



# SMarT News

The newsletter of the Sarah Matheson Trust

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*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 Office

**W**e at the SMT wish all our readers a pleasant 2009. This edition leads with a brief description of autonomic testing centres and various tests carried out at two international neurological centres, which are based in London. You may notice that this edition has been published in colour; we hope you like the new format.

There are one or two staff changes. In September 2008 we reluctantly accepted the resignation of the SMT Administrator, Natalie Fernandes. Natalie had soon settled in and quickly became an efficient and well liked member of the team, but unfortunately had to leave the Trust because of ill health. We wish Natalie all the best for a swift and full recovery. Linda Campbell, a previous SMT Trustee and volunteer for the Trust is now the new permanent part-time SMT Administrator. We welcome Linda back to the Trust.

Lee Potiphar, the full-time SMT Nurse, is leaving to become a UK Clinical Research Nurse within the UK Clinical Research Network, based at St. Mary's Hospital in London. Lee has thoroughly enjoyed his time at the Trust. A new nurse is being recruited at the moment. Samantha Pavey, who works part-time as the MSA Specialist Nurse, will cover all calls and emails while the recruitment process is in progress. Linda will answer calls and emails to the office as normal and pass these on to Samantha, if required. We always endeavour to answer all calls, emails and letters as quickly as possible. However, please be patient with us over the coming 2 to 3 months, while a new nurse is being recruited and trained.

We are looking forward to putting together and publishing the next issue of *SMarT News*. The Sarah Matheson Trust warmly welcomes any contributions that you are able to send (by 15th May 2009 for the next issue) and hope that the contents of this edition will be both helpful and informative.

**Lee, Samantha and Linda**

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**Please note:** There have been a few instances of SMT members calling the wrong telephone number or writing part of the address incorrectly. Please only use the telephone numbers above and if writing to us, use Box 200 as part of the SMT address.

# Treating and Researching MSA and Parkinson's Disease

## – the Role of the Autonomic Nervous System in Health and Disease

Andrew Owens, the Clinical Research Coordinator for the Neurovascular and Autonomic Medicine Unit at Imperial College London, describes the work carried out at two major autonomic testing and treatment centres. He also describes the early stages of an interesting clinical study.

In your treatment for MSA your consultant may have been one of the Patrons of the Sarah Matheson Trust, Professor Christopher Mathias. Professor Mathias has been a Consultant at St Mary's Hospital since 1982 and at the National Hospital for Neurology and Neurosurgery (NHNN), Queen Square since 1985. He is Professor of Neurovascular Medicine at Imperial College London and the Institute of Neurology, UCL. Professor Mathias is Clinical Service and Research Director of these two leading departments that specialise in autonomic and neurovascular disorders. Both Units are referral centres for the UK, Europe and

worldwide. The Neurovascular and Autonomic Medicine (Pickering) Unit at St Mary's Hospital is also home to the Sarah Matheson Trust's London-based office.

At the two Units, scientists, clinicians and specialist autonomic nurses work together in treating a wide spectrum of autonomic disorders and dysfunction, particularly in neurological disorders, such as Multiple System Atrophy (MSA) and Parkinson's disease (PD). Other cardiovascular autonomic disorders treated include, postural hypotension, neurally mediated syncope (fainting), vasovagal syncope, abnormalities of



*Professor Mathias*

temperature regulation (hyperhidrosis [excessive sweating] and anhidrosis [lack of sweating]) and medical diseases involving the autonomic nervous system, some common such as diabetes mellitus and others

with devastating outcomes, if untreated, such as amyloidosis (a condition where amyloid proteins are abnormally deposited in organs and/or tissues).

The breadth and depth of their work in many diseases enables the team to deal with the various complex autonomic-allied problems with MSA. This holistic approach is crucial in improving care and preventing complications in MSA.

The Autonomic and Neurovascular Medicine Units have pioneered and implemented many advances for autonomic and allied conditions that aid diagnosis, understand underlying abnormal mechanisms and thus improve care for patients with various forms of autonomic failure. Treatments include drug therapy and are combined with lifestyle management, education, information and counselling. In addition the Sarah Matheson Trust offers an integrated service for patients with MSA, providing advice and support.

### *The Autonomic Team at the National Hospital for Neurology and Neurosurgery*



### MSA & Parkinson's Disease – Droxidopa (L-Dops) Clinical Study

As well as their clinical services, both Units have earned international recognition as unique ground-breaking centres for advancing the field of clinical autonomic research.

One drug advance is likely to be the replacement drug Droxidopa, which will be tested shortly in a large international trial. Professor Mathias is a Principal Investigator for Europe and his units are key research centres in the clinical study to define the efficacy of Droxidopa on reducing orthostatic hypotension in MSA and Parkinson's disease. Droxidopa has a major advantage as it can be given by mouth and is converted in the body to noradrenaline, the depleted natural neurotransmitter, which can otherwise only be administered intravenously. Detailed description of the trial and details of enrolment will be described in the next edition of *SMarT News*.

The Units are also embarking on a collaboration with the Parkinson's and Ageing Research Foundation in Bangalore, India, to determine if certain types of autonomic dysfunction signify the early onset of MSA and Parkinson's disease, even before the typical motor features occur. If successful, this may not only prevent the onset of the debilitating disabilities that characterise the disorder, but also make it easier for MSA and PD to be diagnosed and differentiated early on in the disease process. This has potential implications for using neuroprotective drugs at a very early stage of these diseases.

The Units' many research contributions of direct relevance to patients' well-being include the key role of cardiovascular autonomic responses to essential activities in daily life, such as exercise, eating and standing upright. These unavoidable stimuli can trigger hazardous responses, if the patient has a malfunction of the autonomic nervous

Continued on page 4

### Clinical Autonomic Scientists at St Mary's Hospital

The Clinical Autonomic Scientists in the Neurovascular and Autonomic Medicine (Pickering) Unit at St. Mary's Hospital, London are Madeline Tippetts and Michael Peche; with a third clinical scientist shortly joining them. Their roles have been pioneered by Professor Mathias and involve testing and investigating patients with a wide variety of conditions affecting the autonomic nervous system, which supplies every organ in the body and also controls key functions, such as maintaining blood pressure and body temperature.

Autonomic malfunction is a common component of MSA, Parkinson's disease, and diabetes, amongst many other disorders. Such disorders are also a cause of syncope (fainting) in addition to other common disorders such as vasovagal syncope and Postural Tachycardia Syndrome (PoTS). Autonomic disorders affect a broad range of body systems, some crucial for survival, such as blood pressure control during standing (causing postural hypotension) and, thermoregulation (with excessive or diminished sweating, and abnormal overheating or chilling) as well as influencing



Testing on a 'tilt table'

bladder, bowel and (in males) sexual function.



The testing equipment

and exercise) using non-invasive techniques and state-of-the-art equipment. The results of these tests enable our clinicians to diagnose autonomic disorders with greater accuracy, to decipher which aspects need treatment, and to plan the most appropriate interventions and drugs required. Importantly, the tests enable monitoring progression or reversal of disease and the effects of treatment that could cure or reduce autonomic dysfunction.

Professor Mathias states "the Unit has a longstanding reputation as a centre of clinical and scientific excellence for a wide range of autonomic conditions. Michael and Madeline are crucial in diagnosing and evaluating suspected autonomic disorders. Their combination of clinical and scientific expertise enables us to pioneer and introduce new advances in neurovascular and autonomic medicine, which is of direct benefit to patients".

**Andrew Owens, Clinical Research Co-ordinator  
and Lee Potiphar, Autonomic Liaison Nurse**

system. Blood pressure can be dangerously lowered with postural change (such as on standing), food ingestion and modest exertion, which then reduces blood flow to the brain and other vital organs, especially when upright. Symptoms due to postural hypotension can be very debilitating for patients reducing their quality of life and may result in falls and injury. The Units' clinical research thus helps those affected by autonomic malfunction and is of practical importance.

The autonomic nervous system remains a relatively under-appreciated area of medicine and the Units continue

to see patients with medically unexplained symptoms, erroneously thought to be psychosomatic and without a medical basis. This is why we at St Mary's and the National Hospital at Queen Square place considerable emphasis on raising awareness about the autonomic nervous system, its

functions and dysfunctions and wish to spread this knowledge among the general public, healthcare and medical professions.

**Andrew Owens**  
**Clinical Research Coordinator,**  
**Imperial College London**

For further information about Professor Mathias and the Autonomic and Neurovascular Medicine Unit, please visit: [www1.imperial.ac.uk/medicine/people/c.mathias/](http://www1.imperial.ac.uk/medicine/people/c.mathias/) and [www1.imperial.ac.uk/medicine/about/divisions/neuro/npmdepts/clinneuroscience/neurovascular](http://www1.imperial.ac.uk/medicine/about/divisions/neuro/npmdepts/clinneuroscience/neurovascular) respectively. If you would like further information about future clinical research or the upcoming Droxidopa study, please email me at: [a.owens@imperial.ac.uk](mailto:a.owens@imperial.ac.uk)

## Research update

One of the main objectives of the Trust is to improve the scientific understanding of the disease process involved in MSA by funding medical research. Thanks to the wonderful generosity of our donors we have been able to award considerable funds for supporting research.

In the last *SMarT News* (Issue 23) we reported a project supported by the Trust, which began in January 2008. Professor Tamas Ravesz and Dr Janice Holton, who are based at the Queen Square Brain Bank for Neurological Disorders, supervised the project. Its aim was to gain further understanding of the mechanisms involved in the formation of 'glial cytoplasmic inclusions' (GCIs). This research area is of particular importance because it has previously been shown that the number of GCIs increases with the duration of disease and greater neuronal cell loss. The results of this project are currently undergoing analysis and a manuscript is being prepared for publication.

The Trust advertised again in 2008, inviting applications for project grants of up to 3 years. The Trustees sought



advice of members of the Trust's Research Advisory Panel, who reviewed all of the applications that were received. We are delighted to report that they strongly recommended two applications, which we will be supporting over the next three years.

One of these projects will be under the supervision of Dr Holton and will look to extend the current research investigating mechanisms underlying GCI formation. The study should increase our understanding of the development of the cellular pathology in MSA and might well lead to rational treatment development.

Dr Henry Houlden will supervise the second project. Although MSA very rarely runs in the family, a number of risk factor genes may contribute to the development of the disease. This

project will aim to examine these genetic risk factors in order to reveal more about the cause of MSA and potential treatment possibilities.

Dr Houlden is at present creating a bank of volunteers who have been diagnosed with MSA (and where possible, their spouses) to provide blood samples. The blood samples will be used for DNA analysis. For further information about this project, please contact Dr Houlden on [houlden@ion.ucl.ac.uk](mailto:houlden@ion.ucl.ac.uk) at The Institute of Neurology and The National Hospital for Neurology and Neurosurgery, Queen Square, London WC1N 3BG. We will keep you fully informed of the project's progress, in future issues of *SMarT News*.

**Darcy Hare**  
**SMT Trustee**

# Saliva Control

The SMT nurses have received a number of enquires, both via the telephone and at support and awareness days, regarding issues related to saliva control. Samantha Pavey, the MSA Nurse Specialist at the Trust provides a brief overview of issues related to saliva control.



Samantha Pavey

Some people may experience discomfort and embarrassment due to reduced saliva control. Saliva plays an important function in the mouth, helping to break down food while also protecting the mouth from drying out and cracking. However either too much or too little saliva can cause a number of problems.

We all produce about a litre and a half of saliva every day. When we are healthy, we swallow frequently. People with MSA may have a reduced swallow reflex and therefore the saliva can pool inside the mouth. Alternatively, saliva may be thick and difficult to swallow. Some types of medication may cause the drying up of saliva and a dry mouth.

So, what can be done to help reduce the problems of poor saliva control? In addition to your GP, a Speech and Language Therapist (SaLT) is an obvious first point of contact for assessing and providing advice on

issues related to swallowing. Recommendations might be made, by your SaLT, regarding food and drink, posture, changing routine and possible exercises to strengthen the lips. Medication might also be recommended, such as glycopyrronium or hyoscine. However, all treatment should be discussed with your GP, particularly before proceeding with any new medication. The SMT strongly advises anyone who is worried about their medication or any side effects to speak to a Doctor or Specialist Nurse, immediately.

A range of measures can also be carried out to reduce the thickness of

saliva, or if there is a problem with production, helping with too little saliva. I have produced a practical guide detailing saliva control, which should be available on our website soon. I am happy to take calls related to general issues about saliva control: telephone 020 8150 6250.

**Samantha Pavey**  
MSA Nurse Specialist

Please note: The information compiled represents suggestions only. It should not replace individual assessment and treatment by an appropriate specialist.

Please also refer to Issue 19 of *SMarT News* (Winter 2005) for a more detailed discussion of speech and swallowing in MSA. The article can be downloaded via our website, under 'backcopies of *SMarT News*', see: [www.msaweb.co.uk/smart\\_2005\\_winter.pdf](http://www.msaweb.co.uk/smart_2005_winter.pdf).

If you have any particular issues you would like published in future editions of *SMarT News*, please phone Linda at the office on: 020 – 7886 1520.

## Carer Awards – Nominations Now Open!

We are happy to announce the re-introduction of the 'Carer Awards', which were last run in 2006 (see issue 20). 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 want 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.

The second is called the professional award and is for any professional. This could be a therapist, nurse or doctor



but 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 someone write or ring 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 the next edition of *SMarT News*. This is your opportunity to say thank you. Please get your nominations in by the end of April 2009.

The table of regional support groups, published in the previous two issues, proved so successful that we have decided to re-publish it. A new support group has been created in the Gloucester area – we thank Janice Davies for being willing to provide the time, effort and venue for the group. Further information on support groups can be found on the SMT website ([www.msaweb.co.uk/](http://www.msaweb.co.uk/)) under 'our services'.

Region	Contact Point	Address
<b>East Midlands Group</b> Meets twice per year	Mrs Elizabeth Brackenbury Tel: 0115 933 3083 Or, Mr Ian Jones Tel: 0115 919 9294 i.jones5@ntlworld.com	Holme Pierrepont Hall Holme Pierrepont Notts NG12 2LD
<b>Essex Group</b> Meets twice per year	Lady Laurelie Laurie Tel: 01206 210 410	The Old Rectory, Little Tey, Colchester, Essex CO6 1JA
<b>Yorkshire Group</b> Meets twice per year	Ms Karen Walker Tel: 077103 12552 Or, 01274 861 947	In the first instance, please phone or email: karenwalker@BH-CC.co.uk
<b>Lancashire &amp; Merseyside Group</b> Meets 4 times per year	Mrs Ann McLennan Tel: 01704 568 353 annandon@btinternet.com	72 Lynton Road Hillside, Southport PR8 3AP
<b>Cornwall Group</b> Meets 4 times per year	Mrs Jane Handy Tel: 01726 74792 Or, Ms Jan Pearce Tel: 01726 861361 Moonbeams@ymail.com	Address to be confirmed
<b>Gloucester Group</b> Meets (possibly) twice per year	Ms Janice Davies Tel: 01242 224617 <a href="http://www.thehewlett.co.uk/index.htm">www.thehewlett.co.uk/index.htm</a>	The Hewlett, Harp Hill Cheltenham, Gloucester GL52 6QG

These support groups are run entirely by members of the SMT, for the benefit of those whose lives have been impacted by a diagnosis of MSA. If you are interested in the possibility of running your own local support group, the SMT would warmly welcome your enquires and assist in providing relevant information and guidance on how to start one up.

### Gloucester

A new support group was started on 10th December 2008. The first meeting was held in the lounge area of a comfortable public house in Cheltenham (<http://www.thehewlett.co.uk/>). The meeting went very well, with 9 people turning up. The SMT Nurse provided a brief overview of MSA and treatment options. A number of questions were raised by those attending. A selection of sandwiches was provided and everyone left feeling that they had got something worthwhile out of attending. A date for the next meeting will be placed in a future issue of *SMarT News* and on the SMT website.

**Janice Davies**



*Everyone in deep contemplation*

## Cornwall

On Wednesday 1st October, the new Cornwall Support Group organisers held their first SMT meeting at Summercourt Village Hall (in mid Cornwall). It went very well, with everyone enjoying the informal presentation, provided by the SMT Nurse. Everyone had a good chat, with a local Parkinson's Disease Nurse also attending. Coffee and tea was provided, with a range of sandwiches to

choose from, and Jane baked a scrumptious cake!

Finding suitable venues to cover such a large area, as Cornwall, is challenging. So, if anyone would like a meeting nearer to where they live, or has any other ideas on staying in touch; please contact us so that we know where to focus our efforts.

The next meeting is scheduled for Friday 27th March at Connor Downs,



*Chatting, eating cake and drinking tea*

near Hayle. The venue will be in the WI Hall from 11am to 3pm.

**Jan Pearce and Jane Hardy**

## East Midlands

We met on a lovely day in autumn, 1st October, and were very happy to welcome two new members to our group. Some old friends, who have supported us right from the start, were sadly unable to be with us. Our thoughts go out to them.

Lee, the SMT Nurse, came to the support group and talked to us. He provided a brief but informative presentation on MSA, looking specifically at typical symptoms and



*Sitting, chatting and eating cake*

practical day-to-day management. Lee handed out a very good printout of the points he was making and was able to clarify and clear up some previous

misconceptions, which proved very beneficial for all concerned.

We had the usual tea and cakes while people chatted with one another, which everyone enjoyed. A raffle was also held, which raised £16.00. There was a good turnout, with about 15 people present at the meeting. We plan to meet up again on Wednesday 29th April from 2pm to 4.30pm at Holme Pierrepont Hall.

**Elizabeth Brackenbury,**  
SMT Trustee

## Essex

Our support group met again on 30th October when about 28 of us sat down at 1pm in Great Tey Village Hall for a meal of Shepherd's pie and pavlova (a meringue dessert, named after Russian ballet dancer Anna Pavlova). The notice of our meeting in the Autumn issue of *SMarT News* was a great bonus as it resulted in no less than six new members ringing up to introduce themselves and asking if they could join us.

Furthermore Maria Goodman, who lives in Great Tey, is a freelance nurse and a member of the St. John Ambulance, telephoned us to say that she would like to see what happens at a regional support group meeting. Maria was most interested in attending and to meet everybody and hear more about

MSA, particularly as she was at the time helping to look after one of the members of the group (who has sadly since died).

We were very fortunate on this occasion to have Lee, the SMT nurse from the London office, with us. He circulated round the tables at lunchtime and afterwards was able to address our members and answer a great number of questions which we had suggested people should write down and bring in with them. Samantha was unfortunately unable to come at the last moment, but we hope to see her on a future occasion.

We ended the afternoon with cups



*The SMT Nurse discusses MSA*

of tea and cakes and if the noise and laughter was anything to go by, the party seemed to have been a success. Our next meeting will be during the Easter holiday. Please provisionally pencil in 6th April 2009 as a possible date. We hope Samantha will be able to attend and we shall look forward to seeing everyone again.

**Bay Laurie**

For information on future support group meetings please see our regularly updated Events Diary, on the website. Please see: <http://www.msaweb.co.uk/events.htm>.

# Websites of interest

Over 2008, the SMT Nurses have looked at a range of new websites related to MSA. It has been decided to include some of the more interesting sites for you to peruse. Please feel free to contact the office with any interesting MSA related websites you have found, while 'surfing the web'. While the websites are shown here, we do not necessarily endorse their content. They have been listed for interest only.

## 'Patients-like-me' website

Dr Paul Wicks, a psychologist by training, is Research and Development Director at patientslikeme.com. He recently gave a demonstration, at the SMT Office, of his new website that might be of value to our Members. Please note: the website is funded by the pharmaceutical industry, to gauge medication treatment.

The website has been designed to include people diagnosed with MSA, to help them measure their condition, share

outcomes with others and learn more about the condition. The website patientslikeme.com was originally designed for people with motor neurone disease (MND), but over the years has been enhanced to include other neurological conditions including MS, Parkinson's disease and more recently, MSA.

The website allows people with MSA to find another 'patient like me', whether it is someone who lives nearby or who may be taking the same medication. The site is also open to caregivers and healthcare professionals who might want to share information or learn more about the condition. Membership of the site is free - visit [www.patientslikeme.com](http://www.patientslikeme.com).





**'Right care Right deal' coalition website**

A national campaign has recently been launched to build public awareness and support for innovative solutions within the social care system for older and disabled people, their families and carers. Right care, Right deal, a coalition of three of the UK's largest charities – Help the Aged, Counsel and Care and Carers UK – has launched a new campaign website.

With the Government indicating that social care is an urgent political priority, the campaign will urge the government to renew its vision for the future of social care in England. To coincide with the website launch, the coalition has published a major new report on care and support in England in the 21st Century. Entitled 'It's Everybody's Business', the report underlines the difficult task Ministers face as they prepare a Green Paper on social care, due early this year. Visit the website at [www.rightcare.org.uk](http://www.rightcare.org.uk)

**'Easy-fund-raising' website**

Easyfundraising is a shopping directory listing some of the main high-street stores including Argos, Next, Amazon, Debenhams, John Lewis, Toys R Us, HMV and over 600 other well known stores. When someone shops online with

any of the stores, using the links provided on the easyfundraising site, they generate a free donation of up to 15% of the purchase price, which goes to the SMT.

It does not cost a penny more to shop and raise funds in this way. In fact, shoppers might even be able to save money as many retailers give exclusive discounts, special offers and even 'e-vouchers' when they shop through the easyfundraising site. All that is required is to register free at: <http://www.easyfundraising.org.uk/sarahmatheson> and use easyfundraising every time someone shops online.

**'Easysearch' website**

Funds can also be raised, every time someone wants to search the web, via easysearch, a search engine 'with a

difference'. When someone searches online using easysearch, funds will be raised for the SMT for every search made. For example, making just 10 searches a day with easysearch instead of a search engine such as say Google, could raise up to £20 a year for the SMT.

The easysearch system combines the strengths of several internet search engines together, such as Yahoo, MSN and ASK.com. As with other similar search engines, easysearch tracks the most relevant and accurate results from across the internet. Visit: <http://sarahmatheson.easysearch.org.uk>

**Hospital Discharge**

An interesting booklet on help for older people in hospital is provided by the Social Care Institute for Excellence (SCIE). SCIE ([www.scie.org.uk/](http://www.scie.org.uk/)) is an independent charity, funded by the UK Department of Health and the devolved administrations in Wales and Northern Ireland. It identifies and provides information on all aspects of social care throughout the United Kingdom.

The booklet provides help for those planning a hospital stay, particularly guiding older people to understand and manage any feelings, anxieties and concerns they may have when they are entering or leaving hospital. It provides practical suggestions on how patients can be involved in their own treatment and care, and in planning for return home. The booklet can be downloaded from <http://www.scie.org.uk/publications/misc/hospitaldischarge/index.asp>.

Going into hospital can be an anxious time for anyone. People with long standing medical conditions like MSA have additional considerations that may increase this anxiety. Being prepared for admission can reduce worry, will make an admission easier and can even speed up recovery time. The SMT has produced a leaflet called 'Going into Hospital' about these issues, for anyone with MSA, who is planning to go into respite care, day centres and day hospitals or rehabilitation units. Please contact the office, if you would like to be sent a copy.



Thanks to everyone who has raised funds for us in 2008. We are always amazed and genuinely appreciative of the wide-ranging efforts that SMT members and their families make in fundraising. Here are some recent achievements.

### 48 hour 'Dartathon'

Wow! I knew that the people of Lode and the surrounding villages were kind and generous but on the weekend of the 21st November 2008 they surpassed their normal kindness and generosity by a country mile! In July, I decided to try and make a difference to the people who are suffering from Multiple System Atrophy (MSA). MSA is the illness that, with great dignity, my mum Valerie suffered from.

Many of my friends and family said "why 48 hours, why not just 24?" Well, I wanted to make it a real challenge. Setting up at the social club on Friday afternoon almost came to jeopardy when I received a phone call saying that my son Dan had most probably broken his right wrist (he had broken his left one about 3 months previously) but Grandad Clive stepped in as he often does and went to A & E with him. 8 o'clock soon arrived and we were on the Oche, throwing arrows at 4 different boards and recording high scores and checkouts!

As closing time approached the great supporting cast gradually dwindled, promising to come back and support the next day after a well earned rest. This left around a dozen hardy souls to cover the late shift and enter the witching hour and beyond until Saturday breakfast arrived, superbly cooked at 49 Northfields by Clive.

On Saturday from mid afternoon the club was as busy as we've seen it for many a year and this continued into the evening when Dan made his comeback with right wrist in plaster but with throwing arm intact. Somehow we managed to motivate each other until dawn finally broke. Yet more new faces arrived at lunchtime and the last darts were thrown at 8pm to complete the 48 hour-long session.

The Cornell family would like to take this opportunity to thank everyone who sponsored this event so generously. We raised almost £4,000 although we are still collecting money. The total sum raised will be published in February's LodeStar.

**Jonathan Cornell**

### Paul Young's Dover Harbour Swim

After 3 miles swimming into severe headwinds and battering waves, with many of the support boats struggling, the referee called a halt to the race. My Windermere swim ended with me sitting on a remote jetty waiting to be picked up by a safety launch. I still wanted to complete the 10.5 miles (roughly 17km) I had been sponsored for and the best way to do this was a Dover Harbour swim.

On Saturday, 14th October 2008, I awoke at 5.40am to get to Dover harbour to be met by Freda Streeter (mother of Alison Streeter, who has swum the Channel 43 times). After a quick safety briefing by Freda, I was in the water by 8.20am and remained there plodding up and down the harbour for the next 5 hours, stopping only 3 times for a 30 second feed.

Luckily, the weather was kind and the only problem I encountered was an embarrassing sun tan line on my face caused by the swimming hat and goggles. The water temperature was colder than normal for that time of year, but still balmy at 15 to 17°C.

In 2003 my dad was diagnosed with MSA. The disorder, over the past 5 years, has transformed him from an active person to sadly being unable to move from his bed. After a long battle, he died on 21st June 2008.

MSA is a relatively rare disorder and very little guidance and support was provided to my parents upon his diagnosis, until we found the SMT. Initially, they helped prepare us for the years ahead by explaining how the condition would impact upon us and went on to provide constant support and advice to both my parents. Any help that can be provided for carers and sufferers alike is vital, along with further funding for research.



I swam as a tribute to my mum and dad's courage and to help others in a similar situation in the future. Over £3,600 was raised and I would like to thank everyone for their kind donations.

**Paul Young**

(abridged from justgiving.com website)

### Original Mountain Marathon

After months of preparation running up mountains and honing navigational skills, on the last weekend in October, we (Neil Price and teammate Robbie Hall) began the Original Mountain Marathon (OMM). The OMM is a two-day adventure race designed to test a participant's endurance, navigational skills and ability to be self-sufficient. Competing in the A-class, we faced navigating over 40 miles and climbing 3,000 feet.

My father was diagnosed with MSA two years ago and has received tremendous support from the Sarah Matheson Trust. Given the magnitude of the OMM event, I decided this would be a great opportunity to raise funds for the Trust.

The venue for 'OMM 2008' was the Lake District and as race day loomed, weather reports for the area were not looking promising, with predictions of strong winds and heavy rain. In its 40-year history the race has never been cancelled and 2008 wasn't going to be any different. Therefore, waterproofs and careful route selection were the order of the day.

Competitors gathered at race HQ early on the Saturday morning for their various start times. Whilst conditions were dry, even down at low level the wind was already strong, which served to heighten the anticipation. We started at 8.20am, but by 10am the rain started falling heavily and hampered progress.

In this type of event you have to take one hill at a time and sometimes one step at a time. With winds gusting over 100mph, staying on our feet was a



*Neil and Robbie relax at the top of the mountain*

big enough challenge. Conditions worsened throughout the day, with the race organisers taking the unprecedented step of calling off the race. After 6 hours in the mountains and with just 2 checkpoints to reach we were forced to abandon the challenge.

Despite only being able to complete day one of the race, all sponsorship money has been collected making a grand total of £2,457. However, I intend to take on the challenge again in 2009 – let's hope the weather is kinder second time around!

**Neil Price**

### Maureen's Ball

My grandson, Haydn Hammond, decided to organise a fund-raising event to raise money and awareness for the Trust, in memory of Maureen Hammond who died of MSA in 1998. Haydn used Concept Events to hold the fundraising evening, which is an events organising company he runs. The event was held at

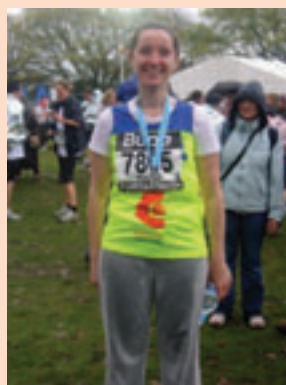
Cardington Village Hall in Bedfordshire on 25th October 2008 and was a great success, with almost 100 people attending. A total of £1,000 was raised.

The next event is planned for the 29th August 2009 at Harrowden Lane, Cardington. It will take place in a themed marquee and is mentioned in the Concept Events web site, see: <http://conceptdiscos.moonfruit.com/> for updates.

**Percy Hammond**

### Linda's Charity Run

I set myself a New Year's resolution at the end of 2007 that I wanted to complete a charity run in memory of my Mum, Bridget Lynch, who had MSA and passed away in May 2007, aged 50 years. I wanted to raise money for the Sarah Matheson Trust because the Trust works hard to raise awareness of MSA, funds research into the illness and also supports families and carers of



*A smiling Linda*

sufferers. When Mum was first diagnosed, it was difficult to know where to turn to for information for this widely unknown illness and I found the SMT very helpful.

As a novice runner, 10 kilometres was difficult for me, but made so much easier by my knowledge that I was raising money in memory of Mum and for such a worthwhile charity. The run took place on Saturday 6th September 2008. There was also a 3k run for children, with Corrie, Robbie, Mathew, Holly, Kelly and Sarah (Molly's grandchildren) helping to raise further funds. In total we raised £366.



*The junior 3k run*

### The Three Peaks Challenge 2008

Mathew Piper scaled the 3 peaks of Scafell, Ben Nevis and Snowdon all within 24 hours to raise £250 for the SMT. The highest mountains in England (Scafell Pike: 978m), Scotland (Ben Nevis: 1344m) and Wales (Snowdon: 1085m) are all part of the Three Peaks Challenge. Each mountain needs to be climbed and equipment transported from one hill to the next (some 450miles) – all in 24hours. Mathew's achievement was only made possible by his father, Bill, driving him between each peak. Mathew's father has a strong link with the SMT.

### Anna's charity event

For my 40th birthday I decided to help the SMT by holding a fundraising evening. I held the evening because my father, seen in the middle of the photograph, has been diagnosed with

## The Lyke Wake Walk Challenge

I completed the Lyke Wake Walk on 7th July. The challenge was to complete a 40 mile walk, from Ravenscar to Osmotherley on the high North Yorkshire Moors, in less than 24 hours. I began my walk at 04:20hrs and finished at 22:10hrs. This achievement enabled me to raise £920 for the Sarah Matheson Trust for Multiple System Atrophy (MSA). My walking partner was George Fothergill and midway through the challenge, his daughter, Alice, provided appropriate encouragement during this demanding walk.

I became aware of the SMT through a mutual friend and set about obtaining sponsorship for the walk. MSA is a progressive, degenerative and adult neurological disorder, which causes problems with movement, balance and automatic functions. Members of the SMT have emphasized that without the support and guidance of the Trust's specialist nurses they would be lost during difficult times.

**John Barter**

*Nick Bunt, SMT Trustee, receiving John's cheque*



MSA-C [MSA with predominantly cerebella features] and we thought that

### Anna and her family



this was a great way of providing funds for the Trust, while also raising awareness of MSA. Some donations were also sent on-line. We all managed to have a great time at the party, with my father particularly enjoying the evening. My daughter circulated around the guests selling children's candy sticks (as candy cigarettes are now called) and got into a bidding war for the final packet, which was eventually sold for £5.00! Over £720 was raised, in total.

# Posters for fundraising events

The Trust has produced an A3 size MSA/SMT poster for anyone wishing to use it for fundraising. We send them out in protective cardboard tubes. The posters have been welcomed by those who have requested a display that describes MSA and the work of the Trust. Please feel free to phone the office, if you would like one: 020 7886 1520.

**...and don't forget the boxes and badges**



## In Memory for 2008

This edition of *SMarT News* will cover the period till 15th January 2009. If you have informed the SMT of a loved one's death and he or she does not appear below, please accept our apologies (we can always rectify this in a later edition). Some members passed away earlier than 2008 and these have the corresponding year in brackets.

- |                         |                          |                       |                          |
|-------------------------|--------------------------|-----------------------|--------------------------|
| • Fred Amor             | • Ina Dolan              | • Trevor Layton       | • Harry Richardson       |
| • Angelo Avino          | • Stanley Edwards (2007) | • Donald MacInnes     | • Margaret Rollason      |
| • Alfred Barber         | • Audrey Ellard          | • Tony McGuire        | • Yvonne Schmid          |
| • Manuel Bautista       | • B.M. Etheridge         | • Betty Mutch         | • Shirley Sharples       |
| • Rose Blackham         | • John Fowler            | • Catherine Notman    | • Marie Sheedy           |
| • Olive Bourne          | • Paul Francesconi       | • Michael Nicol       | • William Shine          |
| • Paula Brett           | • John Gooch             | • Pat Perry           | • Dr Paul Sibley         |
| • Bob Burges            | • Joan Hulse             | • Harry Platt         | • Mary Slocombe          |
| • Nora Calder           | • Patricia Hunter        | • Tom Quigley         | • Susan Smith            |
| • Malcolm Campbell      | • Pauline Johnstone      | • Margaret Read       | • Michael Street         |
| • Joseph Carroll (2007) | • David Jones (2007)     | • Muriel Reed         | • Nick Sullivan          |
| • Joan Cole             | • Eirlys Jones           | • Brian Reilly (2007) | • Kenneth Taylor         |
| • Adrian Cook           | • George Lamb            | • David Rigby         | • John Turner            |
| • Ron Dobson            | • Lyn Landrick           | • Jageet Riyat        | • Reggie Wallace         |
|                         |                          |                       | • Kathleen Warren        |
|                         |                          |                       | • Barry Walters          |
|                         |                          |                       | • Amy Wells              |
|                         |                          |                       | • Margaret Williams      |
|                         |                          |                       | • Beryl Winterton (2007) |

# Sophie's Search for a Cure

**P**rofessor Clare Fowler, Chairman of the SMT Medical Research Advisory Panel, has reviewed a DVD on the life experiences of Sophie Dohm, a woman who was diagnosed with MSA. In the DVD Sophie asks the big questions which all those with MSA most ponder: “what is this disease?”, “where did it come from?” and “why me”?

The middle of the film focuses on Sophie’s efforts to assist with MSA research and in particular to increase public awareness of the disorder. The film ends by emphasising the vital importance of support that can be gained from family and friends. Indeed, the depth of feeling amongst the participants of the film is quite apparent.

The often sad film shares Sophie’s experience of MSA, with the hope that through the filming, those with the disorder and their family may feel less

alone and be able to relate cathartically to the experiences described. So, what are the positives to be had from watching this film? Well, it demonstrates that there is an active concern for finding a cure for MSA in patient communities and that Sophie found contact with other people who have the condition, in person and through the internet, most supportive. Importantly, Sophie highlights that only through medical research are we ever likely to gain the answers to those big MSA type questions. Sadly, Sophie died in 2007.

Copies of the DVD are available for US\$10 plus \$4 postage from Jim Likowski at Rainlight Films. It is best to e-mail him with your



request at: [rainlight@earthlink.net](mailto:rainlight@earthlink.net) or write to: Rainlight Films, PO Box 410, Coloma, CA 95613, USA. [www.rainlightfilms.com](http://www.rainlightfilms.com)

Please note: this is a highly emotional documentary which some members may find unsettling.

## Lightwriter donation

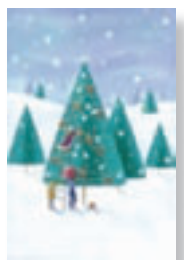
Mr Diston purchased a Toby Churchill Lightwriter for his wife three years ago. Mr Diston states that the Lightwriter was of “immense value to my wife when she first had problems with her speech”. However, the Lightwriter is no longer required. Mr Diston was so impressed with the

Lightwriter that he wanted to loan it to others and has most generously donated it to the Trust for free. The Lightwriter has been serviced and is now being used by another SMT Member. If anyone is interested in a loan of the Lightwriter, please contact the office.



## SMT christmas cards sell out

**T**he selling of Christmas cards for 2008 went really well. We sold out with the remaining sets of cards from the last 2 years also being sold! Altogether we sold 645 packs, which equates to 6,450 cards. Thank you to all who bought the cards. We would also like to take this opportunity to say sorry to all those who missed out – we will print a greater number to be available next Christmas. We will also advertise them on the SMT website when they are ready to be ordered.



## Can Conductive Education help?

Dear SMT Nurses,

When my husband Nick was first diagnosed with MSA, I was constantly looking for anything that would assist him and would make life easier for him and his condition. My daughter who works with children with Cerebral Palsy (The Hornsey Trust, Muswell Hill) suggested that Conductive Education would be beneficial. [Please note: any therapy, such as Conductive Education, should not replace individual assessment and treatment by an appropriate specialist.]

Conductive Education is a form of

special education and rehabilitation for children and adults with motor disorders. It can be used for conditions where disease or damage to the central nervous system affects a person's ability for control of movement. There is an Adult Specialist Centre in Birmingham, with training taking 4 years; it is affiliated to Wolverhampton University.

I contacted the centre in Birmingham and was offered 17 free morning sessions. I felt this was the most helpful activity in improving his mobility. He was given strategies to help with day-to-day activities that

people take for granted such as walking, sitting correctly, standing and general movements. He was also assisted with his fine motor skills to help with handwriting and getting dressed. It enabled him to become more mobile and improve his self esteem greatly. I thought I would share my experiences with your members. I can be contacted on: suemsullivan@hotmail.com.

**Sue Sullivan**

Dear Sue, thank you for sharing your experiences with the SMT. We will look further into Conductive Education to ascertain its usefulness to our members.

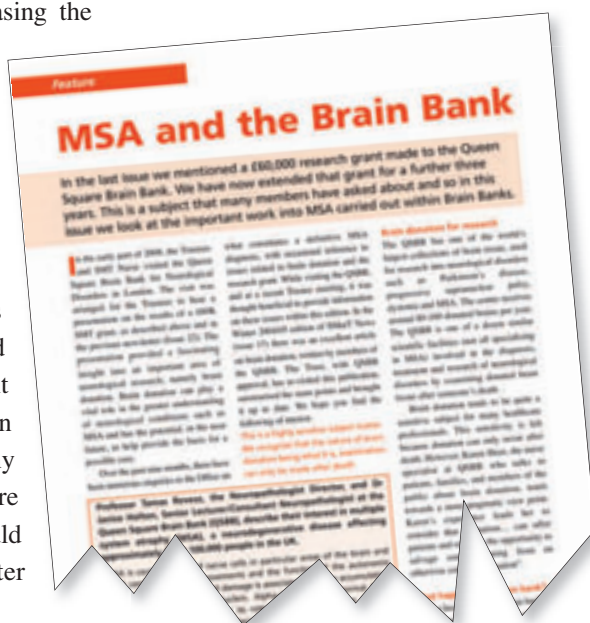
## Donating to the Brain Bank

Dear SMT,

I read your recent article on "MSA and the Brain Bank" with interest, having recently completed a qualitative study as part of my MSc in Nursing. My study aimed to identify and explore the factors that influenced people's decisions when they were asked to think about agreeing to brain donation for research. I would like to share some of the findings arising from the research with your readers.

While there has been much in the news recently about increasing the supply of organs for transplantation, very few participants I interviewed had been aware of the need for organs to further research, before the subject had been raised with them. All participants, regardless of whether they had agreed to brain donation or not, felt that making a brain donation was worthwhile, with many expressing an altruistic desire to do something that would benefit those coming after them.

An influential factor for many participants was being made aware of the need for brain tissue to further research and being asked to consider brain donation, providing the catalyst that translated into a desire and willingness to help others. Interestingly, among those who supported the idea of brain donation for research, the most frequently cited factor significant to their ultimate decision was having the support of their families.



Talking and thinking about brain donation inevitably leads us to consider our own mortality. Understandably, some participants reported these as difficult issues to contemplate and particularly to broach with loved ones. However, my research suggests that asking people to consider making a brain donation not only raises awareness, but more importantly gives potential donors and families the opportunity to come to a considered decision, whatever that may be, with the benefit of accurate information, time and support.

**Clare Harris**  
**Research Nurse**  
**University of Aberdeen**

### References

Taylor, K. et al (2006) Pilot Study of the Incidence and Prognosis of Degenerative Parkinsonian Disorders in Aberdeen, United Kingdom: Methods and Preliminary Results. *Movement Disorders*; 21(7), 976-82.

*We welcome letters that share news and experiences from all our members. We will publish as many as space permits in each issue of SMarT News.*



Sarah Matheson Trust for  
Multiple System Atrophy

Information, Support, Education and 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

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Registered Charity Number 1062308

**Membership Numbers  
as of January 2009**

Current MSA members	810
Other patient members	39
Relatives and carers	440
Professionals	1487
Others	161

# Ways to support the SMT and help the Trust grow

## Become a regular donor

Donations by 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 SMT 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](http://www.justgiving.com). This facility can be used for anything from a personal occasion to the dedication of a person's life.

## Contribute to SMarT News

Sharing your experiences and tips with other members helps keep it your newsletter.

## Form a local SMT group

Link with the SMT 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.

*Don't forget: the SMT is your charity.*

## 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 SMT. This Gift Aid could raise the SMT's income by as much as £20,000 extra per year. We have Gift Aid forms available at the SMT office.

### Next issue

I have thoroughly enjoyed writing the last 3 newsletters. I have been particularly impressed by the tremendous efforts people have put into fundraising for the Trust. The Trust only exists because of the continued fundraising efforts and kind donations of our members.

The next edition (issue 25) is planned for posting to you in June 2009. If applicable, please provide articles by 15th May 2009. All articles received after this date will appear in the following edition (issue 26).

Lee Potiphar SMT Nurse and Editor

**All articles aim to provide as much information as possible. However, since some information involves personal judgement, their publication does not mean the Sarah Matheson Trust necessarily endorses them.**