothes with a Christmas theme. They raised £400 for the Trust on the day by donating money for the privilege to dress up. Ms Fulton (right), classroom assistant and a member of the Northern Ireland MSA Support Group, worked alongside Mrs Camblin (left) the school's charity coordinator, to organise the event and, most importantly, raise awareness of the charity.

Running the streets of Manchester

Susan Wood ran the Manchester 10k in May 2010 in memory of Doreen Hatfield who was diagnosed with MSA in 2006 and passed away last January 2010. With husband Andrew in support, together with Doreen's husband Peter and daughter Kath urging her on, Sue came in a very creditable 1 hour 14 mins. Sue commented: "It was hard but I felt Auntie Doreen pushing me all the way home." Doreen's family would like to say a very big thank you to Andrew and Sue for organising the event in support of the family's charity and also to the many friends and family who contributed to the wonderful sum of £350, including Gift Aid.



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'

We're on the lookout for a new Honorary Treasurer!

Our Honorary Treasurer, Nick Bunt, is looking for a successor!

Nick is looking to stand down from this volunteer role within the next 12 months and we'd be very keen to hear from people who might be interested in getting involved in this aspect of the Trust's work.

The Honorary Treasurer is responsible for ensuring that the Trust's operational/strategic financial planning is undertaken and executed in the best possible way. He or she sits on the Trustee Board and works closely with the Chairman, Executive Director and



Nick Bunt

the Trust's Finance Sub-Committee. There are usually four Trustee Board meetings a year and two Finance Sub-Committee meetings; the Trust employs the services of an accountant and auditor to contribute to the preparation of internal and statutory paperwork.

If you, or someone you know, would like to understand a little more about what the role entails, please contact the Trust's office for a role description and/or email Nick at nickbunt@btinternet.com.

We look forward to hearing from you!

Sharing experiences

Have you got a story you'd like to share with other readers of MSA News about living with MSA? Perhaps you have experience of speech therapy, going into hospital, going on holiday – or other aspects of daily life with MSA you think readers might be interested to hear.

Perhaps you have some tips you've learnt that have made life easier, more comfortable, more enjoyable?

Well if you have, we'd love to hear from you!

Please write to Nickie Roberts at the Trust's office in Southbank House or email her at nickie.roberts@msatrust.org.uk. We will try our best to include your contributions.

The state of caring in 2011

Carers UK is conducting a major new piece of research into the impact on people's lives of caring responsibilities.

It is vital to gather experiences from every part of the country so that they can highlight how carers are affected differently.

Carers UK needs your help in making sure carers' experiences in your area are counted, by:

- Completing their online survey at www.surveymonkey.com/stateofcaring
- Emailing steve.mcintosh@carersuk.org to request a PDF version of the survey to fill in and return to the charity using FREEPOST

CARERS UK
the voice of carers

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. Members passed away during 2010.

- | | | | |
|-------------------|------------------------------|-----------------------------|---------------|
| • Terry Aldridge | • June Harrop | • Berjinder Sehmbi | • Keith Smith |
| • Alan Birkbeck | • Sheila Hibbert | • Diana Sharpe | • Gerda Still |
| • Tung Biu Lo | • Don Jackson | • Brenda Simpson | • Denis Tobin |
| • Bronwyn Bond | • Robert Jess | • William A J Sketch (Tony) | • Ruth Twena |
| • Edward Clarke | • Irene Jones | • Christine Smith | |
| • Irene Davidson | • Robert Killone | | |
| • Doreen Davies | • Anne McCabe | | |
| • Kevin Digby | • Marinos Nicolaidis | | |
| • Margaret Diston | • Marina Osmond | | |
| • Peggy Donovan | • Alison Pearce | | |
| • Malcolm Dunnell | • Ann Rushton | | |
| • Dorothy Gordon | • Denis Ryan | | |
| • Emile Harris | • Myrtle P A Seabrook (Tigs) | | |

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



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

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Hugh Matheson
Geoffrey Murray
Hon Mrs Clare Powell
Eileen Lady Strathnaver OBE
Karen Walker

Executive Director and MSA News Editor:

Nickie Roberts

All correspondence and enquiries to:

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www.msatrust.org.uk

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Company Number 7302036

Membership Numbers as of the end of 2010

Current MSA members	820
Other patient members	34
Relatives and carers	531
Professionals	1395
Others	190
Total	2970

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 support for people affected by MSA.

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 taxpayer 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 2nd May 2011

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.

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