Issue 25 Summer 2009

MSA SMarT News

The newsletter of the Sarah Matheson Trust

Contents

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 Trustees

The Sarah Matheson Trust was established in 1997 and since then has been very successful in providing support to members, their families and carers, raising awareness of MSA and funding research. We are the only UK Charity that provides support to those affected by MSA.

In recent months the Trustees have been considering how best to embark on the next phase of our development in order to raise our profile, offer greater and better support to our members and fund further research into the condition. As a result of our discussions, we have decided to recruit an Executive Director who will report to the Trustees and be responsible for drawing up and delivering a strategic business plan that will help us achieve our objectives. Advertisements have appeared in the national press and on relevant websites. We are looking forward to finding an excellent candidate and hope in our next *SMarT News* to be able to announce the appointment.

As you know, in the meantime Lee Potiphar, our full-time SMT Nurse, has left to take up his new role with the UK Clinical Research Network. We wish him all the best for the future and would like to thank him for his hard work and enthusiasm at SMT. Whilst we recruit an Executive Director we will not be seeking to appoint a new Autonomic Liaison Nurse and Samantha Pavey, our current Nurse Specialist, will continue to cover all calls and emails. Linda Campbell will, as usual, answer calls and emails to the office and pass these to Samantha as appropriate.

This is a very exciting time for us and the Trustees are looking forward to growing and developing the services we offer to our members and increasing the funding available for research into the causes of this distressing condition.

Eileen Strathnaver, Chair of Trustees

SMT seeks new Trustees

A number of our Trustees are founder members of the Sarah Matheson Trust. Having seen the Trust grow and establish itself as a vital support service for those with MSA, their carers and professionals, some feel now is the time for them to stand down and hand over to new Trustees.

The Trustees meet in London four times a year. In addition, there is a finance sub-committee plus ad hoc committees set up to cover specific matters.

If you, or someone you know, would be interested in becoming a Trustee, please contact Linda in the office to discuss the possibility in the first instance.

Contact details for the SMT Team

Samantha Pavey (Specialist Nurse): **020 8150 6250**
samantha.msa@googlemail.com

Linda Campbell (Administrator): **020 7886 1520**
linda.campbell@imperial.ac.uk

The Sarah Matheson Trust
Box 200, St Mary's Hospital, Praed Street, London, W2 1NY
Fax: 0207 886 1540 www.msaweb.co.uk

Holiday directory

As it's holiday time again we are printing, with the permission of the PSP Association, some useful holiday information. SMT has not tried or tested any of the suggestions and so cannot give any recommendations, comment on their suitability or guarantee the accuracy of the information. However, most have websites that are, hopefully, informative and accurate.

Access Travel (Lancs) Ltd

A holiday organisation that provides a wide range of locations and accommodation styles for people needing accessible holidays

6, The Hillock, Astley, Lancashire M29 7GW
Tel: 01942 888844
www.access-travel.co.uk

Accessible Travel

A holiday organisation that provides a wide range of locations and accommodation styles for people needing accessible holidays

Avionics House, Naas Lane,
Quedgeley, Gloucester
GL2 2SN
Tel: 01452 729739
info@accessibletravel.co.uk
www.accessibletravel.co.uk

Assisted Travel Services

Offers a door-to-door service for trips anywhere in the world, with possible care assistance.

1 Tank Lane, Purfleet RM19 1TA.
Tel: 01708 863198.
www.assistedholidays.com

Bond Hotel, Blackpool

Award winning specialist hotel for the disabled. Special offers and themed weekends throughout the year.

120 Bond Street, Blackpool, Lancs,
FY4 1HG
Tel: 01253 341218
reception@bondhotel.co.uk
www.bondhotel.co.uk

Calvert Trust (Exmoor)

Provides accessible outdoor activity breaks and courses for people with disabilities, together with their families and friends.

Tel: 01598 763221
calvert.Exmoor@btinternet.com
www.calvert-trust.org.uk

Carers Holiday Guide

Handy list of organisations offering holiday and travel facilities for people with disabilities and their carers.

www.carersguide.info/holidays.html

Can Be Done

Specialises in travel for people with disabilities.

11 Woodcock Hill, Harrow HA3 0XP.
Tel: 0208 907 2400.
www.canbedone.co.uk

Disabled Friendly Cottages

Bircham, Norfolk The site is 5 miles from Sandringham and 10-15 miles from Hunstanton.

Tel: 01485 578606
www.norfolkdisabled-friendlycottages.co.uk

Disabled Holiday Directory

A holiday organisation that provides a wide range of locations and accommodation styles for people needing accessible holidays.

6 Seaview Crescent, Goodwick,
Pembrokeshire, SA64 0AZ
Tel: 01348 875592
www.disabledholidaydirectory.co.uk

Enable Holidays Ltd

Overseas holidays for disabled people, their families and friends.

26, The Green, Kings Norton
Birmingham B38 8SD
Tel: 0871 2224939
info@enableholidays.com

Grooms Holidays

Offer holiday venues for disabled people and their families at accessible sites in the UK. Wide range of locations and accommodation styles (hotels and self-catering) for people needing accessible and affordable holidays.

PO Box 36 Cowbridge, Vale of
Glamorgan, CF71 7GB
Tel: 08456 584478
www.groomsholidays.org.uk

Tourism for All

A national charity providing information about transport, accommodation, respite care establishments etc to enable people with all kinds of disability to holiday where possible in a mainstream environment.

Tel: 0845 124 9971
www.tourismforall.org.uk

Jane Hodge Resort Hotel

A respite and holiday centre for adults with disabilities. For guests who require a holiday with their family or carer.

Trerhyngyll, Nr Cowbridge
Vale of Glamorgan
CF71 7TN
Tel: 01446 772608
jgjhh@globalnet.co.uk

National Express

Offer wide variety of coach trips and coach holidays across the UK.

Helpline: 0121 423 8479
Text phone: 0121 455 0086
www.nationalexpress.com

Park House Hotel

Run by Leonard Cheshire Foundation as a country house hotel for disabled people and their companions. 24 hour nursing care is provided.

Sandringham, Kings Lynn
Norfolk PE35 6EH
Tel: 01485-543000
parkinfo@lc-uk.org
www.parkhousehotel.org.uk

Seaside Holiday, Southend (Essex)

Hotel offering holidays for people with disabilities and their carers, including organised trips and entertainment. 24 hour care available offering respite for carers.

Tel: Pat on 01702 345365

Stackpole Trust

Provides self-catering holidays for families or groups including people with severe disabilities. They have a hydrotherapy pool and leisure facilities on site including music, art and theatre workshops.

The National Trust,
Stackpole Centre, Old Home Farm
Stackpole, Pembroke, Pembrokeshire
SA71 5DQ
Tel: 01646-661618
gsten@smtp.ntrust.org.uk

Trust Caring and Nursing Agency

For holidays in the north-west of Northern Ireland, TCNA provide 'CityBreaks with Care' – holidays for tourists with physical or sensory disability. (Can also help find medical, nursing or caring support needed for holidays in other parts of the UK or Ireland if an up to date patient-handling risk assessment is provided.)

57, Abercorn Road,
Londonderry
BT48 6TQ
Tel: 02871 373843
www.tcna.org

Vitalise (formerly The Winged Fellowship)

Holidays for disabled adults and their carers at specially adapted holiday centres in England. 24 hour nursing care available. Centres are equipped to look after people with movement disorders, can cater for the person 24/7 and the family can have a break whilst they are all there together. "Had a great break there" - Feedback from PD patients staying at Southampton

12 City Forum, 250 City Road,
London EC1V 8AF
Tel: 0845 345 1972
www.vitalise.org.uk

UK and Indian collaborative research study aims to improve diagnosis of Parkinson's disease and Multiple System Atrophy

SMT patron, Professor Christopher Mathias, is leading his medical units at St Mary's Hospital (Imperial College Healthcare Trust) and the National Hospital for Neurology and Neurosurgery (University College London Healthcare) in a large-scale international collaborative study to improve diagnosis of Parkinson's disease (PD) and Multiple System Atrophy (MSA). The London-based units will be working closely with Dr Uday Muthane's team at the Parkinson's and Aging Research Foundation in Bangalore, India, in an effort to evaluate cardiovascular autonomic function using non-invasive autonomic testing to examine patients in the early stages of PD, with postulated autonomic dysfunction, early MSA patients with autonomic failure, healthy family members of PD patients and elderly subjects at increased risk of developing PD. In addition, the London and Bangalore teams will investigate differences in cardiovascular autonomic function and MSA pathology between Indian and UK patients.

The study is financed by a grant awarded by the UK-India Education Research Initiative (UKIERI), a program established by the British and Indian governments to enhance educational links between the two nations and ensure long-term educational partnership. The UK Principal Investigator, Professor Christopher Mathias, is an internationally recognised expert in the autonomic nervous system (ANS).

The ANS is comprised of defined areas of the brain, spinal cord and the periphery, through which its various systems control the inner environment of the body, such as heart rate (HR), blood pressure (BP), swallowing and body temperature, as well as activity of vital organs. The ANS was previously only thought to be affected in the later stages of PD; however, recent studies indicate autonomic function is affected earlier than previously considered, in fact, before movement is affected.

The other UKIERI Principal Investigator, Dr Uday Muthane, is a specialist in PD and has found key differences in the number of neurons between Indian and UK brains and indications of neurological and parkinsonian differences between UK and Indian populations. Dr Muthane recently completed a study investigating the genetics of PD in Indian patients, during which he identified families with individuals at risk of developing the disorder. These at-risk individuals will now be examined to determine if they develop autonomic dysfunction and hyposomia (reduced smell perception)

One of the main objectives of the Trust is to improve the scientific understanding of MSA by funding medical research. In the last SMarT News (Issue 24) we reported on two projects that the Trust will be supporting over the next three years.

One of these projects is under the supervision of Dr Henry Houlden, who is based at the Institute of Neurology and The National Hospital for Neurology and Neurosurgery. It will aim to examine genetic risk factors that may contribute to the development of MSA.

Dr Janice Holton, who is based at the Queen Square Brain Bank for Neurological Disorders, is supervising the second project. This will follow on from previous research, also funded by the Trust, investigating mechanisms underlying GCI formation. This previous research was carried out between January and December 2008. Details of the previous research will be reported in the next issue of this newsletter.

Darcy Hare, Trustee

before the onset of the typical shaking palsy that is associated with the disease. Dr Muthane and Professor Mathias' teams will also investigate if there are racial differences in autonomic abnormalities in PD and MSA patients, especially early on in the disease.

Early-stage PD and early-stage MSA have never previously been compared but this study will explore whether there are functional differences between PD and MSA in relation to excitatory autonomic control of heart rate. There are four key questions that the research co-operation intends to answer:

- Can cardiovascular autonomic dysfunction be detected in the early stages of PD?
- Do the results differ from early MSA patients, who also may present with parkinsonism?
- Can these tests detect autonomic dysfunction in non-affected family members of genetic/familial PD, and/or subjects at higher-risk of developing PD?
- Are there differences in autonomic dysfunction between Indian and UK populations?

Answering these questions will permit detection of people at risk of developing PD and MSA before the disease has manifested in the disabling and irreversible motor symptoms that typify the condition. It is intended that the research will create an early window in treatment during which protective therapies can be implemented to far greater effect than previously possible and also improve treatment strategies for individuals at risk to help slow PD, perhaps even making a cure for PD's motor symptoms a reality.

Studying these patterns may also enable a clearer diagnostic separation of PD from MSA at an earlier stage, thereby further improving treatment by ensuring correct diagnosis sooner. Autonomic dysfunction is a primary symptom of MSA, but is also increasingly recognised in PD and causes significant morbidity so earlier recognition will improve treatment, avoid complications and aid forward planning for patients. The collaboration will also benefit both nations by determining if there are ethnic differences in the clinical presentation and autonomic testing between Indian and UK patients. In recent years, there has been a steady increase in the elderly population of both nations and PD and other parkinsonian disorders commonly occur in the elderly. However, awareness amongst the Indian population is low and parkinsonian disorders can present with many different symptoms, hence an exact diagnosis can be delayed and treatment unaffordable due to patients having to travel to larger cities for attention. Since diagnosis of MSA and PD is largely clinical, mainly through autonomic testing, educating doctors and improving awareness will enable a diagnosis to be made as early as possible and serve to greatly improve the quality of life of PD and MSA patients in India, the UK and beyond.

Andrew Owens
Clinical Research Coordinator,
Imperial College London/
Imperial College Healthcare Trust

For further information about Professor Mathias and the neurovascular and autonomic medicine unit, please visit
http://www1.imperial.ac.uk/medicine/people/c.mathias
http://www1.imperial.ac.uk/medicine/about/divisions/neuro/npmdepts/clinneuroscience/neurovascular

For further information about the UKIERI or any other studies, you can contact at a.owens@imperial.ac.uk

Do You Live in Greater Manchester?

The Movement Disorders Research Group at Salford Royal Hospital is undertaking a study looking at pain in patients from the Greater Manchester area with conditions including Parkinson's disease and MSA. We know that pain occurs in these conditions, but don't know how different conditions compare or what might be causing the pain.

This study involves a series of questionnaires that take about half an hour to complete.

If you are interested in taking part and would like more information please contact:

Dr Chris Kobylecki, Research Training Fellow, Faculty of Life Sciences, 1.124 Stopford Building, University of Manchester, Oxford Road, Manchester M13 9PT Tel. 0161 275 5382 christopher.kobylecki@manchester.ac.uk

or

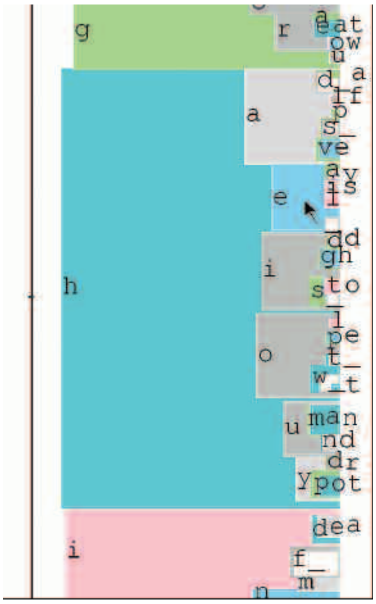
Patsy Cotton, Nurse Specialist, Hope Hospital, Salford, Manchester. patsy.cotton@srft.nhs.uk

Dashing off a letter...

Dasher appears to be software that could be of help to those who have difficulty in using a traditional keyboard. *SMarT News* have not tested it out, but it looks fun and can be downloaded from the website given below. Perhaps this introduction will whet your appetite. It would be fantastic if any readers who do try it out could let us know what they think of the software and how they found it to use – either write an article for us to print in the next edition of *SMarT News* or send a letter and we will re-introduce the letters page.

Dasher is an information-efficient text-entry interface, driven by natural continuous pointing gestures. Dasher is a competitive text-entry system wherever a full-size keyboard cannot be used - for example:

- when an individual has limited manual dexterity
- when operating a computer one-handed, by joystick, touchscreen, trackball, or mouse
- when operating a computer with no hands (i.e., by head-mouse or by eyetracker)



Words are created by selecting letters offered by the software

The eyetracking version of Dasher allows an experienced user to write text as fast as normal handwriting – 29 words per minute; using a mouse, experienced users can write at 39 words per minute.

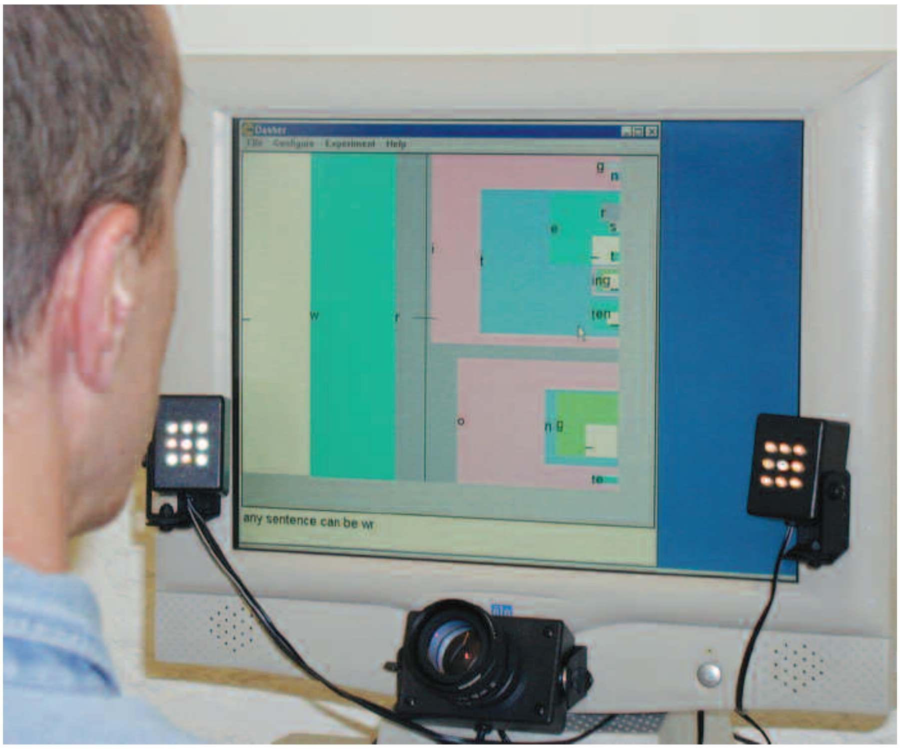
Dasher can be used to write efficiently in any language and users say it is fast and fun to learn.

Dasher is a zooming interface. You point where you want to go, and the display zooms in wherever you point. The word into which you are zooming is painted with letters, so that any point you zoom in on corresponds to a piece of text. The more you zoom in, the longer the piece of text you have written. You choose what you write by choosing where to zoom.

To make the interface efficient, Dasher uses the predictions of a language model to determine how much of the word is devoted to each piece of text. Probable pieces of text are given more space, so they are quick and easy to select. Improbable pieces of text (for example, text with spelling mistakes) are given less space, so they are harder to write. The language model learns all the time: if you use a novel word once, it is easier to write next time.

A big advantage of Dasher over other predictive text-entry interfaces that offer word-completions to the user is that it is mode-free: the user does not need to switch from a writing mode to an 'accept-model-predictions' mode. Another advantage is that it is easy to train the model on any writing style: simply load up an example file, then write away. And it is absolutely free!

The software being used using an eyetracker



To find out more about Dasher go to: www.inference.phy.cam.ac.uk/dasher/DasherSummary.html

Useful organisations

Following last issue's *Websites of Interest* article, here are a few more organisations that may be of use to people living with MSA. Please let us know if you have any more suggestions that you would like to share with our membership.

AbilityNet

Ability Net is a national charity that helps disabled people access their computers and the internet by using adaptions and tailor-made devices. Whatever the disability or problem, they hope to be able to provide a solution for everyone. They have telephone helpline and if necessary an assessor can visit for free to make recommendations. They are also able to advise regarding changing needs.

Tel: 0800 269545.
www.abilitynet.org.uk

Disabled Living Foundation

The Disabled Living Foundation is a national charity giving practical help, up-to-date information and advice on disability equipment solutions for independent living. They have telephone helpline that can be contacted at local rates and is open from 10am to 4pm. They can assist with finding a supplier or a particular appliance.

Helpline: 0845 130 9177
Text 020 7432 8009
advice@dlf.org.uk
www.dlf.org.uk

The Ceiling Hoist Users Club

For some people living with MSA, mobility may become extremely restricted and you may find that using a hoist can help your daily life.

This CHuC was set up by Equal Ability CIC to promote the interests of those less able people who need to use hoists. They have a very helpful website which not only talks about the pros and cons of hoists, but also has a forum for discussion.

There are also some very interesting other links on their site, including the accessible property register which covers adapted residential property for sale or rent and holiday accommodation. There is a list of hotels in various areas that are keen to accommodate the disabled traveller.

General Ability CIC, Amco House,
Cedar Court Office Park,
Denby Dale Rd, Wakefield, WF4 3BA
www.chuc.org.uk

WB4 - The TV and Radio Charity

WB4 can provide new radios and TVs to those who find it financially difficult to provide a set for themselves; in particular those who are less able to leave the house. They would be happy to hear from anyone who might benefit from this service.

Contact Emma Greenhalgh on
0161 408 0162 or by email at
emma@w4b.org.uk

New Devon group proposed

Dennis Westrip has kindly agreed to start a new support group in Devon. The first meeting will take place on Friday 24th July between 2 and 4pm at the Tomlin Hall, Bickington. Samantha Pavey, the MSA Nurse Specialist, will attend the meeting to give a short presentation and answer any questions you may have. We are delighted that Dennis has agreed to start the group as before people living in Devon had to travel to Cornwall if they wanted to attend a support group meeting.

If you would like to attend, please contact Dennis on 01271 378273.

Regional Support Group Contacts

Further information on support groups can be found on the SMT website (www.msaweb.co.uk/) under 'our services'.

Region	Contact Point	Address
East Midlands Group 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
Essex Group Meets twice per year	Lady Laurelie Laurie Tel: 01206 210 410	The Old Rectory, Little Tey, Colchester, Essex CO6 1JA
Yorkshire & Humber Group 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
Lancashire & Merseyside Group Meets 4 times per year	Mrs Ann McLennan Tel: 01704 568 353 annandon@btinternet.com	72 Lynton Road Hillside, Southport PR8 3AP
Cornwall Group Meets 4 times per year	Mrs Jane Handy Tel: 01726 74792 Or, Ms Jan Pearce Tel: 01726 861361 Moonbeams@ymail.com	In the first instance, please phone or email
Gloucester Group Meets (possibly) twice per year	Ms Janice Davies Tel: 01242 224617 www.thehewlett.co.uk/index.htm	The Hewlett, Harp Hill Cheltenham, Gloucester GL52 6QG
Devon Group Meets (possibly) twice a year	Dennis Westrip Tel: 01271 378273	In the first instance, please phone or email

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.

Lancashire & Merseyside

Since the last newsletter we have held two meetings.

The Spring meeting was held on 5th March and twenty four people came along to enjoy tea and homemade cakes. New families joined us and hopefully they went home knowing that they had made contact with people in the same situation as themselves and that support is always there for them. Over £70 was raised from the raffle, the majority of people going home with a prize.

Over thirty people came to our June meeting and everyone enjoyed and benefited so much from having Samantha present. She was kept very busy talking to groups and answering the many questions that were put to her. On behalf of everyone I would like to thank her for coming to see us and for her invaluable advice. Also a big thank you to my merry band of helpers who were kept busy making tea and coffee and persuading everyone to eat all the cakes!

The Group has now been going for eighteen months and it is good to see so many people coming to the meetings and to welcome new families. It can be quite daunting to come along to such a gathering but we are a very friendly group and enjoy meeting new members and their carers. It is a wonderful forum for helping each other with exchange of ideas on both how to help each other and how to help the Sarah Matheson Trust.

Ann McLennan

Tea, coffee and cakes go down well at the Lancashire & Merseyside meetings

Gloucester

The last Gloucester support group meeting was held on Monday 16th March and was attended by the Nurse Specialist, Samantha Pavey. She gave a presentation on the complexities of MSA. This was the second meeting and most of the people who came to the first one were there as well as three new members. Those who attended found out much more about the condition and had many of their questions answered. Janice is intending to hold a further meeting in late September/October. Details will be posted on the website as well as invitations being sent out.

Janice Davies

East Midlands

The East Midlands Support Group met at Holme Pierrepoint House on 29th April. We were delighted to welcome six new members in addition to two old friends. Samantha Pavey attended and gave us a very good talk covering all the aspects of MSA. Afterwards Samantha talked privately to individuals, which I gather was very helpful. I think she must have been pretty weary at the end having talked for three hours without stopping and then having to drive home. We are really very grateful to her. Being presented with the facts in such a kindly way does indeed make it easier to cope with the different problems that arise.

We had our usual tea and a cake, plus the raffle at the end of the afternoon. Our next meeting is on Wednesday 7th October 2009.

Elizabeth Brackenbury,
SMT Trustee

Cornwall

Our meeting was held in West Cornwall, near Hayle. We were delighted to welcome Samantha Pavey from the Sarah Matheson Trust, along with a new group of people who we had not previously met. One person had travelled from Totnes, as we were the nearest group to him. Samantha gave an informative presentation and was able to answer all questions put to her. We all very much appreciate her visit and hope she enjoyed her trip to Cornwall.

Finding suitable venues to cover a large area, such 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.

Our next meeting is to be held on Wednesday 29th July at the Memorial Hall Summerscourt from noon to 3.30pm. We will provide soup and rolls, tea and coffee, and Jane will probably be persuaded to bake another of her delicious cakes. All this for £2 per head. If you need directions to the venue please ask.

Jan and Jane continue to be in telephone and email contact with people from all over the West Country. Our vast geographical area prevents many of us from meeting and we very much hope that, with the new Devon Group having its first meeting in July, between us we can reach more people who would like the support of others who fully understand what living with MSA is like.

We look forward to meeting with all who can make our next meeting.

Jan Pearce and Jane Hardy

Yorkshire & Humber

The Yorks & Humber group met on Tuesday 29th April at their usual haunt, the Pinfold Lane Health Centre. We had a good discussion and chatted about holidays; some very useful information was shared by members as to the selection of holidays and some follow-up notes will be issued soon regarding the topics discussed. A key issue is the difference in help and support given by different health authorities. Sometimes this was simply due to “if you don’t ask, you won’t get”, but sometimes it appeared that knowledge of the condition was very limited in certain areas and I was asked to stress to the Sarah Matheson Trust the need for further information days to try to increase local health authorities’ understanding.

As Yorkshire is such a large county, we have decided to try to rotate the venue. A kind offer by a member from Doncaster means that the next meeting will be held in the Church Hall of St Leonard’s Vicarage in Scawsby. Full directions will be sent when the notice for the meeting is issued. The proposed date is the week commencing 5th October. The Vicar has kindly also promised to locate a venue for the group in Harrogate for the following meeting. I would like to extend an invite to anyone who hasn’t yet been to a meeting to come along and have a cup of tea and a chat; we might even throw in the odd biscuit or two!!

As the support group organiser, I am very happy to talk to anyone who needs a listening ear, but do need to point out that I am not from a medical background, so it is Samantha, SMT’s nurse specialist, who needs to advise on medical matters. If however you just fancy a chat to bemoan the price of eggs, then give me a bell; it would be great to hear from you!

Karen Walker

Essex

At our meeting in April our numbers increased and thirty six of us sat down to lunch, so many in fact that we had to use the larger room in the Great Tey Village Hall to set up our tables as well as the sitting area where we have usually held our meetings. Our wonderful helpers Sue, Marian and Amanda were kept on the go looking after everybody.

It was lovely to welcome new people and to see all the familiar faces as well. Also we were very lucky to have Samantha, the specialist MSA nurse from SMT, with us. After lunch Samantha not only answered questions from the Group but also managed to speak to everyone individually which was greatly appreciated. The time seemed to fly by with all the talk and the renewing and making of new friendships.

We are called the Essex Support Group although people have attended from Suffolk, Norfolk, Bedfordshire, Middlesex, Enfield and London SE 2, which is great for us but does illustrate the need for more groups.

We are now looking forward to our next get-together that will almost certainly be on Monday 26th October (half-term) and to seeing everybody again.

Lady Laurelie Laurie

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

Problems with swallowing

As you know, people living with MSA will have symptoms individual to them, and no two people will develop the same problems. However, some people do develop changes with their swallowing. Samantha Pavey, the MSA Nurse Specialist at the Trust, provides a brief overview of issues related to swallowing.

Samantha Pavey

Over time, the muscles involved in swallowing can become weak and you may notice different foods and fluids make you cough. Generally, foods that crumble may be difficult, such as biscuits or toast. It is easier to swallow thick things than thin things; so a glass of water or a cup of tea may cause you to cough, whereas a fruit smoothie or a bowl of thick soup will slip down more easily.

In the first instance you should ask your GP to refer you to a Speech & Language Therapist (SaLT) who not only looks after speech problems, but also assesses your swallowing for you. Initially you may be advised to avoid certain foods, to thicken your fluids with a powder (available on prescription from your GP) or to change your diet to soft or liquidised foods. If you develop marked weight loss, the SaLT will refer you to a dietician for advice on how to increase your calorific intake with foods that are easier to swallow.

If the swallowing problems are left untreated, there is a risk of food "going down the wrong way" i.e. going into your lungs instead of into your stomach. This can cause a chest infection, which in turn can lead to pneumonia that can be very serious. Because of this risk, it is important that you see your SaLT on a regular basis to review things for you.

For a few people, the swallowing problems can become severe and the SaLT may advise you that it is no longer safe to eat by mouth. In this instance you will be given information about a PEG (percutaneous endoscopic gastrostomy) which is a feeding tube inserted into the stomach and you can decide if this is something you would like to go ahead with. It is a simple procedure and not as scary as it may sound! If you feel this is something you would like more information about, please contact Samantha to discuss this with you further. You can also contact the office for an information leaflet about PEG feeding. Contact numbers are on the first page of this newsletter.

SMT Information Leaflets

The SMT is always striving to improve its service to those living with MSA and their families. To this end we have just updated and improved our range of information leaflets (see adjacent box). We have also just completed a series of leaflets aimed at children who have someone in their family diagnosed with MSA, to help them understand the illness and to cope with the range of emotions that this will undoubtedly bring for them. They include:

- What is MSA?
- What children understand about disability
- Helping children with their grief

Ideally these should be read as a package, but do ask for individual leaflets you think would be helpful to you.

Readers will recall the report in *SMarT News* 23 (October 2008) of Chris and Anna Dunkerley's walk along the Pilgrim's Trail from Winchester Cathedral to Portsmouth and then continuing in Normandy finishing at the Abbaye de Mont St. Michel. The nine day walk raised over £6000 in memory of their father Peter. In line with their wishes, some of that money is being spent on the leaflets for children and we are very grateful to them for their sponsorship.

We are always planning new leaflets and one on continuous positive airways pressure (CPAP) will follow.

We also have some leaflets specifically for health care professionals, available on request from Linda in the office.

If anybody feels that there is a need for a leaflet we do not have, please contact Linda with your ideas.

Leaflets currently available

- Continence in MSA and other autonomic disorders
- Going into hospital
- Holidays and travel insurance
- Living with postural hypotension
- Managing constipation in MSA and other autonomic disorders
- PEG feeding
- Saliva control
- Someone in my family has been diagnosed with MSA

Thanks to everyone who has raised funds for us. 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.

A Fantastic Birthday Present!

Dennis Westrip, who is starting the Devon Support Group, was 65 earlier this year. To celebrate he decided to hold a fundraising party and raised a grand total of £365 that he very kindly donated to the Sarah Matheson Trust. Well done Dennis. We are very grateful and send you a belated very Happy Birthday!

Dennis Westrip

Great North Run

We should have mentioned in our last newsletter that Allan Comette had yet again been running for the Trust. Allan normally runs the London Marathon for us but had to pull out in 2008 due to injury. However, he managed to get his fitness back for the Great North Run later in the year and raised the fantastic amount of £1,444.50 plus Gift Aid. We are very grateful for yet another contribution from Allan.

Congratulations to all our Marathon runners!

This year we had seven runners in the London Marathon raising money for the SMT. Sadly Ian Kovacs had to pull out at the last minute due to injury – good luck for next year Ian!

Once again, Sunday 26th April turned out to be a hot day for the Marathon and so we were very proud that all our runners managed to get round. We held a reception afterwards at The Warwick public house nearby and four of our runners attended to celebrate with us. So far over £14,000 has been raised with more rolling in – and that does not include Gift Aid. A big thank you to all those who supported our runners and helped raised this fantastic amount.

Below are the wonderful times in which our runners completed the Marathon:

Jane Curran	4:02:14
Shaun Dowling	4:06:27
Ian Filby	3:41:32
Paul Folan	5:30:19
Kathryn Gilbert	4:21:07
Gina Grasso	5:41:00
Fiona Moore	4:51:38

So far, we have already had 21 people express an interest in running for us next year – we are very grateful for all your support.

Ian Filby and Shaun Dowling

Trustee Darcy Hare and runner Kathryn Gilbert

Trustee Lady Harriot Tennant with runner Jane Curran

A Great Climb

Roseberry Topping is an historical landmark in the Tees Valley situated on the edge of North Yorkshire Moors National Park. It is 320 metres high.

Earlier this year Helena Scott, whose husband has suffered with MSA for nearly four years, climbed Roseberry Topping with their daughter Leigh and grandson Matthew to raise money for the Sarah Matheson Trust. They raised a fantastic £225 for research into the causes of MSA.

Helena, Leigh and Matthew at the summit

We are very grateful to Helena, Leigh and Matthew for undertaking the climb and for the funds they raised.

cycle2cannes

Former Trustee of the Sarah Matheson Trust, Peter Murray, first cycled to MIPIM, the world's largest property exhibition and conference in Cannes, in 2006. That year Peter cycled on his

The cycle2cannes riders and (inset) Boris Johnson greets them on their arrival

own, raising money for the Trust. This year, in spite of the recession and down turn in the property market, 63 cyclists set off from Greenwich on the 5th March. The 1500 km ride was assisted by rolling road closures, a motorcycle escort, support team including masseurs and a double decker coach.

The ride, which lasted six days, took the form of a relay and the specially designed baton was finally passed to London Mayor, Boris Johnson, on arrival at MIPIM. On taking the baton Boris said ‘I take my cycling helmet off to these intrepid adventurers. I find pedalling around London a challenge, let alone crossing the length of France.’

The ride raised funds for a range of charities and SMT were absolutely delighted to receive £20,000. The other major beneficiaries were Land Aid, Article 25, Tom ap Rhys Pryce Memorial Trust and the Duke of Edinburgh’s Award Scheme. We are very grateful to cycle2cannes and all the riders for this wonderful contribution to the Trust and for all their hard work and effort in organising and actually cycling the 1500 km.

cycle2cannes was recently registered as a charity in its own right and now hope to organise more rides to Cannes during the year so as to increase the funds they raise. For more information about cycle2cannes please go to www.cycle2cannes.org.

Wes Brown Presents £22,000 Cheque to the SMT

Readers will recall the article written by Wes Brown in SMarT News 23 (autumn 2008) about the Golf Day he organised last July in which he and his football colleagues at Manchester United, Ryan Giggs, Paul Scholes and Edwin Van der Sar, took part. The golf day was followed by a fundraising auction at Manchester’s 235 Casino. The day was a huge success.

Hugh Matheson, Wes Brown and Professor Chris Mathias with the cheque

On Saturday 21 February 2009 Manchester United played Blackburn Rovers at Old Trafford. Unfortunately Wes was on the bench that day due to an injury but Manchester United won 2-1. During half time Wes presented Professor Chris Mathias, SMT Patron, and Hugh Matheson, brother of Sarah, with a cheque for an amazing £22,000.

Wes has direct experience of MSA as he lost his father to the condition early in 2008. We are extremely grateful to him for organising both the Golf Day and evening event and for presenting us with such a fantastic cheque.

Clare on the way down

Clare’s Skydive

On 7th February Clare Cantle bravely undertook a skydive and the photograph above proves it! Clare raised over £2,000 for the Trust plus Gift Aid. Well done Clare and many thanks for an amazing fund raising efforts.

We are very grateful for all your fundraising activities.The Treasurer puts in a small plea however. Could any cheques be made payable to ‘The Sarah Matheson Trust’ and not MSA.

Thanks to Wulvern Housing in nominating SMT as their chosen charity

South Cheshire social housing landlord, Wulvern Housing, was nominated for its Mill House Extra Care Scheme in Nantwich for `the Pinders Design Awards for Independent Residential Homes.

The scheme brings together stylish self-contained accommodation, a spacious residents' lounge, café bistro, library and IT suite, a well-being suite, hair and beauty salon and access to Extra Care facilities that further enhance the quality of life of the residents.

To recognise Wulvern's achievement in gaining a place in the final of this design competition they received a cheque for £500 and donated it to their nominated charity – The Sarah Matheson Trust. Wulvern employee, David Wilson, received the cheque from Pinders. David lost his mother to MSA and expressed his delight that SMT will benefit from Wulvern's achievement. We are very grateful to David, Wulvern and Pinders for their generosity.

David Wilson from Wulvern is on the left and is receiving a cheque from Alan from Pinders on the right with colleagues standing behind

Christmas cards

Last year we sold out of Christmas cards and left many members and Trustees disappointed. This year we have ordered a larger quantity and will be illustrating the two designs and include an order form in the next issue of *SMarT News*. We will also advertise them on our website once they are available. Don't buy your Christmas Cards until you have seen the next issue!

Posters for fundraising events

And remember, 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.

- MSA is a progressive neurological disorder that affects adult men and women
- Degeneration of nerve cells in specific areas of the brain cause physical problems
- Most people have never heard of MSA; this can leave people feeling isolated after diagnosis
- Not knowing or understanding about MSA can be frightening
- Having to explain all about MSA to family and friends can be frustrating
- The Sarah Matheson Trust is the only support group in the UK for people with Multiple System Atrophy

Sarah Matheson Trust for Multiple System Atrophy

Information and advice:
0207 886 1520
www.msaweb.co.uk
Information · Support · Education · Research

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

In Memory for 2009

This edition of *SMarT News* covers the period until 25 June 2009. If you have informed the SMT of a loved one's death and their name does not appear below, please accept our apologies (we can always rectify this is a later edition). Some members passed away earlier than 2009 and the corresponding year is shown in brackets next to their name.

- Jayne Ayres
- Geoffrey Bass
- Jillian Bonello
- Marie Brown (2008)
- Gordon Cann
- Irene Cooney (2008)
- Peter Corbett (2007)
- Philip Crompton
- Philip Duffin
- Michael Fisher
- David Griffith
- John Hawkins
- Diarmuid Hegarty (2008)
- Doris Howe (2007)
- Jean Irving (2008)
- Albert James
- Sheila Johnston
- Brenda Jones
- Graeme Kelly (2007)
- Geoffrey Killick
- Philip Makey
- Jacqui Mann
- Ralph McFarlane (2008)
- Joan McLennan
- Kaptan Miah (2008)
- Trevor Munns
- Barbara Parham
- Theresa Powell (2008)
- Howard Richards
- Graham Roskilly
- Michael Sanderson
- John Simons
- Winifred Sparrow (2007)
- Ruby Tinsley
- Frank Turner (2007)
- Cees van Veen
- Kathleen Williams (2008)
- Kathleen Winnard

Carers Awards 2008

Congratulations to the 10 carers selected for our 2008 Carers Award. The letters we received spoke of the wonderful care people have been receiving.

- **Joyce Heath** was nominated by her husband, John Heath who has MSA.
- **Roberta Newton** was nominated by Joan Allen for the care of her husband, David Allen.
- **Rosemary and Cathleen** were nominated by Jeanette Crompton for the care of her husband, Philip Crompton
- **Wendy Lowry**, supported by her team – **Nicola, Sue and Tracy** – were nominated by Susan Robinson for the care of her husband, Philip Robinson.
- **Donna Mc'Carroll** was nominated by Kim Bonny for the care of her husband, Les Bonny.
- **Paul Hadfield** was nominated by his wife, Janet Hadfield who has MSA.

All ten winners have been given a certificate and a gift voucher in recognition of their invaluable contribution as carers. We hope that they all take a little time away from caring to use their gift vouchers for a frivolous purpose, because they deserve a little spoiling.

Sharing the Caring

We are thinking of starting a small column, where readers can write in and share some of their tips and recommendations for making the caring of a loved one with MSA a little easier. You may have found some gadgets or got some recommendations from a health professional which has made the quality of all of your lives better. If so, we would love to hear about it. Please send any contributions to Linda at the office or email her at *linda.campbell@imperial.ac.uk*

Continuing Health Care Funding

On the telephone helpline Samantha is often asked about health care funding. SMT is in the process of finalising a leaflet for you regarding "Continuing Health Care Funding".

Essentially, health care comes under two different remits. Initially you may require some help with personal hygiene, washing & dressing, household tasks etc, and this is considered to be "personal care". This comes under the umbrella of Social Services who can provide carers in your home to help with such tasks. This is means-tested and those who can contribute to the cost will be expected to do so. In the first instance you should ask your GP to refer you to social services who will then visit you to discuss your care needs.

Later, you may find you need more assistance with specific care needs and the time may come when you require input from qualified nurses. This then becomes "health care", and is provided by the local Primary Care Trust (PCT). You will need to be assessed by an independent nurse assessor who advises the PCT on your suitability, and funding is awarded accordingly. Samantha advises that in her experience the assessor will probably know little about MSA so, if you are in this position, please make contact with Samantha (contact details on the first page) and she will discuss MSA with the assessor before she/he visits and also write a letter of support on your behalf.

Contact Scheme

SMT's Trustees have agreed to re-launch the contact scheme. We recognise that an informal contact scheme operates within some of the support groups but are also very conscious that there are many areas of the country that are not covered by a support group and we intend to address the need for more support groups once our Executive Director is in post. Meanwhile, if you are interested in participating in the contact scheme, which will be telephone and/or email based, please contact Linda in the office.

Tabtime Daily Pill Timer/Reminder

Tabtime pill timers will benefit anyone with MSA or who needs to take pills, medication or tablets at selected times of the day. Tabtime have generously given SMT six Tabtime 5s. With the Tabtime 5 you can set five times during a 24 hour period. If you are interested please contact Linda in the office. As we only have six Tabtime 5s they will be distributed on a first come first served basis!

Lightwriter loans

Many people with MSA find a lightwriter of great assistance when they develop problems with their speech. We currently have some lightwriters in store – all lightwriters are serviced before being loaned to members. If anyone is interested in the loan of a lightwriter you will need to contact your Speech and Language Therapist who must send a letter of recommendation to Linda Campbell at the office.

MSA

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

All correspondence and enquiries to:
Sarah Matheson Trust
Box 200
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

Membership Numbers

as of June 2009

Current MSA members	817
Other patient members	39
Relatives and carers	452
Professionals	1477
Others	175

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. This facility can be used for anything from a personal occasion to an *in memorium* for 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.

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.

Don't forget: the SMT is your charity.

Donate now!

If you would like to make a donation to 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 'The Sarah Matheson Trust'.

☐ I am a UK taxpayer wish all gifts of money that I have made in the past 6 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 'THE SARAH MATHESON TRUST'

Next issue All articles to be received by the office by 31 August 2009.

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.

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