Issue 13 Summer 2003

SMarT News

The newsletter of the Sarah Matheson Trust

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From the Nurses

Thank you for all the positive comments about the colourful new look of SMarT News. We've come along way from just writing, typing and printing our information leaflets and newsletters here in the office. The extra help we now have to produce and print our material leaves us with more time for talking and meeting members. The improved look of our material increases the chances of it being seen and read, which raises the awareness autonomic disorders and of the Trust, which can only be a good thing. We do weigh these benefits up against the costs involved and have been fortunate to find very competitive services.

The revised Postural Hypotension leaflet is now finished, available on request or to download from the website. Thank you to those who helped us. If you are interested in helping with future leaflets by reading draft versions and giving us your comments and suggestions, however brutal, please let us know.

We look forward to seeing as many as you as possible at this year's Fun Walk. We are busy assembling the Fun Walk packs with maps etc. and disappointed that we will not be eligible to take part in the Treasure Hunt as we've planned it ourselves!

Catherine & Alison

From the Assistant Treasurer

Following a 10 year career within the Civil Service in London, I moved to the Court of Protection where I was involved in Estate Management. I subsequently joined the Midland Bank, and prior to early retirement in 1987, completed almost 28 years service. Ten of these years were spent in Branch Management in the West of England where I currently reside with my second wife, Lynn.

Voluntary work with charitable organisations has been part of my life for over thirty years. I was a founder member and Treasurer of the Tree Aid charity, which provides tuition and planting programmes in Central Africa. Additionally I was a Trustee for the British Institute of Brain Injured Children, with whom I travelled to the USA as a courier with groups of children and their parents in search of alternative methods of treatment and support.

I am a family man with three children and three grandchildren. My other interests include travel, family history, gardening, fine food and wines. Sport has always played a large part in my life, having played football as an amateur for West Bromwich Albion.

In 1994 my first wife was diagnosed with MSA and it was at this point that I first became associated with key people who went on to form the Sarah Matheson Trust. My association with the SMT continued following the death of my wife in 1998, and when approached in 2002 was happy to accept the position of Assistant Treasurer to the SMT.

Peter Filby, Bristol

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

Advice on constipation

Constipation is a common reason for calls to the SMT helpline: our statistics show that 70% of members with MSA have problems with constipation.

What is constipation?

Everybody's normal bowel pattern is different; some people pass faeces or 'poo' two to three times a day, others only twice a week. Constipation means having difficulties passing faeces. It can also mean passing faeces less frequently than usual.

How does the digestive system usually work?

The digestive system includes everything from your mouth to your rectum (back passage). It serves two main functions: the breakdown of food into small parts that the body can use and the disposal of unusable food. These two processes take place along the digestive system. The muscles in the digestive system walls rhythmically contract or squeeze the food through the system (a process called peristalsis). The stomach acts as a reservoir for the food, mixing it with acids and enzymes to start its breakdown. The food then moves into the bowel which has two distinct parts: the small intestine (duodenum) and the large intestine (colon). The small intestine absorbs the useful parts of the food into the blood stream. The remaining food waste now passes through into the large intestine where water is reabsorbed and the faeces are stored until they pass out of the body through the rectum.

What do the Autonomic Nerves do in all this?

The movement of food through the digestive system is controlled mainly by the autonomic nervous system. The autonomic nerves keep food moving steadily through the bowel, from the gullet to the rectum. Normally you are unaware of this process. These nerves also eliminate faeces on a regular basis.

In conditions where the autonomic nerves are impaired the movement of food through the digestive system becomes disrupted. The whole process is generally slower and can be uncomfortable and unpredictable. The slowing down results in more water than usual being reabsorbed, making faeces hard and difficult to pass. The slowing down can also cause bloating or cramp. There may be a reduced warning sensation of the need to go to the toilet.

While slowing down is the most common pattern of disruption, there can also be episodes of loose watery faeces or diarrhoea.

What are the effects of being constipated?

Constipation can make you feel unwell in addition to reducing the effectiveness of your usual medication. It can lead to a temporary worsening of some of your other symptoms.

Some of the things you may experience are: headaches, abdominal pains, bloating, flatulence, loss of appetite, nausea, lethargy & depression, restlessness and confusion. Preventing constipation from occurring is easier than treating these individual problems.

Severe constipation may cause diarrhoea (known as overflow diarrhoea) and you should seek medical advice.

Constipation and your blood pressure

Postural Hypotension or a fall in blood pressure is a common problem for many people with Multiple System Atrophy (MSA) or Pure Autonomic Failure (PAF). Postural Hypotension can occur if you are straining to pass faeces. You may feel dizzy or light-headed and you could be at risk of passing out, especially when you stand up to leave the toilet. Some of the advice to prevent straining will also help control Postural Hypotension. For example, drinking plenty of fluid (try for 2 litres or 3.5 pints) helps keep faeces soft and easy to pass, as well as helping to maintain blood pressure.

Other things also influence constipation.

The type of food you eat and how much you drink will affect how efficiently your digestive system works. This can be influenced by your ability to shop, cook, or prepare food for yourself. If you have problems swallowing you will probably not be able to eat and drink as much.

Being able to get to a convenient toilet where you feel comfortable is important. Most people prefer their own bathroom at home to try to pass faeces.

Read the information leaflet before starting any new medication and discuss alternatives which will not have this side effect with the doctor who prescribes them or your GP. The side effect of some medications is constipation.

What can I do to help myself?

Drink plenty of fluids – aim for at least 2 litres (3.5 pints) of fluid per day. This can be water, tea, coffee, juice.

Increase the fibre content in your diet: wholemeal bread, wholegrain cereals, fruit and vegetables. Try to eat some of these at every meal. Some foods, e.g. prunes or figs, can be helpful. A dietician can offer advice on a variety of ways to do this. If you feel full quickly, then you may need to take smaller meals spread out through the day. **Increasing your fibre intake without maintaining a good fluid intake may make things worse.**

If you are able to, then moving helps to move food through the digestive system. Gentle clockwise massage can also help move food along and can ease some of the discomfort you may experience. Consider massaging your abdomen for 10 minutes a day.

Establish a toilet routine. Allow plenty of time to use the toilet, as feeling hurried or rushed can lead to constipation. A physiotherapist will give practical advice about getting to the bathroom and on and off the toilet. Sitting in an upright position will help. Avoid bending forward by using a support rail or a raised toilet seat. An occupational therapist can help organise this. They can also provide advice on clothing to make using the toilet easier, and equipment to help you wipe yourself.

If you need help in the bathroom, an alarm system will give you privacy by letting you call for help when you are ready. A social worker or social service care manager can help organise carers and an alarm system.

Are medications helpful?

Medication to prevent constipation is called a laxative. Laxatives should be used with the guidance of your GP or specialist. Laxatives fall into three groups; they all work in slightly different ways.

- Bulk forming laxatives increase the volume of faeces which will stimulate movement along the bowel. These may take several days to start working. These laxatives need an adequate fluid intake. Examples are Fybogel and Normacol.
- Stimulant laxatives stimulate the bowel and increase movement along the bowel. They usually work within 12 hours but can cause abdominal cramp. Examples are Bisacodyl, Co-danthramer, and Senna.
- Osmotic laxatives keep fluid in the bowel for longer which leaves more water in the faeces to soften it. Some osmotic laxatives can work very quickly; you need to be prepared. Examples are Lactulose and Movicol.

Many people with autonomic conditions need laxatives to prevent constipation. It is important to choose the laxative that will help your particular constipation problems. The type and frequency required will vary for each person.

For example Sally, who has MSA, used a combination of Senna and Lactulose every other day which worked well initially. After several months this became less effective and she gradually changed to using them twice every day. These laxatives helped Sally keep to her routine of passing faeces every day. When Sally began to have frequent episodes of not being able to go for 4-5 days and straining on the toilet, she rang the Sarah Matheson Trust nurses. As Sally was already drinking 2 litres of fluid every day (sometimes with a struggle) and needed a soft diet (which is difficult to add extra fibre to), it was suggested that she try a different laxative, Movicol. Sally's GP was happy to prescribe this and Sally returned to her daily routine.

Healthcare professionals are cautious about the use of laxatives because long-term use can make the digestive system permanently slow. This is not a concern in autonomic conditions as the digestive system is already permanently slow due to the impairment of the autonomic nerves.

Enemas and suppositories can be useful if things have come to a complete standstill and are not responding to other measures. Some people use these in establishing a toilet routine. This allows them to chose the most convenient day, time and place for their circumstances. The community nurses can teach you how to administer these.

Your GP and community nurses are good sources of information and advice on managing your bowels. There are also continence advisors who are nurses with specialist training in managing bladder and bowel problems. Most continence advisors will accept self-referrals.

To find out the name and contact details of your local continence advisor call the Continence Foundation helpline on 020 7831 9831.

The information in the newsletter is also available as a Sarah Matheson Trust leaflet, *Managing Constipation*.

Key points

- Constipation in autonomic conditions is a common problem
- Constipation can make other symptoms worse
- Prevention is the best way to manage constipation
- Drink plenty, at least 2 litres (3.5 pints) a day
- Include fibre in every meal
- Establish a toilet routine – find the way and make the time to be comfortable on the toilet
- Don't worry if you need to take laxatives regularly
- Severe or persistent diarrhoea needs medical attention
- Use the specialist knowledge and advice of the dietician, physiotherapist, occupational therapist and continence advisor

Carers Awards 2003

Any members who are suffering from acute earache from disappointed carers who were not nominated for Carers Award 2002 take heart. We will be inviting further nominations at the end of the year. This will give you a chance to redeem yourselves and get your carers some well deserved gift vouchers.

The Family Fuel Tank

Janet S. Wilson is an Associate Professor, at the College of Nursing, University of Oklahoma Health Sciences. She wrote an article for American community nurses to help them support carers. The information was brief, simple, and very relevant. With her permission we have included it here. We hope that every family member and friend who knows somebody caring will think about following some of her advice.

"Care giving is a little like having a fuel tank: in order to keep pumping gas [fuel] out you have to have a steady supply coming in. There are a large number of family care givers but what about the aid, sustenance and fuel needed to keep these family tanks filled? Family care givers are the ones who must tap an ever changing healthcare system's resources, even when it is not clear what resources are available. These are the people who ultimately bear the exhaustion and isolation that may result from caring. If family care givers do not have some relief in their daily lives, they are at risk of overload and breakdown from stress. Here are some suggestions for supporting the family care giver:

- Ask them how they are doing and what they are feeling. Just having someone listen and understand one's feelings of anger, depression, guilt, frustration, fear (or whatever) can be a relief. You may need to do nothing more than listen.
- Help to provide as much information as they are ready for, want and can understand. Ignorance is not bliss and families have a right to information about health, disease, treatment, medication and care. Everyone in the family can contribute to compiling a list of community services, contact numbers and basic information.
- Encourage the care giver to share thoughts and feelings, particularly about worries. This can be done within the family or by using the Sarah Matheson Trust Nurses, Carers UK Helpline or local carer support agencies. Encourage the care giver to set healthy ground rules for themselves such as: it's ok to have time for yourself, it's ok to have others share in the care, and it's important to take care of yourself and to make sure your tank is filled."

Last of all she suggests being generous in praising the family care giver. It's amazing how much a simple statement of praise can help to fill a family's fuel tank.

Community Care Act 2003

Part One of this Act improves carers' rights to assessments and services prior to a patient being discharged from hospital. Part Two introduces free carers' services (equipment and help) for up to six weeks after the patient's discharge from hospital.

This is important legislation in recognising the problems many people face on discharge from hospital. Whatever the reason for your admission or your length of stay in hospital, your discharge must be planned. Your needs and the needs of your carer should be included in the planning and this legislation means that equipment and/or extra care can be provided.

This legislation won't necessarily mean that hospital staff will remember to ask you how you will manage at home. It does mean that even if it is you that brings it up they have a responsibility to organise an assessment and services.

Learning for Living - Online learning for carers

Learning for Living is a new online learning programme designed by City & Guilds to meet carers and former carers' training needs. It takes into account the practical limitations and emotional implications of caring, and offers opportunities to develop knowledge and skills that will help in planning future education, training, employment and leisure activities. There are two pathways: an informal route which enables you to do as much or as little of the programme as you wish, or an accredited route to a City & Guilds certificate.

Tips & hints

Malt Loaf Recipe [as featured in Issue 11 (Spring 2003)]

This should have read: "keep the cake for 2 days before eating" rather than "keeps for 2 days". Our apologies for that – especially to anyone who made the loaf and ate it in a hurry!

Teeth tip

Think about using a battery-operated toothbrush for cleaning your teeth; it will save time and effort.

Be prepared!

Do not wait until it is needed – use the occupational therapist to assess what equipment would be valuable to help around the home and make you safe.
Ken Johnson, Bucks

For more information about Learning for Living call 0207 294 2800 or email enquiry@city-and-guilds.co.uk

Carers Allowance

Since April 2003 Invalid Care Allowance is now called Carers Allowance. It has a new weekly rate of £43.15. The eligibility criteria remain unchanged (the carer has to be under 65 and earning less than £50 a week.) The carer must spend at least 35 hours a week caring for someone claiming Attendance Allowance or Disability Living Allowance. Your savings are not taken into account for this benefit.

Caring experiences invited

Are you a part-time carer, or living at a distance from the person who needs you? Have you experienced problems with other family members who do not offer as much care as you do?

I have been in this situation myself, being the mainstay for my father and providing increasing amounts of support, for the last three years. He has been determined to stay in his home, a forty-five minute drive away from where I live. As a result I sometimes see him only once a week, but speak to him almost daily.

I have struggled to give myself credibility for what I do, thinking that I should probably be grateful for the fact I have any of my life to myself. I constantly feel that I don't do enough. I can't call myself a carer, so what am I? Are my needs valid?

If you can relate to this, I would be very interested to hear from you. My goal would be to write an article highlighting this issue which, I'm sure, affects many people. I know it would be reassuring to read about other people's experiences of caring at a distance, the ups and downs.

Please write your thoughts and forward them to me by e-mail (heather.golding2@ntlworld.com) or c/o the SMT office. I will treat all responses confidentially.

Learn how to be an expert patient...

It's taken the NHS a long time to empower patients but the EPP courses finally recognise that you are your own expert. Richard Bailey recounts his experiences.

You know how it is... you're sitting in the hospital waiting area waiting to be called for your appointment and your eyes scan the leaflets in the racks. You might find one or two of interest and browse through them, or even take one away. That's exactly how I became aware of the Expert Patients Programme being offered by Leeds North West Primary Care Trust (PCT). I didn't read the leaflet at the time, just put it in my bag to take home.

Reading the leaflet I began to feel that this course would be of some benefit. Its key appeal was to anyone with a long term chronic health condition who wanted to feel more in control of their life, learn how to manage their health and improve their well being, meet others who lived with similar problems and learn how to deal with stress. This was not about making me an expert in MSA but giving me the tools to get the best out of living with MSA. The course was arranged over 6 weeks on Tuesday mornings at the Town Hall in Yeadon about three miles away. There was the first challenge: how do I get there? (I do still drive when the mood takes me but my carer works on Tuesdays) I discussed this with the course team and the PCT arranged taxis.

On the first week I knew that I would have to introduce myself to the others on the course so I prepared myself for that. The introductory session was quite an eye opener in terms of the range of chronic illness and it made me realise that I didn't really understand what chronic meant! So I'd learnt something straight away.

The basis of the event was an agenda as a framework for the participants to relate their experience and use this to show how various approaches can be beneficial. We were introduced to action plans and problem solving early on, as it was to prove the key technique in understanding why things happen and how to get changes made to improve our lives. A very comprehensive work book was provided to enable us to follow up in between sessions. To make the course have immediate effect we were asked to develop action plans during each session and feed back progress at subsequent sessions. The content was to be relevant to me but not necessarily related to the course. It was an ideal opportunity to raise the profile on things that I needed to focus on such as drinking water to help my blood pressure and riding my exercise bike regularly.

The first session enabled the 16 participants to be comfortable with each other and the two leaders. As we did, the discussion broadened and we shared more about ourselves and our experiences. Subsequent topics covered were wide-ranging and varied, including making treatment decisions, communication, living wills, working with your health professional, relaxation & emotion management, nutrition, fatigue, better breathing and depression.

All in all, it was useful for me because I'd been focusing on other things and I'd gained from looking at such things as relaxation and exercise.

I feel that this course has a lot to offer for those of us who want to take control of our lives and need to change the way we do things and the things we do. If having read this brief article, and you are interested in attending a course then contact your local PCT.

Research news

Quality of Life questionnaire

The shortened questionnaires are having their final checks. Once the experts are happy with them they will be landing on your doorsteps this summer. If you completed the original version you will appreciate this shorter version. We would like as many members as possible to complete this questionnaire even new members or anyone who was unable to complete the first questionnaire.

NNIPPS Study update

Natural History and Neuroprotection in Progressive Supranuclear Palsy (PSP) and Multiple System Atrophy (MSA): A double-blind, placebo controlled, stratified, parallel group study of the efficacy and safety of Riluzole in PSP and MSA.

As you know, recruitment for the NNIPPS Trial closed last year with 767 patients having been included throughout the UK, France and Germany. Since the end of recruitment, all 13 centres in the UK have been busy conducting regular follow-up visits to monitor patients’ progress as well as working on the two main ancillary studies linked to NNIPPS: genetics (DNA banking) and pathology (brain donation scheme).

We have now collected genetic samples from 125 of the 204 patients in the UK, plus an additional 94 samples from carers to act as ‘controls’. This is a great achievement and our centres are still approaching patients to ask if they would be prepared to donate a blood sample for this project. This is providing valuable DNA information to help understand the genetic basis of PSP and MSA and building an unlimited DNA bank for future research.

Fewer patients have volunteered to participate in the pathology project, though we are increasingly receiving registration forms from people who have made the decision to participate. Examination of the brain post-mortem is the only way of being sure of the diagnosis and this knowledge is vital for developing accurate diagnostic criteria and for learning more about how MSA and PSP progress. Understandably, this is a project where people need more time to consider whether they would like to register, but we hope that people in the NNIPPS Study will read the information sheet and discuss this with their families. This part of the project will go on long after the NNIPPS Trial of Riluzole itself is finished. Because the brain tissue will be studied by our colleagues in the Sara Koe Research Centre in Queen Square and at the London Neurodegenerative Diseases Brain Bank, this valuable research will continue for many years.

It is still much too early for us to have any results from the Riluzole Trial, but the Safety Committee (a group of independent experts who monitor the safety of the patients throughout the trial) have not raised any concerns, which is very good news.

In February, representatives of the European Commission came to London, along with an independent expert, for the "mid-term review" of the NNIPPS project. This was an opportunity for the people who fund our research to hear exactly what we have been doing and decide whether we are managing, with your help, to do everything we promised. We were delighted to receive a favourable report from them after the review, so we can continue with the project knowing we have their continued support.

I would very much like to thank you for your continued commitment to and enthusiasm for the NNIPPS Study.

Professor Nigel Leigh
for the NNIPPS Consortium

Sarah Matheson Trust Research Fellow

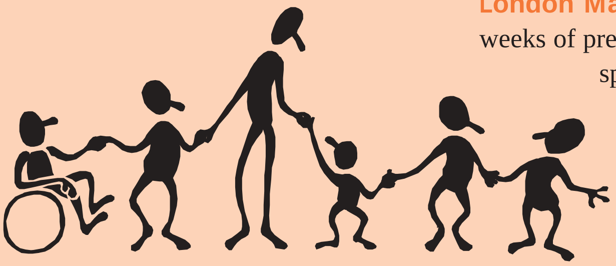
Toulouse Meeting **(European Federation of Autonomic Societies)** I am pleased to say that my talk went well. I was presenting my completed work on the effects of water drinking in MSA. As I have previously described in the Newsletter, I was able to show that

Fundraising

Fun Walk – Sunday 21st September 2003 The venue for this year’s event will for the second year be Hampton Court in Surrey. This year there are two routes: a good five mile trek or a shorter leisurely route around the palace gardens. The shorter route is suitable for wheelchairs or pushchairs and will include a Treasure Hunt. The day will culminate with a picnic provided for all those registering for the event (please provide your own drinks). Entry to the Fun Walk is by donation on the day, sponsorship forms are also available for those who feel able to raise further funds. Contact Alison for more information and to register for the walk. The closing date to register for your free picnic is Monday 8th September.

London Marathon 2003 After weeks of preparation a group of very special runners crossed the start line. Each of them was sponsored wholly or partially on behalf of the SMT and their t-shirts boldly proclaimed this. They all crossed the finish line and the result has been a wonderful boost to our funds of £19,412 before Gift Aid (at the time of going to press) with further expected. Our sincere thanks and congratulations go to them all. Sponsorship totals received to date are from: Rupert

Hampton Court



drinking 480ml (about a pint) of water will improve standing blood pressure in MSA, and that this beneficial effect occurred as early as 15 minutes after drinking. One major aspect of my research is looking for better ways of diagnosing MSA. At present other conditions such as Pure Autonomic Failure (PAF) can present in very similar ways to MSA, and often only time will tell whether an individual patient has MSA or PAF. My talk generated some interesting questions and discussion from the audience, especially regarding the possible means by which water increases blood pressure in MSA and PAF, but not in healthy young subjects. My work has added to our growing knowledge of possible underlying mechanisms by which this may occur.

Carbon Dioxide (CO2) study This is progressing well. You may remember from the last newsletter that we are studying the effects of a single breath of CO2 on blood pressure and skin blood flow. In healthy subjects we know that CO2 will activate the sympathetic ("Fight-or-Flight") arm of the autonomic nervous system. This leads to a very short-lived increase in blood pressure and a slightly breathless, panicky sensation. We think that PAF patients will produce a more normal blood pressure increase after CO2 than MSA patients. This is because of the different areas of nerve involvement in MSA & PAF.

As well as recording the blood pressure response to CO2, we are also measuring the skin blood flow response using a Laser Doppler probe. This is done by lightly taping a small probe to the skin of the thumb. A small Laser light is then able to calculate the blood flow just under the skin. The sympathetic nervous system helps control this blood flow, but not much is know about how this is affected in MSA and PAF. So far we have obtained exciting provisional results from this technique, suggesting that there may be a marked difference between the responses seen in MSA and PAF. If this is confirmed by the end of the study, we would have been able to find a new and potentially useful way of helping to distinguish MSA and PAF.

New Study We are going to follow up these early findings with a study due to start in the next 2 months. This will measure the skin blood flow response to simply performed tests such as an ice pack on the hand and taking a deep breath of room air. As well as using the Laser Doppler we also hope to measure the sweat response. The sympathetic nervous system helps increase sweat production when activated as well as decreasing skin blood flow. Because the pathways involved are slightly different, these combined tests would enable us to obtain a more accurate picture of the autonomic involvement in MSA and PAF.

Another new study ADH is a hormone produced in healthy people in response to several stimuli, including standing upright. ADH not only helps conserve body water, but also helps to increase blood pressure. In MSA the production of hormones such as ADH can be reduced. We will study the effect of upright posture on ADH in MSA and PAF patients. Our provisional studies have indicated that in PAF, when they lie back down after standing, the lying blood pressure will increase to HIGHER levels than when they were lying before being upright. This is termed blood pressure overshoot. This does not seem to happen in MSA patients. We believe that this is explained by the fact that PAF subjects produce ADH during upright posture whilst MSA do not. On returning to the lying position this ADH in PAF patients would then be able to lead to an increase in blood pressure, which would not occur in MSA. Blood pressure overshoot does not happen in healthy people.

Our study hopes to link this blood pressure overshoot with ADH levels in the blood.

Further projects are being planned at present and I will let you know more about them as well as an update on the above studies in the next newsletter.

Dr Tim Young, Neurovascular Medicine (Pickering Unit), Imperial College London, St Mary's Hospital

Fundraising

Fleming (£7,923), Pam Parsons (£2,829), Charlie Campbell (£1,967), Alan Comette (£1,817), Catherine Baker (£1,500), Peter Whittaker (£1,098), Simon Peck (£866), Sue Parker (£824) and Paul Hatfield (£588). There were 100 donations received through the marathon text-message service.

From the Treasurer It's not often that superlatives seem inadequate, but I must admit that in this instance I am lost for the word which could do justice to the efforts of our splendid Marathon runners. This boost to our funds will provide the Trust with much increased flexibility when considering future research initiatives. We all are immensely grateful to the runners and to their generous sponsors.

Pyrenees to Paris – July 2003 Two years agoone of our Trustees, Peter Murray, raised £34,000 for the SMT by cycling from Lands End to John O'Groats. Now fully recuperated, he is following the 100th Tour de France route from Pau in the Pyrenees up the west coast of France and on to Paris (around 1000km). This year he is supporting both the SMT and the National Hospital for Neurology which funds research into neurological diseases, including MSA. We look forward to bringing you news and photos of Peter in the next issue of SMarT News.

London 10km Race Neil Hawker ran in the London 10k race on July 13th to raise funds for the work of the SMT. Congratulations Neil, and we hope the blisters are healing well.

A generous gift The Watsons in Edinburgh kindly donated a luxury holiday to South Africa they won in a photography competition to the Sportsman's Charity Auction where it raised £6,500 for SMT. They have asked the funds be used for research into MSA.

Coffee morning Once again Les & Joyce Ward and their friends in the Sheringham area have come up trumps, raising a further £355.50 for the SMT at a coffee morning. Well

MSA

Sarah Matheson Trust for
Multiple System Atrophy

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

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

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

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The Trust is financed entirely by voluntary donations.

Registered Charity Number 1062308

Therapy Day

I felt I should tell you about the day out at the Therapy Session at Manchester Town Hall on April 8th. My daughter Susan and I took Tom to Manchester by train (first train ride in 30 years after our local station was closed by Beeching). Susan and I had reflexology, a manicure and a facial – Tom had a head and neck massage. A walk through the town to Kendall's for lunch; the staff could not have been more helpful to royalty. A very enjoyable day which got Tom out of the four walls for a change; we will do it again when there is one again in Manchester.

Mrs Fazackerley, Wigan

We'd love to hear from anyone else who has had a good day out they would recommend.

MSA booklet

I am writing to thank you for the MSA booklet. It has already been useful in that just having one's symptoms written down in an authoritative journal makes one feel justified at least. After a long succession of casualty doctors who have given me the glazed stare (they adopt when they think they have a menopausal hypochondriac on their hands), you at least feel that you're not complaining about something you imagined.

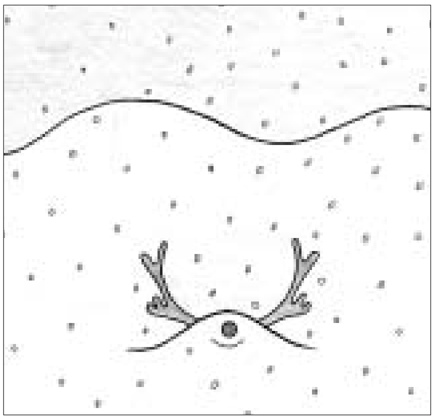
Brenda Rolton, Kent

Further copies of the booklet are available from Alison

Thinking ahead

The Sarah Matheson Trust Christmas cards designed for us by Harry Fleming are once again available for purchase from Alison at the SMT office. The cards cost £3 per pack of 10 cards with an additional 50p per pack postage and packing.

Orders should be phoned/sent to the SMT office with cheques made payable to the Sarah Matheson Trust. For orders of over 10 packs please contact Alison for individualised postage prices.



Diary Dates: Awareness days

Glasgow:	4th September, Southern General Hospital
Kent	24th October, Dartford
Plymouth	(*to be confirmed*)
Manchester	(*to be confirmed*)
Middlesbrough	(*to be confirmed*)

All our members will automatically be notified of any events held in their area, an invitation will be forthcoming once the date and details are fixed

Free to a good home

London: Dunlopillo electric adjustable bed. Arran chair with manual seat riser.

Cheshire: Remploy Stowaway wheel chair with conversion kit to self-propelling.

Contact the Sarah Matheson Trust for further information. All items must be collected from the donors. Donation in lieu of payment to the SMT.

The SMT recommends that you are assessed by an occupational therapist before obtaining disability equipment. The SMT does not accept responsibility for the safety and suitability of any advertised items.

In Memory

Donations received with gratitude in memory of:

- Elsie May Barker
- Janet Bingham
- Rita Cyril
- Gertrude Fear
- Rhoda Field
- Lillian Ford
- Louisa Ford
- George Mitchell Hill
- Gerry Huxham
- Paul John
- Joan Kaye
- Myfanwy Kidney
- Ted Larkin
- Brian Moore
- Audrey Ramsden
- Rita Siddle
- Gretel Stone
- Richard Taylor
- Edward Wilkinson

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