Issue 20 Autumn 2006

SMarT News

The newsletter of the Sarah Matheson Trust

Contents

The Sarah Matheson Trust comedy Night held at the Comedy Store, Leicester Square

The Sarah Matheson Trust provides a support and information service to people with Multiple System Atrophy (MSA) and other autonomic disorders, their families and carers, health care professionals and social care teams.
We also sponsor and support research into MSA

From the SMT Office

Welcome to all our readers. This edition has a contribution from Professor Clare Fowler, the chair of our Medical Advisory Panel. She has been responsible for co-ordinating this panel, who, in line with the research position of the Trust, decide how to make the best use of the money available for research. We are in the fortunate position of being able to sponsor research in MSA and hope that just like our last researcher, Dr Tim Young, the next researchers will be regular contributors to SMarT news.

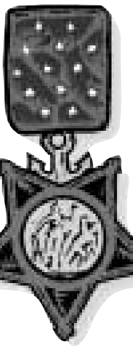
Our ability to sponsor research is possible, largely due to the contributions of our members, and their family and friends. The generosity of spirit shown by our fundraisers does generate welcome funds but the time and energy they devote though their endeavours is inspirational and a strong weapon in the fight against MSA. We hope you enjoy seeing (we have lots of great pictures) and reading about them here.

This edition also welcomes a new addition to the Trust team, Ian Bainbridge, the new support nurse. His background is acute nursing and more recently, with a men's health charity but he is already settling into his new role. I am sure that many of you will speak to him on the telephone or see him at support meetings over the coming months.

Now that our team is back to full strength you can expect to see the next edition early in the New Year and as ever we welcome any contributions that you are able to send us.

Catherine & Niki

Carer Awards 2006



We are happy to announce that nominations for our 2006 carers awards are now open.

We have two kinds of awards. The first, the personal carer award, is for a spouse, partner, family member, friend or neighbour. We want to know who helps you get through the day or the week, who keeps you smiling or who makes a difference by doing or saying the things that matter.

The second, the professional award is for any professional. This could be a therapist, nurse or doctor but it could equally be the shopkeeper who puts a chair out especially for you or the librarian who tracks down the talking book you want to listen to.

To nominate someone write or ring us with the persons name and the reason 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 the next edition of *SMarT News*.

This is your opportunity to say thank you. Get your nominations in by December 15th.

The SMT Medical Advisory Panel

by Professor Clare J. Fowler

Every morning when I get to Queen Square I put my swipe card in the reader to enter the National Hospital through a rather undistinguished looking black door, formerly a wheel chair entrance to the Hospital. But however unremarkable the door appears, if you look up there is a wonderful message above it: this is in the form of a panel sculpted in 1938 by Arthur J.J.Ayres RA a photograph of which has been produced at the top of this page. The message is inspirational and true: "Research - every addition to true knowledge is an addition to human power". Multiple System Atrophy is a condition for which we must be empowered to fight.

Since bladder problems are often such an early and constant features of MSA I have met countless patients with the condition over the years - probably seeing at least one patient with it every week, either an old friend or a new suspected case. For a long while I have felt, as must every other person who has contact with such patients, surely the cause and possibly a treatment will be found soon? Sadly there are no immediate solutions, although there is now some light. Through the generosity and determination of members of the Sarah Matheson Trust a considerable sum of money has been raised (see Treasurer Val Fleming for details!) and the Trustees have decided that it should be spent on medical research. I was honoured to be asked to chair the medical advisory panel and having accepted this position my first task was to select three highly regarded neurologists to assist me. These are Prof John Newsom-Davis, Prof Martin Rossor and Dr David Burn.

When deciding how a charity's money should be spent on medical research there is inevitably some tension between the decision to spend it in ways that alleviate the difficulties of patients now or to spend it on basic science as an investment for the future. So far the money you have raised has been spent in the former way but I and the other members of the medical research advisory panel felt that the time was right and the necessary money is there, to place an advertisement for the first Sarah Matheson Trust Research Fellow to undertake a basic science project. Applicants have been asked to submit proposals "focused on the mechanisms involved in the disease process of multiple system atrophy, with the

"Multiple System Atrophy is a condition for which we must be empowered to fight."

John Newsom-Davis CBE, MD, FRCP, FMedSci, FRS

John Newsom-Davis received his training at the University of Cambridge, the Middlesex Hospital Medical School, and the National Hospital, Queen Square, London. He was appointed MRC Research Professor of Clinical Neurology at the Royal Free Hospital and the Institute of Neurology in 1980, and Professor of Clinical Neurology in the University of Oxford in 1987, becoming Professor Emeritus in 1998. He was a Member of the MRC Neurosciences Grants Committee 1978-1980 and Neurosciences Board 1980-83 and 1992-96. He served as Chairman of the Neurosciences Board 1983-85, of the MRC Health Services Research Committee 1986-87, and of the Neurosciences Human Health Steering Committee 1992-1995. He was a Member of the Department of Health Central Research and Development Committee 1994, and Consultant Adviser in Neurology to the Chief Medical Officer 1994-96.

He completed seven years as the Editor-in-Chief of Brain in 2004. He was President of the Association of British Neurologists 1999-2001 and is a Founder member of the Academy of Medical Sciences. He was elected a Fellow of the Royal Society in 1991, serving on Council 1996-97. He was elected Foreign Associate Member of the Institute of Medicine, USA in 2001.

He remains active clinically and his research focuses on the pathogenesis and treatment of autoimmune and genetic disorders affecting the neuromuscular junction.

David J Burn FRCP, MD, MA, MB BS

Dr Burn is a Consultant Neurologist and Reader in Movement Disorders at the Regional Neurosciences Centre, Newcastle upon Tyne, UK. He qualified from Oxford University and Newcastle upon Tyne Medical School in 1985. His MD was in the functional imaging of Parkinsonism. He runs Movement Disorders clinics in Newcastle upon Tyne while his research programme is conducted through the Institute for Ageing and Health, University of Newcastle upon Tyne. Research interests include non-dopaminergic complications of Parkinson's disease and progressive supranuclear palsy. He was the Royal College of Physicians' representative on the Parkinson's Disease Guidelines Development Committee of the National Collaborating Centre for Chronic Conditions / National Institute for Clinical Excellence (2004-2006) is currently a member of the Medical Advisory Panels for the Progressive Supranuclear Palsy (Europe) Association and Parkinson's Disease Society. He has been the Association of British Neurologists' representative on Parkinson's disease Subsection of British Geriatric Society since 2003. He was a member of the Special Interest Committee Task Force of the International Movement Disorder Society for Diagnostic Criteria for Parkinsonian Disorders (2002 - 3) and is currently a member of the Dementia in Parkinson's disease Task Force. He has published over 98 articles on movement disorders in peer reviewed journals. In his spare time, he runs for Heaton Harriers and Northumberland Fell Runners.

potential of finding the cause and treatment of the condition.” The advertisement has been placed in a medical journal and we are waiting expectantly to hear from applicants. I very much hope it will be possible to give you an update of progress with this in the next edition of SMarT News.

A considerable amount of work needs to be done to enable medical research to come about – terms of agreements with academic institutions drawn up, details of finance to be sorted out and job descriptions prepared and much of this work has been done by Darcy Hare. However I know she would like me to acknowledge the unstintingly generous help given by Brigadier Michael Kobe who had done this work for the PSP Society and allowed us to use his documents as templates. We are very grateful to him.

Prof Martin Rosser MA, MB, BChir, MD, FRCP

Professor Martin Rossor graduated from Jesus College, Cambridge and Kings College Hospital Medical School, London. He directs the Dementia Research Centre at the Institute of Neurology and established a specialist cognitive disorders clinic which acts as a tertiary referral service for young onset and rare dementias. Clinical research interests are in neurodegenerative disease. He is consultant neurologist at St Mary's Hospital and the National Hospital for Neurology and Neurosurgery where he is Chairman of the Division of Neurology. He is editor of the Journal of Neurology Neurosurgery and Psychiatry and was recently appointed Director of the new Department of Health Clinical Research Network for Dementias and Neurodegenerative Diseases (DeNDRoN).

He holds positions on a number of academic committees and editorial boards as well as memberships of various learned societies.

Away from work he enjoys horse riding and sailing.

Volunteer required...

Readers will know too well that I normally write about the finances of the Trust. This note is on a different subject, it concerns the Trustees.

The Sarah Matheson Trust was formed in 1997 by Sarah herself, by members of her immediate family and by a few of her close friends of whom I count myself fortunate to have been one. Our average age was such that we were not all in full time employment and thus could give the necessary time to the creation of this fledgling support group.

Sarah has passed on, as readers will know, and there have been three retirements from amongst the original trustees as well as three additions; all younger people and working hard at their careers, but able to attend trustees' meetings and to carry out various tasks on an ad hoc basis.

All goes well, therefore, with one exception. Having served as treasurer of the SMT since its inception I have reached the age where - reluctantly - I too need to think of retirement. The role of treasurer is not arduous in the way it was initially, but nonetheless it does require a degree of focus and application which may appeal to someone approaching or having reached retirement age. As a reader of SMarT news he or she will already have some connection with MSA and might welcome the chance to join us in our determination to provide all the help we can to future sufferers.

Should the concept of becoming a trustee of the SMT appeal to you and more especially should you be interested in taking on the specific role of treasurer, please feel free to write to me c/o SMT at St Mary's Hospital. I should be delighted to hear from you and happy to talk with you further about what such a commitment would involve.

Val Fleming

Fundraising for the S

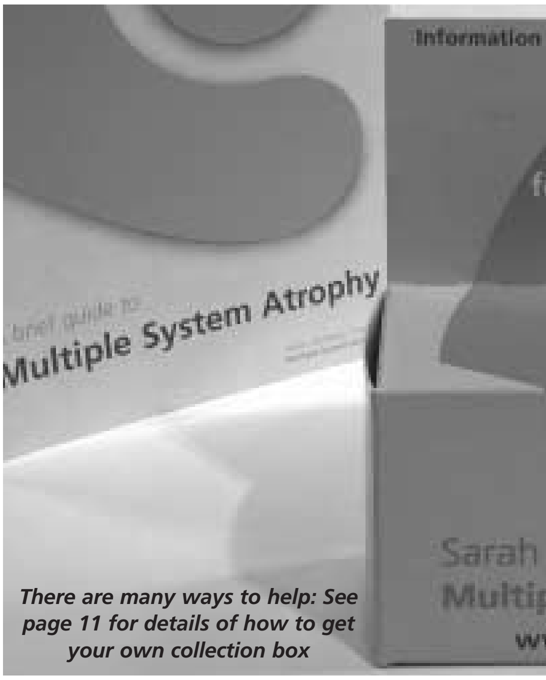
The Sarah Matheson Trust was founded by Sarah in 1997 in response to the shortage of information and support available when she was diagnosed. Sarah and the Trustees, many of whom were Sarah's friends and family, secured initial funding and financial pledges to sustain the trust through the first few years.

Because the Trustees knew that to maintain and develop services, fund raising would be an integral part of their role, they have led by example. They work tirelessly, organising and supporting events and have helped to inspire members who have the same motivation to raise funds. Our fundraisers are people who;

- want to provide finances to address the information shortage than can occur upon diagnosis of a relatively rare condition like MSA. They understand the value of the right information at the right time and want to make sure everyone else who gets a diagnosis gets the leaflets and someone to talk to.
- want to make sure that the Trust can provide free local training to health care professionals about the management of MSA. This training enhances the care they provide to people with MSA, another service vital with a rare condition.
- are passionate about contributing to research to help understand, treat and ultimately cure MSA.

Fundraising also enables families and friends who are not able to provide daily support, for example if they live a distance from the person with MSA, to do something tangible to show their support.

Although fundraising is hard work (sometimes the event is easier than collecting the cash!) it can also be fun, as you will see from the photos. It can help people to achieve personal goals like getting fit and gives you a great sense of accomplishment.



There are many ways to help: See page 11 for details of how to get your own collection box

What motivates me to raise money?

I was a member of the governing Council of the Architectural Association School of Architecture when Sarah Matheson was its Deputy Chair. She was always terribly jolly, vivacious and kept us very well organised. So it was a particular shock when, a couple of years after I had resigned from the AA Council, I received a letter from the school telling me of a new trust which Sarah had set up to help people suffering from the same little known and incapacitating disease as she was. Apart from my sadness about Sarah, I am ashamed to admit that the setting up of the SMT made little impact on me and I had little idea of what MSA was.

A couple of years on and my brother's Parkinson's Disease had been re-diagnosed as MSA and, having seen first hand the trauma that the lack of knowledge about MSA could bring to families, I asked my brother if there was a support organisation dealing with the condition I could give some money to. "Yes" he said "It's called the Sarah Matheson Trust". I remembered the letter from the AA school. Whether it was fate, God or just plain coincidence - I knew my number had been called.

So that got me started. I am not a sporty person but I had taken part in a few charity bike rides and thought that if I did something really extreme people would support me. I started with Lands End to John O'Groats, then I did the route of the Tour de France and recently organised a relay ride from London to Cannes in four days. I've raised about £200,000 in the last five years for several charities including SMT.

What drives me on is a mixture of things. It is talking to the SMT nurses; I am inspired by the work they do and how there is so much to be done which we cannot yet do. It is looking at the accounts and realising that that without money we can do nothing. It is meeting people who are dealing with suffering with great courage. It is the anger and guilt I feel when I recall my brother struggling to rise from a chair, falling over, telling old jokes in a voice that was barely audible with a smile that was barely recognisable. My ability to pedal for long distances is the antithesis of his condition; I know the pain and the exhaustion I feel is nothing to that which he felt, and that helps me carry on.

I am also driven by the satisfaction of doing it; when in March I went

arah Matheson Trust

We are keen to maximise any money raised by keeping administration costs are kept to a minimum. All our Trustees work without pay, with the exception of the support nurse, are staff are part time, like Niki or like Catherine, are part funded by the Trust and part by the NHS.

We use office supplies economically whilst understanding the need to have information that is readily available and free of charge.

The Trust believes strongly in the benefit of partnerships and has been fortunate since its beginnings to have the ongoing support and expertise from Professor Mathias and the organisations he is associated with; Imperial College University, University College London, St Mary's NHS Trust and the National Hospital for Neurology & Neurosurgery (part of UCL Hospitals NHS Trust).

We are always delighted to include all fundraising activities together with pictures in the newsletter and believe in thanking and acknowledging individuals or teams - we love to provide a certificate of recognition. However we can also help before the event as we are a small enough team to take a personal interest. Niki, our administrator has developed a fundraising pack which can be customised to your specific event. She has information about MSA and what you are fundraising for, sponsorship forms, information about on-line sponsorship, gift aid information and much more. She can also help with publicity and is keen to help with a publicity plan to raise awarness of your events and the SMT. Anything that we can do to support your fundraising we will try to provide. Let us know as soon as you can before an event, Niki works part time, so if you let us know your plans early it gives us a chance to get organised.

We hope the following fundraising photos and stories will get you thinking and planning…

Peter Murray celebrating a past fundraising event

to meet the runners who were supporting SMT at the end of the London Marathon, the pride in achievement is every evident - and I think that for people to sustain their money raising activities it is essential that they get something out of it too.

As to raising money I start from the premise that those that have money, who enjoy the benefits of a good and productive life have a duty to support those with less. So I have no reservations or shyness about asking for money. My tip for raising money is to be able to plug into companies' marketing budgets rather than their charity department. This means you generally have to display their logo prominently and they will have to perceive this as a commercial benefit. So often a letter to the person dealing charity donations comes back "You will be aware we receive many requests for such charitable donations, however we are sorry to say that we have allocated all our funds for this financial year but we wish you the very best in your endeavours." I am lucky to bin contact with people in the property business who not only often have quite a lot of money but are in a business with a tradition of very generous giving. Companies will pay £500 to put their logo on my shirt particularly if I can get a photograph of myself in one of the trade papers showing off their logo. Collecting smaller amounts from friends and relations is a lot harder work, but it has to be done!

I try to do my rides every couple of years so that donor fatigue doesn't set in and I always send out a thank you leaflet with photos to prove I've done it and to show how tough it all was!

Peter Murray, Trustee

Fundraising events across the UK & beyond

Croydon 10k run

Sarah Moulsdale raised a fantastic £550.00 by completing the Croydon 10k in 1hr 11mins. Her husband Kris sacrificed trying to beat his personal best to run with Sarah all the way. Running is now a family affair as Sarah's sister Faye ran the London Marathon in 2004 for SMT

Bath Half Marathon

The Johnson Family run! 11 members of the Johnson family ran a great race raising valuable funds from individual and corporate sponsors, but also raised awareness through an amazing amount of press coverage for the Trust and Multiple System Atrophy.

Some of the Johnson family

The Plymouth to Banjul challenge (in a Ford Sierra)

Matt Grove and friends are to be congratlauted on their quest to conquer the Sahara desert in their blue Ford Sierra! What an experience it must have been driving through from the UK, down to Spain, Morrocco via the Atlas mountains to the sandy planes of Western Sahara and Mauiritania - finally reaching Banjul in the Gambia.

Its unbeliavablke that everyone came out unscathed in what became a

Comedy Night at the Comedy Store, Leicester Square

The Sarah Matheson Trust Comedy night on Monday Feb 13th was a fantastic success. Firstly it was a great laugh - an essential ingredient of any comedy night, secondly we had a packed house selling almost 400 tickets to fill The Comedy store and thirdly we raised £6,500 for the Trust!

Host Mark Maier had assembled a fantastic line up of comics: Paul Tonkinson opened up followed by the quick fire Adam Bloom. Radio 4's Count Arthur Strong preceded the well known Irish Comic Ed Byrne. The last two acts were Brummie Andy Robinson and Ventoliquist Paul Zerdin.

Lots of people donated fantastic prizes which were raffled off throughout the course of the evening.

Compere Mark Maier

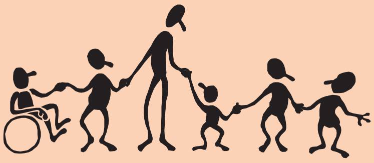
Sid Cantle with Paul Zerdin

One of the SMT members who came to the night said "Since being diagnosed with MSA most of my experiences have been about doctors' appointments and disability. I came to the comedy night and had a great time, It was wonderful to finally have a positive experience because I have MSA". In fact one of the stars of the show was MSA sufferer Sid Cantell who ended up on stage as Paul Zerdin's ventroliquist's dummy, it proved a fitting finale the evening reminding everyone that they were to have some fun and to support everyone affected by MSA. The smile on Sid's face was a mile wide!

It was such a good night that we're planning on repeating this roaring success next year too!

Mark Maier with a lucky prize winner Gregor legendary car! Matt and his fellow desert devils managed to raise funds for the SMT and gained support from a host of corporate sponsors.

These included: *The Daily Telegraph* Adventure & Travel Show, Saxon Forge, Verwood Ford, Tesco (Salisbury), Clarion Events, BBC radio Solent, 2CR fm, *The Daily Echo*, David Lloyd Leisure, Oswald Bailey, Big Head Fasteners, *Verwood Viewpoint Magazine* and the Real Log Cabin Co



Thoresby Park Walk

We held our 2nd Thoresby walk on Sunday 10th September 2006. It was great fun and successful in every way. We raised £1,000 for SMT. About 40 people met at the Thorseby Gallery in Thoresby Park near Ollerton, Notts. The 6 mile walk was led by Hugh Matheson through the beautiful park, with many of the ancient trees laid out by Repton in the 18 century.

We stopped for a picnic lunch at the stone pyramid built to comemerate the Battle of the Nile. Afterwards we were led through some of what remains of Sherwood Forest with it's mighty oaks and across the chestnut avenue where we met a flock of what looked like wild sheep.

We ended up walking down an avenue of massive cedars and back to our starting point where we were provided with delicious tea and cake. It was a chance to meet and talk as well as providing a huge challenge for some of our members who had been sponsored and so were determined to complete the walk despite their disability.

We look forward to doing this walk again next year and we hope you can join us in 2007. Entry for this funwalk is either by sponsorship (forms available from the SMT office) or by donation on the day.

Calais to Cannes bike challenge

Our aim was to ride the 1500km to Cannes for the MIPIM property exhibition (the biggest event in the real estate calendar) in the shortest time we could and raise ?100,000 to share between four charities including SMT and the National Hospital for Neurology and Neurosurgery.

Our original plan was to cycle in relays 24 hrs a day, sleeping in a double decker bus with bunks as we went, but legislation controlling the number of hours our bus drivers could drive without rest meant that we had to content ourselves with riding from 5.00 am to 10.00pm.

There were 17 of us - architects, lawyers, surveyors, all involved with property in some way. We divided into three teams who cycled three hours on, six hours off. The English leg of our journey was from The Mall to Canterbury - roughly following the route of the Grand Depart of the Tour de France in 2007.

We left Calais on the morning of Friday March 9; the sky was overcast but the wind was behind us, a piece of luck that didn't change the whole journey.? As the day went on so the rain came; cyclists arrived at the Soissons campsite in sodden state. On Saturday as we sped on towards Dijon we hit a numbing blizzard and as the snow began settling dangerously on the road, riders were ordered off the road. The planned campsite was abandoned and an hotel found to thaw out feet and hands. The next morning was thirsty work for the five o'clock riders who couldn't drink after their water bottles froze solid in the sub zero temperatures.

As we moved south the ice gave way to more rain, we passed through the valley of the flooded Saone river and then into some big hills. We didn't make the camp site for Sunday night and instead slept in a supermarket car park a few miles west of Mont Ventoux, one of the most famous climbs in cycling.

On Monday the weather miraculously improved with bright blue skies and a following wind? we moved through the Luberon in perfect cycling weather. Fantastic scenery and some great descents. We stayed? the night at Frejus before riding into Cannes on Tuesday March 14. The whole team rode up the Croisette to the Palais de Festival where each rider was presented with a commemorative medal by the managing director of the MIPIM organisers and then on to the London stand where Mayor of London Ken Livingstone was presented with the baton that had been carried all way from from the Mall.

The Everest Trek: Michael Gooding, Andrew Giggs, Daniel Parnell, Martin Lewis, John Staniland, Rachael Staniland, Johanna Grove, Mathew Grove and Clive Grove

Hydro Active Women's Challenge

On Sunday September 3rd the Hydro Active Women's Challenge came to Hyde Park. Living a mere half a mile from the starting point, I could hardly say no to taking up this challenge, even if with a great deal of nervous excitement. I've had dreams of taking part in a marathon event - and admire anyone who does, but I think that this is a reasonable target to set myself for now!

I'm glad to say that I somehow encouraged my colleagues at St Mary's hospital to join in. So Hannah, Madeline (the two scientists within the neurovascular unit) and I ran for the SMT - The Hydro Active is also taking place at the City Centre, Birmingham and Sefton Park Liverpool….why not join in….

Donna Wilson with her husband Keith, after having completed The Great North Run in 2 hours 31 minutes. She raised £1,070 for SMT

Helen Parker, with her fatherPeter Coombe who has MSA, showing her Great North Run medal. She completes the course in 2 hours 28 minutes. She raised £250, which her employer, Barclay's Bank, will match.

Flora London Marathon

Congratualtions to the Sarah Matheson Trust runners, all of who successfully completed the 26.2 miles. Most of them still had enough energy to make it tothe Red Lion pub in Great Windmill Street. We are grateful to Marie, the landlady of the pub for giving us the space for free. This proved to be a great place for the family and friends of the runners to meet their athletic relatives and admire their well deserved marathon medals. Several of the trustees were also able to welcome the runners. They were delighted to be able to thank people in person for the contribution they make to the Trust.

Runners' times:

Allan Comette	4 hours 43 minutes
Mark Doherty	6 hours 04 minutes
Ludovic Floch	3 hours 58 minutes
Simon Harrison	3 hours 50 minutes
Robert Leslie	4 hours 31 minutes
Mark Steel	3 hours 51 minutes

Allan Cornette

Mark Steel with his partner Helen and baby Lottie age 6 weeks...

...and with fellow runner Robert Leslie

We will publish any reports and photographs in the next edition of *SMarT News*. Please let us know of any fundraising events taking place so that we can let the Sarah Matheson Trust membership know.

The Sarah Matheson Trust Christmas Card

Number of packs	Total cost including postage
1	4.00
2	7.75
3	11.50
4	15.30
5	19.25
6	23.00
7	27.85
8	31.65
9	36.00
10	39.50

Cards of one design are available in packs of 10 for £3.50 per pack + postage.

The greeting reads (in colour)
“With Best Wishes for Christmas and the New Year”.

Please send us the order slip below telling ushow many packs you would like.
Please make cheques payable to the “Sarah Matheson Trust” and send to:
Sarah Matheson Trust, Pickering Unit, 2nd Floor, QEQM Wing,
St Mary’s Hospital, Praed Street, London W2 1NY

Thank you for your support.

Sarah Matheson Trust Christmas Card Order

Name ....

Address ....

Postcode ....

Tel no. ....

Number of packs ....

Total payment sent ....

In Memory

Donations received with gratitude in memory of:

- Dr Mary Anderson
- Richard Bailey
- Alan Bartlett
- Leonard Beckett
- Pamela Boshell
- Iris Branch
- Irene Buchan
- Sid Cantle
- Jessie Carrington
- Brian Carter
- Moly Coles
- Sheila Cronin
- Marlene Cumpstey
- Hugh Duncan
- Vera Faulkner
- Stanley Frost
- Leonard Green
- Geoffrey Greenwood
- Robert Godsell
- Jeremy Hewlett
- Mike Hooper
- Peter Johnson
- Roy Light
- J Lindley
- Ethel Loydall
- Megan Knibbs
- Irene Masters
- Robert Mears
- Yvonne Mew
- Kathleen Montgomery
- Barbara Morgan
- William Moseley
- Mollie Parkinson
- Fred Parsons
- Joyce Pollard
- Vincent O'Reilly
- Gwen Roberts
- Bob Roberts
- David Rundle
- Abraham Rutherford
- Barbara Smith
- Linda Stone
- Rodney Sowden
- Jan Stevenson
- John Terry
- Dudley Thomas
- Frederick Herbert Thompson
- John Towers
- Peter Visagie
- Kenneth Webb
- Bill Webster
- Jean White
- Brian Whittle
- Michael Wilson
- Declan Woods

Legacies received from the estates of:

- Royston Lindley

Permobil Entra available

I have a Permobil Entra fully adjustable wheelchair, which I am prepared to lend free-of-charge for as long as it is required to anyone with MSA. The borrower would have to arrange transport and be prepared to maintain the chair in good order, including an annual service (approximately £100) which would become due in November 2006. Please call leeds 0113 256 9466 if interested.

Gillian Rawson

Badges

Enamel lapel badges are available that members can wear or sell to raise awareness. They come mounted on card with information about MSA and the Trust. Contact the office for more information.

Collection boxes

Flat pack cardboard collecting boxes are available on request. Collections/donations however small are always appreciated by SMT and help us to continue our services free of charge.

Tips and hints

Difficulty chewing?

Are you having difficulty chewing? Have you been advised by your speech therapist to have a soft diet? Help is at hand to keep your diet varied, tasty and interesting. Try 'The Non Chew Cookbook' by R Wilson (available from Amazon) or the following websites:

British Dietetic Association - http://www.bda.uk.com
East to Swallow - http://www.easytoswallow.co.uk
Bon appetite!

Sarah Matheson Trust for
Multiple System Atrophy

Information, Support, Education & Research in Multiple System Atrophy and other autonomic disorders.

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

- Information leaflets and newsletters
- Specialist nurses
- Telephone advice line
- Regional support meetings
- Training and education sessions
- MSA research
- Communication Aid Loans
- Welfare Gift Scheme

All correspondence and enquiries to:
Catherine Best (Nurse)
Niki Ranade (Administrator)

Sarah Matheson Trust
Pickering Unit
St Mary's Hospital
Praed Street
London W2 1NY
020 7886 1520
020 7886 1540 (fax)

www.msaweb.co.uk

The Trust is financed entirely by voluntary donations.

Registered Charity Number 1062308

Ways to support the SMT

Become a fundraiser

Events such as coffee mornings, car boot sales and a wide variety of sponsored events bring us valuable income every year. New ideas always welcome!

Use our online fundraising/donation facility

We now have the facility for you to use the online fundraising package on www.justgiving.com . You can create your own personalised online sponsorship page to raise money for the SMT for a sporting event (such as a marathon or trek), a personal occasion (a birthday or anniversary), a sponsored event (such as a spellathon for your school) or maybe in memory of someone who supported the SMT. You can also make online donations.

Become a regular donor

Donations by monthly or annual direct debit however small will help us maintain our services.

Gift Aid

Don't forget to GiftAid any donations to increase the value of your donation by 28% if you are a UK taxpayer.

Contribute to *SMarT News*

Sharing your experiences and tips with other members helps keep it your newsletter. We would particullarly like to hear of any experience with complimentary medicine in relation to MSA.

Form a local SMT group

Linked with the SMT but independently run to provide what the local group wants (e.g. information, mutual support and social contact). There are currently two groups: East Midlands and Essex.

Raise awareness about MSA

Share our information with family, friends and all the health professionals and care staff you meet.

The SMT staff can offer practical guidance if you are interested in taking part in any of these activities.

Gift Aid It!

Did you know that if you are a UK taxpayer we can increase the value of any donations you make to the SMT by 28%? This could raise the SMT as much as £20,000 extra per year to support our work.

We now include Gift Aid in all the sponsorship forms and fundraising packs. Gift Aid declaration forms are available from the SMT office.

Awareness Day dates for your diary

- **Cornwall** – Thursday 9th November
- **Kent** – Friday 24th November

All our members will automatically be notified of any Awareness Days held in their area; an invitation will be forthcoming once the date and details are fixed.

Membership Numbers

as of May 2006

Current MSA members	741
Past members (since 1997)	480
Other patient members	39
Relatives & carers	315
Professionals	1291
Others	126

Newsletter Mailing:

Thank you to those of you who updated their information after the last SMarT News was mailed for us by the Mailsort company. Please do continue to let us know if your circumstances change.

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