

MSA SMarT News

The newsletter of the Sarah Matheson Trust

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Have you ever wondered what the SMT nurses do? Between writing the newsletters Catherine and Alison are kept busy with a wide range of activities that keep them on their toes. Find out more about a typical week in the life of the SMT nurses.

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From the Nurses

We hope you all enjoyed the new MSA guide. Thank you to all who helped us prepare the contents – patients and professionals. We hope that the high quality design reflects the quality of the contents. The guide, like all our other literature, remains free of charge.

On the 19th February the Sarah Matheson Trust office relocated within the St Mary's Hospital site. The new office is easier to get to and we hope this means we will see more members face to face. Apologies for any delays in responding to your calls and letters while the relocation was in progress. All our contact details remain the same.

This edition includes several contributions from our members. We would love to see your contributions making a regular appearance. SMarT is a good way to spread the news and views of people with MSA to others with the condition and all those who are involved in their care here in the UK and around the world. So write to us or telephone in your ideas.

Thank you to the nine members who nominated someone for a SMT Carers Award. As well as a mention in this newsletter each nominee received gift vouchers as a thank-you.

Finally, we apologise to our valiant fundraisers who did not receive their due credit or appear in all their glory in the last edition, due to some printing errors. Their full stories and colour pictures can be found on our website – www.msaweb.co.uk

Catherine & Alison

Administration vacancy

The Sarah Matheson Trust has been expanding its areas of activity as it seeks to support all those touched by MSA. The administration associated with this work has now created a position for a part-time administrator based in Central London. Should anyone feel they have the relevant experience for what will be a thoroughly rewarding role could they please telephone or write to Alison in the SMT office. Whilst our preference would be for a volunteer, expenses or a salary are negotiable.

Help required

Do you live near enough to travel into London and have some time to spare to help with mailing out the newsletter? We would greatly appreciate some help with this – we currently mail to nearly 1700 people, that's a lot of envelopes to stuff! If you may be able to help then please let me know. There will be a glass of wine involved!

Are you running a local SMT fundraising event? If so then please contact me so that not only can we advertise the event for you but I can also produce a fundraising pack for your specific event.

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

A week in the life of...

So what do the SMT nurses do? Catherine and Alison give us an insight into a typical working week

Catherine

After completing my nurse training in the North East I moved to the National Hospital for Neurology in London. Apart from brief periods in Accident and Emergency, and in the Outback of Australia, all my nursing experience has been in neurology and neurosurgery. After caring for people with MSA and other Autonomic conditions during their hospital admissions, the opportunity to progress from a ward sister to a Nurse Specialist with this group was ideal. The Sarah Matheson Trust funds part of my post. This allows me to combine patient care at the National Hospital with my commitments to the Sarah Matheson Trust. While I devote time to specific activities at both the National and the Trust, this is variable from week to week. This variation in my working week can be challenging at times but is very satisfying.

Alison

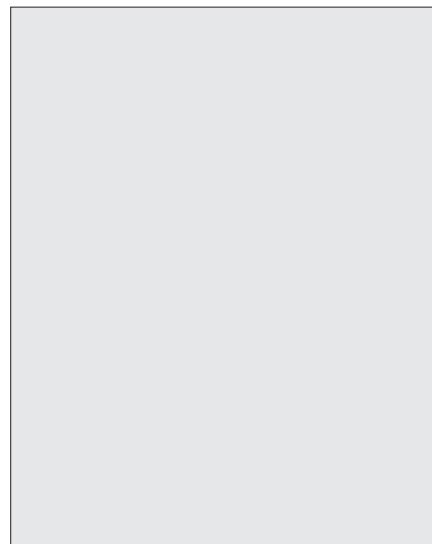
I trained in East London in a busy district general hospital and have arrived at my current position by a very circuitous route. My nursing experience has been very varied with periods in Intensive Care, cardiac surgery, A&E and general medicine. In between times I worked in academic research in two London Universities. I joined the Trust because I was looking for a post that combined the variety of nursing experience I have gained with my other areas of interest, in particular counselling and support work. I started on a steep learning curve, having the excellent reputation of my predecessor Bridget to match up to. My post is funded entirely by the Trust and I combine my time in the office with participating in the clinical work of the

autonomic units both at St Mary's Hospital and at the National Hospital. This is a truly fulfilling job with never a dull moment; you never know what the next call will bring.

Monday

An early start for both of us as we are in Colchester (Essex) for an MSA Information Day. Alison got underway with the welcome for the morning group. The session was attended by 30 professionals from the surrounding area who had come for an update on MSA and its management. It was a good mix of nurses, therapists and a GP from hospital, rehabilitation and community teams. We present information using computerised slide display together with a handout that people can keep for future reference. The sessions help those attending to forge links with each other and with the Trust. For us the sign of a successful presentation is (1) the absence of snoring (2) the number of questions afterwards. This session was successful, with a very lively audience who participated with enthusiasm and no snoring!

After a brief lunch with Juliet Ashton, the local Parkinson's Disease Nurse Specialist who helped organise the day, we returned for the afternoon session to find the room crammed with an eager crowd of members and their families. Whatever worries people may have had about attending the afternoon session appeared to have been left at the door. The 18 people present only needed the gentlest persuasion to join the discussion. We covered areas such as holidays, the difficulties in getting diagnosed, local services, applying for benefits, and sleep problems. A long coffee break gave everyone the opportunity to speak more privately to



Catherine journeying home after a similar MSA Information Day.

both of us and to the other members. We hope meeting other members will encourage people to join the Contact scheme and have ongoing support from other people sharing similar experiences. The local members are now on the lookout for a pub in the area with good wheelchair access and toilets for a follow-up meeting.

We continue to learn more about MSA through these sessions and it is a wonderful way of personalising the service we provide over the telephone. The information days give us an understanding of the services and their availability in an area, which is useful for future members.

At the end of the day we returned home a little wiser, very satisfied and absolutely shattered!

Tuesday

It was back on the underground to get to work, both of us heading for the National Hospital for our weekly teaching session, ward round and clinic. The first meeting of the day was to hear Tim Young present

the findings of his research on the effect that drinking water has on postural hypotension. This was in preparation for presenting the work to an international medical conference (see Research section). We then reviewed all our inpatients on the ward round before starting the outpatient clinic. We try to eat our sandwiches together with the Autonomic Unit staff which allows us to catch up with all the news and gossip, MSA and otherwise, from a growing team of doctors, scientists and researchers. This is a day with lots of face to face contact with patients and carers, which we both enjoy. Working together also gives us the opportunity to discuss anything that has worried or challenged us over the last week – we call this debriefing. This is a vital part of the week as we work on different sites for much of the rest of the time. Between ward round, clinic and debriefing we rarely manage to respond to telephone calls on Tuesdays.

Wednesday

Catherine was concentrating on catching up on answering telephone calls. These included a call from a member who needed help managing constipation. This is one of the most common problems that we discuss over the telephone. In recognition of this the next newsletter will include an article on managing constipation. Another call was from somebody who was newly diagnosed with MSA and was ringing after seeing our information on the website. They were glad to speak to someone who knew about their condition, as everyone else they had spoken to had not heard of MSA. This is a recurrent issue, which the Trust addresses both by providing information and support to people affected by MSA and by trying to raise awareness, especially amongst health professionals.

Meanwhile Alison was busy mailing out invitations to the MSA Awareness Days planned for the following month in Hull and Liverpool. Although Alison's

computer skills are more advanced than Catherine's, this is still a time consuming task but one that has great benefits when we get to meet members.

A lull in phonecalls meant that Alison had time to produce personalised sponsorship forms for a runner in a half marathon together with information about MSA and the SMT for their sponsors.

Alison also collated the donations received in the office and sent them to our Assistant Treasurer, Peter Filby, who acknowledges and banks them.

Thursday

As part of her ongoing professional development Catherine spent Thursday at South Bank University studying Ethics and Law in Nursing.

Alison checked the Contact scheme, and finding there were plenty of requests, got to work matching people together. Unlike Dateline this is not a computerised science! Alison matches people with their communication preferences (e-mail, telephone or letter) together with similar age, area and home circumstances where possible. Sometimes a second contact is needed; this isn't a problem.

Alison spent some time searching the on-line library databases for new articles on MSA and symptom management. It is important for us to keep up to date in this way and also to be able to provide this information for our professional members. After a while on the computer, it was a welcome

relief to answer a call from a Scottish neurologist who wanted to know more about managing postural hypotension for one of his patients.

Friday

We worked together this morning preparing the content of this newsletter and planning the revised version of the postural hypotension leaflet. We are fortunate to have professionals who can check our work for accuracy and some members who check its readability. We always welcome comments about the information we produce and suggestions for new leaflets.

Alison was due to be away from the office the following week on a well deserved week's holiday so the afternoon was devoted to answering outstanding letters and preparing information packs that could be sent out while she was away. Catherine reviewed the Communication Aid loan scheme; all 11 Lightwriters were in use and there were three people on the waiting list. Next task was responding to a request from a social worker who was trying to find funds for a reclining chair for a SMT member. From 2003 the Trust is able to provide £100 towards welfare requests such as this, so it was a pleasure to be able to contribute towards a really useful piece of equipment.

Weekend

Well we do all have them –we usually collapse on the sofa with our families and cats!

From the Treasurer

With an earlier edition of SMarT News there was included a Gift Aid form together with the following message: "Charities are actively encouraged to make use of this recent introduction whereby we can claim tax to the tune of 28% on all donations from donors who are themselves UK taxpayers". I went on to express our gratitude to all MSA patients and their families for their very many acts of very real generosity to the Trust. My point in repeating this a year later is that the Trust is still, in many cases, missing out on this opportunity to increase these acts of generosity in a manner which the Chancellor actively encourages. Please do consider the use of Gift Aid with any donations; Alison Aberly has the forms and can readily supply them. Thank you.

Val Fleming

Carers Awards 2002

Congratulations to the nine carers nominated for our 2002 Carers Award.

Most carers care for their spouse or partner and our first five nominations fit into this group.

Barry Heaton was nominated by his wife Sue. Sue says he that he makes her laugh, he encourages her, they can talk about things together and he listens to her. All these things help her cope with her illness.

Jenny Shaw was nominated by her daughter Alison. Jenny cares for her husband Martin and has continued to be a great support to the whole family.

Michael Day was nominated by his wife Susan. Becoming a carer has meant a real change for Michael who was in Susan's words a workaholic. However he has taken on his new role providing lots of physical care as well as emotional support and encouragement.

Chris Jones has nominated his wife **Louise Jones** who is a tower of strength for Chris and manages to find the energy and enthusiasm to combine a full-time job with caring for Chris. Meanwhile keeping her wicked sense of humour. Louise also finds time to

organise fundraising events for the SMT – see the item on the Moat Swim. Louise – a big thank you comes from Chris and from us too.

Bev Simmons has been nominated by her partner Colin who wants to say thank you for looking out for his best interests and doing the worrying for both of them. He hopes that this award will show how much he really appreciates her.

Most neurological conditions effect the whole family and our next two carers are family members who have responded positively to this change in family life.

Sam Seaborne was nominated by her mother Lena. Lena feels that she wouldn't be able to cope without your help and support despite having her own family, and hopes she won't be embarrassed by the nomination.

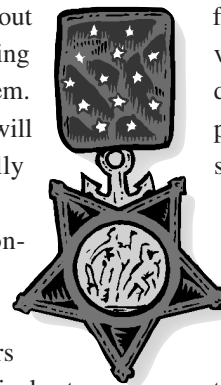
Vera Winterton cares for her daughter Beryl who made the nomination. Vera is no stranger to caring as she has previously looked after her husband. We're far too polite to

mention Vera's age but she cares for Beryl with remarkable spirit and energy.

Friends are the family we chose and some of our members have chosen very well. **Gwen Cosgrove** was nominated by Marie Pandolfo. Marie is caring for her husband Vincent and Gwen's visits to them lift their spirits. Gwen does this despite having health problems of her own. Marie says she has a "heart of gold".

Peter Mente nominated his friend **Ann Savage**. Moving house is always a stressful event but Peter's move to a ground floor flat was made easier with Ann's contribution. As well as organising helpers she did lots of sorting, packing and unpacking. Peter feels he could hardly have done it without her.

All nine carers 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.



Tips & hints

Socks

A source of good, comfortable, compression socks & stockings are Medi UK Ltd, Plough Lane, Hereford HR4 0EL. enquiries@mediuk.co.uk. 01432 351682

They are quite expensive but I find they are worth it as they are very comfy!

Maureen Watkins, Gloucestershire

Moving tip

Try using 2 plastic rubbish bags on the seat of the car to help someone slide in with the helper round the other side grasping the top one and leaning their weight back (not pulling and thus injuring their back)

Pam McClintock, PD Support worker, Dorset

Constipation cure: Malt Loaf Recipe

1 cup Albran
1 cup mixed dried fruit
1 cup soft brown sugar
1 cup liquid (milk or juice or tea)
1 tablespoon black treacle
1 tablespoon malt extract
(or 2 tablespoons black treacle if preferred)

Mix well together and soak overnight

Add 1 cup flour

Line bottom of small loaf tin. Cook on Gas Mk 4 for one hour. Leave to cool in tin then wrap in greaseproof paper. Will keep for 2 days.

Janet Sowden, Berkshire

A holiday experience

Paul Griggs relates his recent trip to Spain

With the MSA starting to bite, it's into the wheelchair I go. Holiday time looms shortly. We had planned to go to the Caribbean, but suffering from sleep apnoea and most of the flights back going overnight, this was a no go. So we started to look around for alternatives, got every brochure under the sun, but could find nowhere suitable to go or that we fancied.

After speaking with Alison at The Sarah Matheson she sent us information from a Parkinson's Disease Society publication Short Stay, Respite Care & Holidays. It gives various numbers and places all around the world, most essentially for the disabled and it gives details of the facilities available; a worthwhile publication.

We decided to go to Spain. A place called Huelva (pronounced Wal-va), on the Atlantic coast between the Portuguese border (we flew into Faro) and Cadiz. We stayed at a hotel called the Confortel Islantilla. Advertised as having 16 rooms with disabled facilities, it looked reasonable so we thought we'd give it a try.

The hotel was a modern building, Pyramid shaped, with rooms similar to a Travel Lodge, quite roomy but more importantly air-conditioned. The disabled splash room was excellent. A good size with a height adjustable sink, shower and toilet. A glider chair was provided by the travel agent, Can-do Ltd., which made life easier. Our room was on the third floor and obviously reached by a lift. The lift was just big enough to take a wheelchair and two other standing people. The corridors are wide and you can easily pass another wheelchair coming from the opposite direction. It was good to see so many wheelchairs flying about. (by that I mean the fact that the hotel was able to cater for them)

We stayed on a half-board basis. The restaurant was large and the food was very good and served buffet style, help yourself and eat as much as you want. The outside at the rear has large gardens with more than enough sun chairs to go around in the busy times and a bar serving drinks and snacks. It has a large swimming pool with a depth range from about 3 feet to 8 feet and a hoist to enable the disabled to enter the water safely. It also has a toddler pool. All overseen by a lifeguard. There is an entrance from the gardens which leads onto the sea front.

Set just outside the town, this is a relatively new resort with lots of apartments being built. The sea front has been refurbished and re-paved with block paving. The beach has been rejuvenated with sand being brought in to create dunes and planted out to hold it all together. Pathways ways have been cut through the dunes to get down to the sea. For wheelchair users there is a big buggy with ball type wheels to get you onto the beach. This is operated by the lifeguards. Being the Atlantic coast of Spain the sea is lively. Watch out for strong under currents. And always look

out for the warning flags for safe bathing. Good to see lifeguards on a Spanish beach though.

Just a short walk from the hotel is a small shopping complex with the standard souvenir shops, a supermarket and several bars and restaurants. For the fit and able there is a golf course nearby and there are tennis courts on the complex. The surrounding terrain is reasonably flat. Entertainment is provided by the pool bar and in the bar by reception in the evenings.

We travelled 14–21 September. Few kids and relatively quiet. The weather could have been better but it has been bad all over Europe this year. Still we had 3 or 4 days sunshine and the heat didn't affect me too much. Given the problems with the MSA we coped fairly well.

I never recommend anywhere I've been however good it is. It's for you to decide. One mans cup of tea, another's poison and all that. But given the facilities you should have a reasonable time if you decide it's for you. We used an agent whose address was in the Parkinson's brochure, Can Be Done Ltd, 0207 907 2400.

In Memory

Donations received with gratitude in memory of:

- Melvyn Bara
- Margaret Hewitt
- Alexander Steel
- Wilf Buffery
- Brian Hobley
- Jean Steeples
- Patrick Brolly
- David Humphris
- Bernard Stenning
- Dorothy Butler
- Harry Hutchinson
- Ina Sudbury
- George Cawdron
- Graham Jones
- Dr Jack Turner
- David Clarkson
- Patricia Lindley
- Eddie Smith
- Jospeh Edgley
- Brian Nichols
- Vic Stevens
- Bill Griggs
- June Oakes
- Roy Walters
- Michael Hampton
- Basil Pasley
- Jackie Whiting
- Audrey & Stanley Hepworth
- Joan Peryer
- Tom Stafford

SMT Research Registrar

Water study I have now completed my analysis of the water ingestion studies in MSA and pure autonomic failure (PAF). There is a clear improvement in standing blood pressure in both groups 15 and 35 minutes after drinking about a pint of water. This has allowed us to give clearer guidelines to patients about the timing and volumes of water to be taken to improve standing symptoms. Of particular interest I have been able to show for the first time that there may be a difference in the response to water between these two groups. This finding may have importance in trying to differentiate between MSA and PAF (in the early stages they can present in an identical manner). In addition, it will contribute to our knowledge of the mechanism by which water drinking increases blood pressure in autonomic failure, an effect which is still not fully understood.

I have now presented this work at the Clinical Autonomic Research Society meeting in Birmingham (I was very nervous, this was my first major presentation!) and at the Royal College

of Physicians. In addition I have been selected to present further aspects of this work at the European Federation of Autonomic Societies meeting in Toulouse in May 2003. In my next update I will let you know how I get on at the Toulouse meeting!

Carbon dioxide study This is a project to help better understand the autonomic dysfunction seen in MSA. I aim to study this difference by comparing hormones, blood pressure and heart rate responses to a stimulus which excites the sympathetic nervous system at a central location. The stimulus I am using is a single breath of a carbon dioxide/oxygen mix. In healthy people this produces a feeling of anxiety which rapidly resolves in about 10 seconds (I can testify to this having been a control subject myself). There is a corresponding blood pressure rise for about 30 seconds. Our theory is that MSA subjects will show much less of a response than healthy or PAF subjects because of their condition. I will be analysing the cardiovascular response to this breath in detail using the Finapres and Laser Doppler. The study also involves taking some blood samples

during the study period of about 1 hour. I have full ethical approval for this study and have started testing patients. I would be very interested to hear from any patients with MSA or healthy volunteers (aged between 40 and 75 years) interested in taking part in this study. Ideally patients would have been seen or tested at some point in the past by Prof. Mathias' team at St. Mary's Hospital, or the National Hospital for Neurology, in London.

*Dr Tim Young
Neurovascular Medicine
(Pickering Unit), St Mary's Hospital,
London W2 1NY*

Quality of Life questionnaire

What are we doing?

This is an update on the progress of our Quality of Life in MSA study. We would like to express our thanks to all those of you who were able to complete our questionnaires, as without your help this research would not have been possible. It is of the utmost importance to ensure that information is obtained from a large enough sample when carrying out

Fundraising

Moat swim 29th December was a wet and windy day between the excesses of Xmas and New Year. The rain overnight had left the ground in Surrey like a quagmire and the grey day was not encouraging. Despite all this a memorable event took place in Newdigate thanks to the efforts of Lousie & Chris Jones, Mike Huffey (whose moat it is) and the whole village community. An assortment of intrepid

Ready for the off



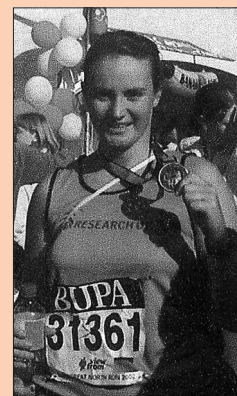
swimmers braved the weather and the swans to circumnavigate the moat at Cudworth Manor. Other events included a duck race (yellow plastic ones), a balloon race and a tug of war competition. The tug of war was a bit like mud wrestling so all credit goes to those participating and those doing the laundry! With music and commentary, a bar and hot food the event was a real family affair. And it raised well over £6000 with the proceeds to be shared between the SMT and the local hospice. Thanks to all those who organised it and all those who supported it.

Great North Run Congratulations and thanks go to an intrepid band of runners! Joanna Knott and her daughters ran the Flora Light Challenge for women in Hyde Park raising funds for the SMT. Rosemary Vidler valiantly completed the Great North Run for the SMT, raising funds and awareness in the North East. Kami Marshall also

completed the Great North Run (pictured) and still had enough energy to collect £305 of sponsorship money. Melanie Catling will be running in the Berlin Half Marathon on 6th April.

Good Luck Melanie!

Other events Meanwhile more sedate events have included Sutton Bowling Club's Gala Day – one of their members Doreen Dowling is an SMT member. Doreen herself has been making hand made cards to raise funds for SMT. The Martha Fellowship in Sutton Coldfield held a Xmas Fete with the proceeds coming to the SMT and once again Les



Kami Marshall after the Great North Run

research of any kind, in order to be confident that any results obtained are representative of the whole population. The tremendous response that has been achieved in our MSA study assures us that the final questionnaires will indeed be capable of accurately reflecting the views and feelings of patients with MSA and their carers.

The Global Perspective

In addition to the postal questionnaire, we have also had help from patients with MSA attending centres in the USA. This is important as it will allow for the development of a more global measure, which can be used internationally. We are also in collaboration with the European MSA association, who have agreed to incorporate the finalised questionnaires into the final stages of its programme of research. The fact that this programme is scheduled for 3 years will allow us to test how sensitive the questionnaire is to detecting change.

Developing tools

At this stage of the research, the data obtained have been studied fairly extensively. This has led to a large

reduction in questions on both the patients' and the carers' questionnaires. It was found that several questions were much less important to you than were others, and that there was some overlap and duplication of answers. We also took into account when analysing the data the relevance of any question to those with MSA. For example, some questions returned a large number of 'not applicable' responses. In these cases it was assumed that such issues were not directly related to MSA, and therefore were excluded from the measure. It was also important to take note of how often each response was selected. This is because the patient's questionnaire is intended to be able to differentiate between those in the early and later stages of MSA.

Using these methods, shorter patient and carer questionnaires have evolved, which will be less time-consuming to fill in but at the same time will be just as informative and hopefully more efficient than the longer versions.

The next stage

The shortened questionnaires will soon be sent out again to patients with MSA and their carers. We hope to be able to

get the same excellent response as when the questionnaires were initially sent. Those of you who find yourselves able to participate will find your questionnaire easier to complete. We look forward to analysing the data once again, in order to see whether our question reduction has been successful. The new MSA questionnaires will be reliable and valid measures for the assessment not only of the quality of life of MSA patients and their carers, but also of how quality of life changes throughout the progression of MSA.

Finally: Thank You!

Thank you again to everyone who has helped so far with this study by completing the questionnaires; also to those who have made telephone contact with information regarding their MSA and how this could be incorporated into the questionnaires. It is always good to speak with you. Your comments, suggestions and questionnaire answers have been invaluable. Our sincere and heartfelt thanks go once again to the Sarah Matheson Trust and to all of you for your help in enabling us to undertake this study.

Dr Anette Schrag

Institute of Neurology

& Joyce Ward with the help of their friend Anne Horton raised funds at a Coffee Morning in Norfolk. Another seasonal fundraiser was the carol concert held by the Lea Singers in Hatfield.

A special thank-you goes to the children at Lessness Heath Primary School in Kent who raised over £1,300 for the SMT with a 'Sponsored Spellathon'. Well done all – your efforts are greatly appreciated.

London Marathon – April 13th

2003 We have been inundated with requests for Golden Bond Places this year and have been lucky enough to fill all seven available places; unfortunately we have had to disappoint several runners who were unsuccessful in their bid, we hope they will apply again next year. Additionally we have several other people who applied independently through the ballot and have offered to run on our behalf. We will be providing all runners with an SMT t-shirt so they

are easily identifiable whilst running.

This year we also held a 'social evening' so that all our runners had a chance to meet before the big day. One of our Patrons, Sir Roger Bannister kindly attended the evening along with several of our Trustees. Sir Roger offered advice gained through his experiences along with support and encouragement.

The Golden Bond runners are: Peter Whittaker, Steven Smith, Simon Peck, Allan Comette, Catherine Baker, Pam Parsons and Charlie Campbell. Independent runners are: Karl Digby, Nick Rogers, Paul Hatfield, and Sue Parker. This means that this year we will have had at least 11 people running for the SMT – well done everyone.

Anyone wishing to make a donation in support of the London Marathon runners can send a cheque to the SMT office or donate by text message: text HOPE to 89148 (you will be charged

Fundraising

£1.50 plus text message cost, at least 80p of this charge will go to the SMT; see www.mkodo.com for donation update and T&Cs).

JOGLE 2003 July 7th will mark the start of a bike ride from John O'Groats to Lands End raising funds for the SMT and the Motor Neurone Disease Association. The riders are Justine Molloy and Alex Pandolfo with Martin Backhouse as their full-time driver and back up. All three have experience of family or friends with MSA or MND. The team members are committed to raising the profile of MSA (and MND) along the way as well as raising funds to support both charities. Anyone wishing to become involved or help raise funds can contact Justine Molloy (justine.molloy@btinternet.com or 0161 743 0947).



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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Professor CJ Mathias DPhil DSc FRCP

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Michael Cook AO
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Eileen Lady Strathnaver OBE
Lady Harriot Tennant

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London W2 1NY
020 7886 1520
020 7886 1540 (fax)

www.msaweb.co.uk

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Registered Charity Number 1062308

From where I'm sitting...

A message from Alison – “Can you write a few words for SMaRT?” Yes says I, thereby giving myself an instant headache. It's a good job there's a delete key on a computer keyboard, and here's why, SMaaaaaaaaaaaaaaaaRT. Sometimes my finger gets “stuck” to the keys. Been there?

Not being able to walk anymore, if I want to go out it's into the wheelchair I go. What I didn't realise was that I was going to be transported to a different planet where I become invisible. Let me explain.

Off we go to do some shopping. I'm being pushed along the shopping precinct and the first thing I notice is the amount of people who don't get out of the way or take evasive action at the last minute. They just don't see me. Sometimes, if it wasn't for the reactions of my driver, there'd be some people with sore legs.

You want to window shop, get pushed to where you want to go and have a look only to be pushed past the window whilst the driver does the window shopping for you, completely forgetting you're there. And what if you bump into people you know, friends and colleagues. You stop for a chat but where are you? Sitting outside the group whilst everyone talks over the top of you, not really including you in the conversation.

Is there a case here for driver training?

And the terrain. This is horrendous. Does anyone make a 4 x 4 wheel chair off road version? That's just to go along the pavements. When you're fit and well you don't feel or notice the undulations underfoot but what a difference in the iron chariot. Is there

anybody out there making a chair with independent suspension? Have any of the designers ever travelled in one I wonder? This is without doubt the most uncomfortable form of transport it's been my misfortune to travel in.

Oh well, perhaps one day!

Paul Griggs, Middlesex

From Sarah's sister Elizabeth

As a trustee of the Sarah Matheson Trust, and also being one of Sarah's sisters, I am writing to say how thrilled we are with the great success of the Trust. Sarah would have been delighted that so many people are benefiting from the knowledge and experience of Catherine and Alison.

The Trust is also involved with four research projects: a Quality of Life Survey by Dr Anette Schragg, Research in Parkinson's Plus Syndrome (including MSA) by Professor John Hodges, PSP/MSA DNA bank with Professor K Morrison, and our own three year SMT Fellowship for Dr Tim Young.

A number of people have had very successful fundraising events, which have made an important contribution to the Trust, and we are very grateful. The more money we can raise, the more the Trust can do.

I would like to encourage anyone who has an idea, or would like to contribute in some way. Perhaps by forming regional fundraising groups, or even joining a fundraising committee. Please write or ring me up if you think you would like to join us.

*Elizabeth Brackenbury
Holme Pierrepont Hall,
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0115 933 3083*

Christmas card sales

Thanks to all of you who bought our cards last year – every card spreads the word to someone who may not have heard of MSA. All profits go directly to the SMT. They will be available again later in 2003.

Diary Dates

Kent Maidstone June 4th or 11th
Glasgow
Plymouth