

MSA SMarT News

The newsletter of the Sarah Matheson Trust

Contents

Speech and swallowing in MSA 2

SMT people 5
Comings and goings in the office

Quality of Life Scale 6
Update and thanks

Accounts 6
Summary of 2004/2005 finances

Support groups 7
News from Essex and East Midlands

Fundraising 8



Trevor's Day for SMA

Bits and pieces 11

Membership Numbers 12

From the SMT Office

We must start with our apologies for the late running of our newsletter service but we hope it is worth the wait. We are very grateful to Mrs Tricia Gilpin, Speech and Language Therapist at the National Hospital for Neurology & Neurosurgery for producing the feature article on speech and swallowing problems in Multiple System Atrophy. Tricia is one of a team of Speech therapists who have considerable experience over many years of the types of problems members may encounter. Did you know that many speech therapists also assess swallowing ability? The article describes the kinds of problems members may encounter and acknowledges the impact this can have on the person and their family. Importantly the article also gives a guide to how to get referred to a speech therapist and what treatment may be on offer. This is one set of problems that you literally don't have to suffer in silence.

For our web-savy readers you can now visit our improved web site. It is still the same location www.msaweb.co.uk but has more features including an email facility to contact the office which we hope will suit those of you who want to contact us but whose available moments fall outside office hours. For those less familiar or comfortable with the web get someone to lead you on-line for a look, amongst our many requests for the new site was a need to be friendly to new web users. Thank you to Al Loehnis, SMT Trustee and our web experts Coull designs for helping us realise our objectives.

You will read in this edition about the staff changes here in the office, some temporary and other permanent but all for great reasons. Niki, our administrator is on maternity leave and Linda Campbell is providing cover for her and Alison our nurse is also leaving us. We are currently recruiting a new nurse and will introduce them to you soon. Staff changes, especially when the staff were great, is sad but we are looking forward to the energy and enthusiasm a reformed office team will bring to our services in 2006.

Wishing you all a peaceful and happy New Year from all the Sarah Matheson Trust staff.

Catherine

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

Speech and language therapist Tricia Gilpin, reports on the presentations of speech and swallowing problems and the therapists role in treating people with MSA.

Speech and swallowing in MSA and other autonomic disorders

What does a Speech & Language Therapist do?

Speech and Language Therapists are involved with both children and adults with many different types of disorders. These include developmental difficulties, stroke, head injury, brain tumours and many different degenerative neurological diseases.

The SLT will see patients with any of the following problems:

- **Dysarthria:** a motor speech disorder, where there is loss of function or co-ordination in the breathing mechanism, or in the lips, tongue or soft palate
- **Dysphasia:** a disruption to the language centre in the brain which may affect understanding of the spoken word, spoken output, reading & writing
- **Dysphonia:** the loss of the voice due to physical or psychological difficulties. This must always be checked by an Ear, Nose and Throat specialist to eliminate the possibility

“Dyspraxia is a motor speech programming disorder – messages from the brain become disrupted.”

of structural damage to the larynx

- **Dyspraxia:** a motor speech programming disorder. There is no loss of movement in the lips, tongue or soft palate, but the messages from the brain to them becomes disrupted
- **Dysphagia:** this is a disturbance in the process of swallowing. A person with dysphagia may report any of the following signs:
 - difficulty with hard, dry foods or mixed consistencies
 - problems with thin liquids
 - coughing and choking when eating and drinking
 - food becoming stuck in the mouth or falling out of the mouth
 - extended meal times
 - excessive saliva and/or dribbling
 - having a 'gurgly' voice after mealtimes or drinks
 - difficulty opening the mouth sufficiently
 - weak cough
 - weight loss
 - chest infection
- **Tracheostomy:** SLTs also work with patients who have a tracheostomy.

Classification of Multiple System Atrophy

There are three different aspects to MSA:

- Parkinsonian or Extraparamidal signs
- Cerebellar signs
- Autonomic Impairment

The disease can present in any of these three ways, or often as a combination of two or three of them. The speech and swallowing characteristics of the patient will vary according to the clinical picture, and may change over time.

What speech characteristics should I expect if the presentation is mainly Parkinsonian?

This type of MSA is now called MSA-P. The type of dysarthria seen in Parkinson's Disease, and in MSA-P is called hypokinetic dysarthria. This is characterised by:

- festination of speech – that is difficulty getting started and then speech coming out in a rush
- quiet speech
- slow and hesitant speech
- speaking in a monotone and at the same pitch

What should I expect if the presentation is mainly Cerebellar?

This used to be called Olivopontocerebellar Atrophy but is now called MSA-C.

This type of MSA involves the cerebellum and brain stem and the type of dysarthria seen is called ataxic or cerebellar dysarthria. This is characterised by:

- staccato (or chopped up) speech
- imprecise consonants
- slow and slurred speech

Unfortunately, this type of dysarthria can make you sound as if you have been drinking too much alcohol.

What if it is the Autonomic Presentation?

The third type of MSA is the predominantly Autonomic presentation where the patient often has postural hypo-tension. This may lead to general feelings of dizziness and exhaustion and you may not feel very much like talking at all.

A drop in the blood pressure can result in a decrease in the volume of the speech.

Spastic Dysarthria

In addition some patients present with a spastic dysarthria where the speech is characterised by:

- imprecise consonants
- strained or strangled voice
- quiet voice

It is important to remember that speech characteristics in MSA can be mixed between the different types of presentation and therefore the different types of dysarthria.

A research study by Kluin *et al* in 1996 looked at 46 patients with MSA and looked at the speech characteristics and concluded that:

- **Hypokinetic** components predominated in 48%
- **Ataxic** components predominated in 35%
- **Spastic** components predominated in 11%
- the remaining 6% were **mixed** dysarthria

What can the SLT do to assess my speech and communication?

The SLT may decide to do a formal dysarthria assessment. This consists of looking at the different aspects of the speech process:

- respiration (breathing for speech)
- phonation (production of sound)
- movements of the facial musculature
- prosody (intonation patterns – the ability to change pitch in speech)

- articulation (ability to produce clear sounds)
- intelligibility

Alternatively, the SLT may assess you in a more informal way by talking to you and to your family.

What can the SLT do to help me with my speech and communication?

Unfortunately, there is no cure for the speech difficulties experienced in MSA but the SLT can help by giving information to the patient and to the family.

“It is important to remember that speech characteristics in MSA can be mixed between the different types of presentation and therefore the different types of dysarthria.”

Many people with MSA experience other difficulties with their communication in addition to the speech.

- many people experience a lack of facial expression
- others find making and maintaining eye contact difficult
- some may have a forward head tilt which hampers communication, feeding and vision
- others will have displays of inappropriate laughter or crying
- some people have difficulty switching attention from one topic to another
- some people will experience a low mood

Often it is helpful just to be able to discuss these matters and try to find a way, with the therapist, to manage these difficulties. It can be helpful to discuss ways to avoid very noisy situations, or to cut down on background noise when trying to communicate (even turning off the TV can be helpful).

For the family and friends of the person with MSA it is important to try to make time to communicate, even though the process may be slower than previously. It is often helpful to be able to watch the face of the person to help with understanding and to ask for repetition in a different way if something cannot be understood. It is important not to pretend to understand if you have not, and to ask for clarification.

Will the SLT give me exercises to do to improve my speech?

It is important to realise that exercises will not improve the speech. However, sometimes the therapist will decide to focus on a particular aspect of the speech mechanism to try to maintain and preserve speech for as long as possible. It may be helpful to work on:

- exercises to improve facial expression
- breathing exercises to maintain an adequate respiratory drive for speech
- relaxation exercises to reduce tension in the muscles used for communication
- voice exercises to maximise volume
- speech exercises to improve overall intelligibility and fluency

Are there any Communication Aids for people with MSA?

- some people find that a small speech amplifier can be helpful
- there are other communication aids such as Lightwriters which allow the patient to type out their message and the machine talks for them
- some people prefer to use a pen and paper if they are finding speech difficult

Continued overleaf

I have heard that sometimes people with MSA need to have a tracheostomy. Is this true?

Unfortunately, some patients with MSA may experience difficulty opening the vocal cords in the larynx sufficiently to allow the normal amount of airflow. This may be due to vocal cord palsy and can result in:

- excessive snoring
- inspirational stridor – a sound like snoring but on the 'in' breath
- sleep difficulties and vivid dreams
- breathing problems, particularly at night
- sleep apnoea, where the person stops breathing for a short time during sleep

In extreme cases the ENT surgeon may recommend a tracheostomy. This is a small tube which is fitted into the neck below the level of the vocal cords, allowing the patient to breathe comfortably.

The Speech and Language Therapist can assist in advising whether or not a speaking valve is appropriate.

What happens to the normal swallow in people who have MSA?

The normal swallow is made up of 3 stages:

- the oral stage
- the pharyngeal stage
- the oesophageal stage

All three stages of the swallow may be disrupted in MSA. A research study by Smith & Bryan in 1992 looked at ten patients with MSA and found the following:

Oral stage:

- 90% had decreased control of what was in their mouth
- 40% had poor tongue movements pharyngeal stage:
- 80% had a delayed swallow
- 100% reported the feeling of 'something stuck in the throat'
- 30% experienced 'silent' aspiration – where food or drink goes 'down the wrong way' and enters the lungs, but the patient does not cough

Oesophageal stage:

- some patients with MSA or other types of autonomic dysfunction experience dysmotility of the gut
- this can result in constipation but also in dysmotility of the oesophagus with patients reporting a feeling of 'something stuck' in the centre of their chest

How will the Speech and Language Therapist assess my swallow?

The SLT will start by taking a full history of the disease process and also of the eating and swallowing problems from both the patient, and if possible, from the carers.

The SLT will then probably complete the following assessments:

- a 'bedside' assessment of the swallow including:
 - assessing the cranial nerves of the patient, looking at the functioning of the face, tongue, lips, soft palate etc.

“In extreme cases the surgeon may recommend a tracheostomy – a small tube which is fitted into the neck below the vocal cords allowing the patient to breathe comfortably”

- trial the patient on various foods and drinks, observing their ability to cope with different consistencies
- possibly perform a videofluoroscopy (this is a moving x-ray of the swallow which is filmed onto video). This shows the safety and efficiency of the swallow and can

assist the therapist in making recommendations regarding:

- appropriate consistencies of food
- positioning
- possible modifications to the diet

It may be that the SLT, in consultation with other members of the multi-disciplinary team, may suggest a PEG. This is a Percutaneous Endoscopic Gastrostomy which is a small tube which is passed directly into the stomach to allow the patient to be fed with liquid feed, should this become necessary.

A PEG is often used in conjunction with continuing to eat and drink. It may be that the patient is finding eating and drinking very time consuming, slow and difficult and may find it much more pleasurable to get all the necessary hydration and nutrition through the PEG leaving the opportunity to eat and/or drink small amounts for pleasure.

The Multi-Disciplinary Team and the Speech and Language Therapist

The SLT may discuss a number of complex issues with you regarding your speech and swallowing and also have discussions with you regarding the placing of a PEG tube or a tracheostomy.

It is important to remember that any complex decision that has to be made will always be after joint discussion between members of the MDT, the patient and his/her family. The MDT may include the Neurologist, the GP, the clinical nurse specialist for MSA, other nurses, the dietician, the physiotherapist, the occupational therapist and the speech and language therapist.

In the discussions regarding the placement of a PEG or a tracheostomy it is vital to allow time for discussion with the patient and his family and to take into account the individuals right to make decisions about his or her quality of life.

**Tricia Gilpin
Senior Speech and Language
Therapist November 2005**

From The Trustees

At the end of October we said goodbye to Alison Abery, who has served the Sarah Matheson Trust for the past four years as Liaison Nurse. She will be missed.

We are all immensely grateful to her for the dedication and skill which she has brought to her time with us – not least of which has been her knowledge

of the intricate ways of modern technology! This has proved invaluable in our continuing efforts to ensure that our members benefit from the most up-to-date techniques. E-mail, web site, electronic files, desk-top printing: none of it phased Alison.

All of us – those who have met her and heard her speak on one of our away

days, those who have been comforted and encouraged by her voice at the end of the telephone and those who have worked together with her in the office and at our Trust Board meetings – would like to say a great big thank you to Alison and to send her our very best wishes for her future happiness

Eileen Strathnaver, Chairman

From Alison

It is with mixed feelings that I write this, my farewell to all of you SMT members and supporters.

After nearly four years as Liaison Nurse for the Trust (where did the time go?) it will be really hard to leave. I wish my successor as much fulfilment as I have found in this varied and often challenging post.

I never knew I would develop such diverse skills as a nurse – author, editor, designer, typist, computer operator... but they certainly all developed here!

I will be leaving the SMT at the end of October. 2005 will certainly be a year to remember – a 40th birthday and getting married to my partner of ten years, Andrew. I feel this will be hard to top in our future together.

I didn't feel I could slip away without saying a huge "thank you" to you all: for your support and encouragement over the years, and for the privilege of sharing in your experiences as you and your families have lived with MSA.

I have learnt much about the difficulties posed by degenerative neurological conditions like MSA, but I have learnt twice as much from the spirit and determination of you all to live life to the full and try and find the best way to do this. I will for ever appreciate the sense of humour and courage that you use to

face each day as it comes, and am glad to have had the opportunity to be here to try and offer support and information

when you have needed it. I particularly enjoyed meeting some of you at events and support meetings as well as the contact we have shared by telephone and email over the last four years.

I'm sure this won't be a final farewell – merely an "au revoir", as I am sure Andrew and I will remain active supporters of the invaluable work of the Trust.

With my best wishes to you all,

Alison



From Niki

It's been a long nine months, but I'm happy to say that I will soon be having my second baby, due on September 27th!



My daughter, Saskia is very excited about having a baby brother and we're all looking forward to having another little bundle around (nappies and all).

I will be taking some time off to be a mummy, but will be back in the office by early next year. I will of course keep in touch with all that's happening at SMT and will be thinking of you all whilst I'm on maternity leave. It's been very hard to tear myself away, but it's not for long, so until the New Year I wish you all the best.

Niki

We are pleased to report that Niki's son, Luca, arrived safely on October 8th.

From Linda Campbell

After having spent a very enjoyable 18 months working as a volunteer one day a week in the office, I am now temporarily joining the Trust on a more permanent basis.

Babies obviously seem a theme at the St Mary's office, so to cover Niki's maternity leave, I am going to work two days a week until she returns.

I have already spoken to a lot of you on the phone and met others in Essex, Bristol and Cornwall. I really enjoy helping out, so this seemed a perfect opportunity to extend my support of the Trust. I look forward to being of assistance to all of you as well as to Catherine and the Trustees.

Linda

Update: Quality of Life Scale for MSA

Many thanks to everyone who helped us with this study! With your help, the project to develop a quality of life scale for patients with MSA has now been completed, and we have a fully validated scale ready for use in clinical trials. Those who have participated will remember that the aim is for this scale to assess the severity of symptoms of MSA from the point of view of the person with MSA including its impact on daily life, social functioning and also its emotional aspects.

Thanks to your help, with completion of between one and three batches of questionnaires, we now have a questionnaire that has been demonstrated to be robust and valid and will provide a scale acceptable to the scientific community to be included in clinical studies. The results from all the different stages of the questionnaire development are now being

summarized in an article that we hope to publish in a medical journal to make this information available worldwide. The Sarah Matheson Trust is also planning to produce a little booklet to make it easier for researchers to use.

Here is again a short summary of the different stages of its development:

- After interviewing people with MSA and sometimes their carers we had a long list of issues and areas where you felt MSA had affected your quality of life.
- A long questionnaire based on these issues was sent out to members of the Sarah Matheson Trust, and a large number of you completed these original questionnaires.
- After statistical analyses of these answers we derived a shortened questionnaire which we then sent out once again together with other questionnaires to make sure the new questionnaire is robust and valid.

- Many of you also completed the second shortened questionnaire a while later to help us test its ability to measure change over time.
- Now that we have a questionnaire we hope that it will soon be included in clinical trials to help improve quality of life in MSA!

We would like to thank all of you who took the time to return these questionnaires to us, and a big 'thank-you' to all the carers who helped. Your responses were very important to this project. We are particularly appreciative of those of you who took the time to complete several of these questionnaires. None of this work would be possible without your time and support and we are truly grateful. Our sincere thanks also go once again to the Sarah Matheson Trust for your help in enabling us to undertake this study.

**Dr. Anette Schrag
and Dr. Caroline Selai**

Accounts

It has been suggested that an abbreviated version of the financial results of the Trust could well be of interest to readers:

As you will see income was more than satisfactory, not least on account of sponsorship generated by our wonderful marathon runners.

Costs were below budget due to lower expenditure on research, the principle reason for which was a pause in the smooth running of our research advisory panel. This small group of eminent specialists is now under new leadership and I have no doubt that it will result in an increase in this key element of the Trust's activities during 2006.

Val Fleming

| | 2005 | 2004 |
|---------------------------------|----------------|----------------|
| | £ | £ |
| Incoming Resources: | | |
| Donations | 97,166 | 65,117 |
| Fundraising activities | 32,895 | 47,888 |
| Other | 10,466 | 3,858 |
| Total | 140,527 | 116,863 |
| Resources expended: | | |
| Nurses | 57,150 | 48,056 |
| Support costs | 18,455 | 16,815 |
| Research | 24,273 | 63,290 |
| Other | 5,015 | 6,316 |
| Total | 104,893 | 133,477 |
| Net Income (Expenditure) | 35,634 | 16,614 |

Support around the country



Essex Support Group

On May 23rd Bay & Lauralie Laurie hosted the Essex group at their home in Great Tey near Colchester. The informal afternoon tea party was attended by around 20 members and supporters which included Alison and Linda from the SMT office. The Laurie's friend Sue once again provided a sumptuous range of sandwiches and cakes – highly recommended!



East Midlands Support Group

The spring meeting of the Support group was held at Holme Pierpont Hall on 27th April. The speaker was Mr David Richmond who chose the subject of “Golden years of Hollywood”. This was illustrated with photographs of the famous Hollywood stars both past and present and he spoke of his personal relationship with some of them and an insight into the person behind the face. The meeting was well attended by both patients and carers to the extent that additional seating was required.



Margaret & John Biddolph

The Presentation of a crystal bowl was made to Margaret Palfreyman and husband to be John Biddolph, prior to their wedding on the 11th June at the Eastwood United Reformed church. This was a wonderful and moving occasion, the church was packed, Margaret looked radiant and both looked very happy together.

Anyone looking to establish an SMT Group in their area should contact Catherine or Linda in the SMT office for help and advice in getting things off the ground. Local support groups can provide opportunities for mutual support, encouragement and information exchange. You may also like to use them for raising awareness about MSA and fundraising to support the work of the SMT.

Tips and hints

In Case of Emergency (ICE)

Following recent events in London and the ensuing confusion, several ambulance services, including the East Anglia Ambulance Service (www.eastanglianambulance.com), launched the In Case of Emergency (ICE) idea.

The idea encourages you to prefix your important contact numbers with ICE (ICE1, ICE2 etc) store in your

mobile phone address book so that in an emergency the Emergency Services aiding you will know who to contact. For more information look at www.icecontact.com – the company on this site also offers annual subscription to a worldwide medical notification service.

Fundraising events across the UK & beyond

Parachute Jump

On July 3rd Simon Webb & Sally McLennan completed a tandem parachute jump to raise funds for the SMT. Their total raised so far is over £1600! Sally's father Don has MSA. And to top it all Sally & Simon got married in August – good luck!



London Marathon 2005

The grand total raised so far from the efforts of our runners in this year's event stands at £24,170. Once again we would like to thank the runners who raised funds for SMT.

SMT coffee morning – 7th August

Les & Joyce Ward of Sheringham once again held a fundraiser for SMT and raised an impressive £205. Their daughter, Linda, who has MSA, joined them on the day with her husband Kieran to offer support.

Triathlon Relay Swim

Clare Laurie, daughter of Bay & Lauralie Laurie who run the Essex Support Group, took part in the London Triathlon, completing the swimming leg in the “shark infested” docks at London Docklands to raise funds for SMT. Her relay team (Clare swimming, Annie cycling & Anna running) came in 116th out of 168, they were one of the few female teams competing. Clare's brave efforts have raised SMT over £2400.



The footballers playing on the day; Trevor and Alison, Trevor and his family; the day's programme



Trevor's Day for MSA

This event on 18th June attracted wide ranging support from both the teams participating in the football tournament and the general supporters who turned up to watch matches and enjoy the sideshows. In blazing sunshine and blistering heat the teams played on, the BBQ kept cooking and the side stalls, theatre, music, raffle & balloon race attracted steady support. It was a great day out and has raised over £8,000 for the SMT. In July Trevor, his wife Caroline and sons Chris & Rob popped into the SMT to drop off the cheques.

Clay Pigeon Shoot – 29th September

This event was organised by Nick Bolsover, whose mother in law has MSA. The day raised funds jointly for SMT and Macmillan. Nick reports “This was the 4th year this charity event has been held and the day was blessed with fine weather. 24 Teams from all parts of the pub trade connected with Enterprise Inns PLC took part, ranging from individual publicans to solicitors, from the brewers to pub builders. A great day was had by those who have and have not shot before, with a wide variety of prizes won. It was good to see a lot of ladies taking part and they were mean shots! The day ended with a hog roast and a few beers to help wash



away sore shoulders. The Aim of the day was to raise money for charity in a fun way and I feel we succeed and as long as my maths is correct the two supported charities should receive approx £1500 each."

Great North Run – 18th September.

We know that at least 7 runners took part in this year's Great North Run for SMT. Alison Wild, Helen & Simon Parker, John Russell (who ran in memory of his grandmother who had MSA), Donna Wilson, Ludovic Floch & Scott Luckey all participated in the main run and Patrick, Georgia & Dominic Luckey took part in the Mini Run. We thank them all for their efforts and will bring you a fundraising total in the next edition.



John Russell

Everest Trek

The Everest Team are in training and will start their adventure this October. The brave trekkers are: Michael Gooding, Andrew Griggs, Clive Grove, Matt Grove, Johanna Grove, Martin Lewis, Daniel Parnell, John Staniland and Rachel Staniland. The team will be taking SMT t-shirts with them to wear at the target destination for the Team photo – these are generously being

designed & donated by INQ Design. Thanks Martin & Mike.

'We've got High Hopes'

On the 8th October, our group of nine will depart to Kathmandu to begin a 25 day trek to the Eastern Base Camp of Everest and back. Our aim; to raise as much money as possible for the SMT.

My own personal aim is to complete the trek in memory of my father, Paul Griggs. It had long been an aim of his to undertake a similar trek of Everest, and he had begun practising when he was diagnosed with MSA. After he passed away in September 2003, I had wanted to help the Trust, and after some inspiration from Peter Murray, the marathon runners and many of the other fundraisers, our plan was born.

Our trek is nearly upon us and after months of preparation we are ready for glaciers, snow, walking, camping and Yeti's! Further information can be viewed on our website at

www.etsplc.com/everest.asp, for this I greatly thank Michael Gooding for all his time and effort. I'd also like to thank Clive Grove (dad's mate) for his extensive help with arranging the trek, and I'd like to wish all fellow trekkers the best of luck!!

Andrew Griggs



SMT Guided Fundraising Walk

Thoresby Park, Nr. Ollerton, Notts., NG22 9EN – Sunday September 11th

The walk follows a route of 7 miles, partly through the ancient woodland of Sherwood Forest.

Registration is at 11am for an 11.30am start. There is a lunch stop planned mid walk for 12.30pm, please bring your own picnic. The walk is unsuitable for wheelchairs and those



Picnicers in the park; the Bara family and a small visitor; the Bara family with Catherine; Allan Comette and Davis Webber



SMT Family Picnic in Battersea Park

Two dozen people were able to get together for the SMT picnic in Battersea Park on Sunday 7th August. We gathered by Fountain Lake in brilliant sunshine and enjoyed our picnics in the company of family, SMT staff and members. Although an informal occasion it was a great opportunity to meet members and their families to exchange news and views.

less sure footed. Dogs on leads are welcome. The event will end with a gathering of walkers, friends and supporters for tea in the Stables Courtyard at 3.30pm. Entry to the walk is by donation on the day or by sponsorship (forms available from the SMT Office).

Bath Half Marathon

Julie Johnson completed this event in March for SMT and the local hospice, Dorothy House Hospice Care, where Julie's mother-in-law Janet has some of her care. The hospice gained £185.00 and SMT gained over £1,100.00.



Julie Johnson

Manchester Run

Ross McLennan completed the BUPA Manchester Run and raised £518 for SMT. Congratulations Ross.

Wallingford Fun Run

Liz Balmford, one of our SMT office volunteers, completed the Wallingford Fun Run on July 24th raising £206 for SMT. Liz's father, Malcolm Dickenson had MSA.

Wedding donations

When Sarah Bingham and Mark Stringer married on the 20th May this year they asked for donations to the SMT in lieu of wedding gifts. The generosity of family and friends has raised the SMT over £2,000. Sarah's mum Janet had MSA; here Sarah tells us a little about her family's experience and where they are now. She hopes others will find support and encouragement from their story.

My mum Janet Bingham was diagnosed with MSA in spring 1991 at the age of 49. At that time she was a science teacher in Newark, Nottinghamshire, and my dad Walter was a lecturer at Nottingham Trent University. My brother Stephen was doing a PhD in Norwich and I was about to do my finals at university. Mum was a very intelligent woman having obtained a degree and PhD at Sheffield University (where she met Dad in the 1960's). She was a great inspiration to me and encouraged me to go to medical school and pursue my own career.

Following her retirement, my mum found it very frustrating not to be able to get out and pursue her many interests. All her life she was always interested in the world around her, particularly the natural world, geology and history. Our neighbours were a great help in the years before Dad retired. They often took her out on trips and they went swimming once a week. We also had help from a local hospice called Dove Cottage, Crossroads and Leonard Cheshire Homes. My Dad went part time a few years after her diagnosis and finally retired in 1996 to look after her full time. Obviously things got very difficult at home in the later years, but Dad was there for her 24hours a day. She used local residential homes for respite and only entered full time care in autumn 2000. She died on 3rd March 2001.

Mark and I got married on 20th May this year. We had a civil ceremony and reception at Bagden Hall Hotel in West Yorkshire. We had a fantastic day with fine weather surrounded by family and friends. We honeymooned off the west coast of Scotland.

I'm now a consultant rheumatologist in Leeds Hospitals and my husband Mark Stringer (I'm keeping my maiden name) is a senior aseptic pharmacist in St James Hospital, Leeds. My brother Stephen is now a research physicist in Bath. Dad still lives in Nottinghamshire and busies himself with photography (at which he is very good) and going on trips in his camper van.

Sarah



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

Taking Care of the Carer: A Recharge for Mind & Body

This is a residential course for unpaid carers running at Lancashire College, Chorley from 2-4 December. The course covers issues such as stress management, relaxation & massage techniques, and some craft activities. Costs start at £30. For more information contact Donna Galway on 01257 516325 or insight@ed.lanscc.gov.uk

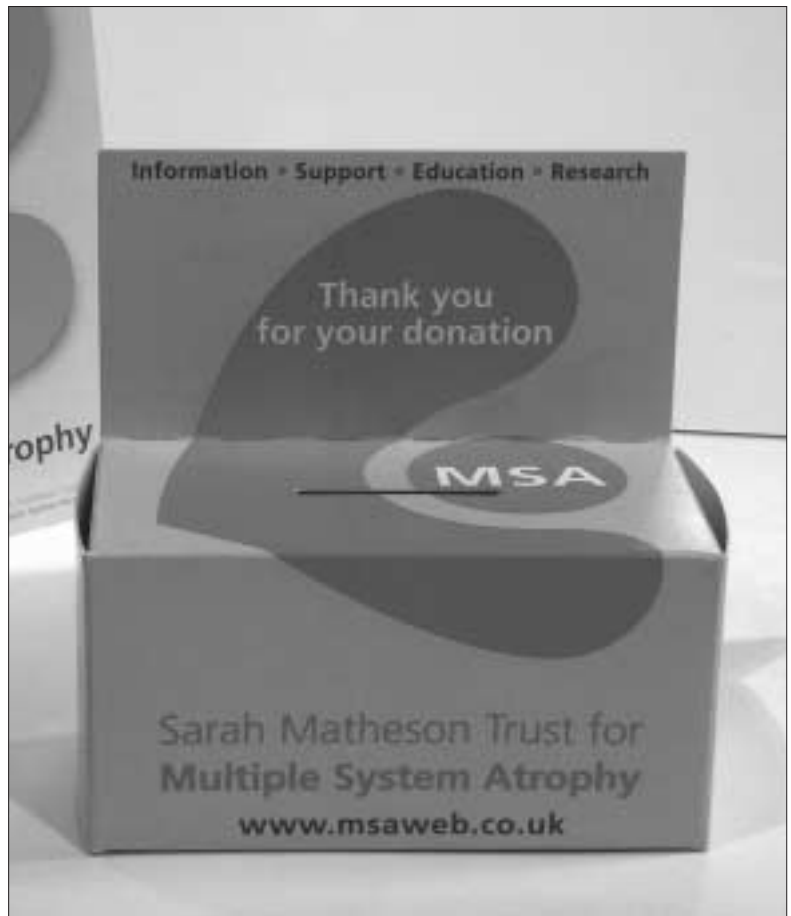
Articles on offer

Shop Rider Scooter. Dismantles to go in a car with detachable battery and seat, can easily be lifted into a car. Red in colour with two baskets. Will stand on end to save space. Can deliver to certain areas, hardly used. £395 ono. (£1500 when new Jan 2005) Wirral 0151 632 3804

Forever Active Discovery Mk2 4 Wheel Scooter. Excellent condition, 18months old, recently serviced. Swivel seats, basket, lights, indicators, mirrors, horn, owners manual and charger. Silver colour, range: 15miles, max speed: 6mph. £600ono (£2250 when new) Call Chris 0208 258 2566 or 01727 856706

Badges

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



Collection Boxes

We now have flat pack cardboard collecting boxes available on request to members wishing to collect money for us: either for small events & memorials, or for collection of coins etc. at home/work. Collections/donations however small are always appreciated by SMT and help us to continue our services free of charge. These colourful boxes carry our logo and details of the SMT and MSA.

Please let us know if you would like to receive one/some and we'll send them out as soon as possible.

In Memory

Donations received with gratitude in memory of:

- | | | | |
|-----------------------|-------------------|------------------------|---|
| • Susan Abbott | • Roland Gand | • Julie Molins | • Nancy Temperley |
| • Ian Adams | • Albert Glover | • Carole Oakes | • Malcolm Threlfall |
| • Jessica Aspey | • Stuart Grainger | • Denise Parker | • Stella Trivass |
| • Kenneth Atherton | • Paul Greensill | • Lena Pearce | • Ann Vale |
| • Alan Boice | • Cuthbert Healy | • Hilda Peters | • Susan Ward |
| • Robert David Burrow | • Alan Hewitt | • Evelyn Petty | • Gale Watson |
| • Jean Clark | • Enid Hill | • Ivan Pickering | • Margaret Watson |
| • Jean Clayton | • Alan House | • Christine Richardson | • Anne Whitelock |
| • Alan Cooke | • Pamela Icke | • Jenny Rollitt | • Ron Williams |
| • Isabel Cracknell | • John Jopson | • John Rosier | • Ray Young |
| • Malcolm Dickinson | • Gunilla Kelly | • David Sands | |
| • Winston Duerdoth | • Janis Magee | • Mr Sillwood | Legacies received from the estates of: |
| • Roger Dunnell | • Peter Male | • George Skipper | • Helen McGregor McNie |
| • Ken Forster | • Ian Marshall | • Agnes Stark | • Miss BE Moor |
| • Ronald Foster | • Peter Mente | • Charles Tanner | • Mrs M Wyatt |



Sarah Matheson Trust for
Multiple System Atrophy

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

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

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

Patrons:

Sir Roger Bannister CBE FRCP
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Christopher Marsden
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All correspondence and enquiries to:

Catherine Best (Nurse)
Linda Campbell (Administrator)

Sarah Matheson Trust

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

www.msaweb.co.uk

The Trust is financed entirely by voluntary donations.

Registered Charity Number 1062308

Ways to support the SMT and help us to grow

• **Become a regular donor**

Donations by monthly or annual direct debit however small will help us maintain our services. Don't forget to GiftAid any donations to increase the value of your donation by 28%.

• **Become a fundraiser**

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

• **Use our online fundraising/donation facility**

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

• **Contribute to SMarT News**

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

• **Form a local SMT group**

Linked with the SMT but independently run to provide what the local group wants (e.g. information, mutual support, social contact).

• **Raise awareness about MSA**

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

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

Gift Aid It!

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

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

Dates for your diary

- **Birmingham** – 26th January 2006, Moseley Hall Hospital

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

For details of meetings outside your region please contact the SMT office.

Membership Numbers as of October 2005

| | |
|-----------------------|------|
| Current MSA members | 692 |
| Other patient members | 39 |
| Relatives & carers | 299 |
| Professionals | 1260 |

Newsletter Mailing: This edition of *SMarT News* has been sent by an automatic mailing. This will save us money and hopefully speed up the delivery to you in the future. We would like to assure you that your address details are not held by the mailing company to maintain your privacy. Please continue to advise us of any change of address details.