Issue 16 Summer 2004

MSA SMarT News

The newsletter of the Sarah Matheson Trust

Contents

Faye Stammers raised funds for SMT in this year's London Marathon

Next issue:

- Research at the Brain bank

From the Nurses

This issue has a focus on a very personal subject: continence. Having difficulty with any aspect of bladder control can have a big impact on confidence, restrict social activities and can really get people down. Added to this, some people find talking about toilet problems embarrassing and difficult to discuss, even with health professionals. Continence is now a highly specialised area within healthcare and particularly within neurology as many neurological conditions affect the bladder. There is a greater understanding of what can go wrong and lots of developments in managing the problems. We hope that armed with the information in this issue all our members will recognise that continence is a real option for them and they will know where to go to get help.

You will see from our Treasurer that we are fortunate to have a wonderful new assistant, Niki, and a regular volunteer, Linda. This helps us to devote more time to the services for members. One positive result is the number of Awareness Days we have been able to arrange around the country. We mentioned these days in the last *SMarT News*. At an awareness day we speak to health professionals in the morning, presenting information about Multiple System Atrophy and its management. Once they leave at lunchtime, the afternoon is dedicated for our MSA members, their family and friends to meet together for coffee and lots of conversation. These are great afternoons for us as it puts faces to the voices we have heard on the phone. It also helps to establish relationships with members who may not have been in contact yet. We are really looking forward to seeing many more of you at these afternoons around the country.

Catherine & Alison

The Carers (Equal Opportunities) Bill passes through the Commons

In April the Prime Minister, Tony Blair, pledged to offer a new right to flexible working for over three million carers looking after elderly parents, infirm relatives or close friends. The new right to request flexible working hours, or part-time work from employers mirrors the successful introduction of the same request rights already granted to parents of young children. Currently carers can only request time off for emergencies.

Improved legal rights for carers came one step closer on the 14th May, with the smooth passage of the Carers (Equal Opportunities) Bill through its Report Stage and Third Reading – the final stages in the House of Commons. The Bill aims to give anyone providing regular and substantial care to a sick or disabled person, new rights to information and greater choices and opportunities for work, education and life-long learning.

Action for Carers & Employment National (ACE) can be contacted for further information on developments by telephone on 020 7566 7843, or by email: scott@ukcarers.org

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

Continence in

As children, once we have control of our bladder it becomes one of the bodily functions that it is not polite to talk about. This can mean that when, as adults we experience problems, it can be difficult or embarrassing to talk about them. Today it is possible to successfully manage most bladder problems even if they cannot be cured. This is certainly the case with many of the bladder symptoms that are common in Multiple System Atrophy (MSA). They can aslo apply to other autonomic disorders , for example Pure Autonomic Failure (PAF).

How the bladder works

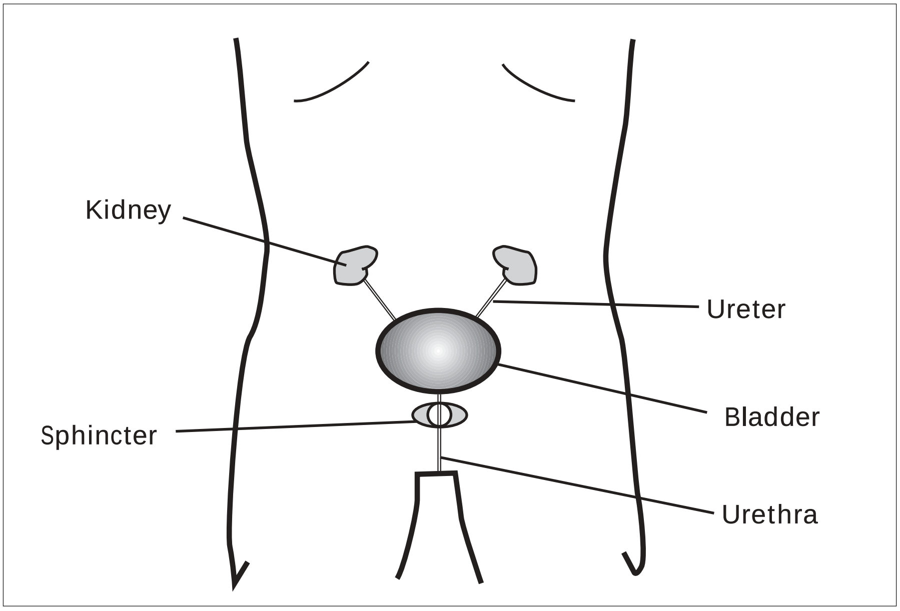
Urine is produced in the kidneys and moves down tubes called ureters into the bladder.

The bladder is a balloon shaped muscle, which is designed to store urine. It is situated at the bottom of the abdomen behind the pubic bone. The valves or 'sphincters' at the base of the bladder makes it water tight and stop any leakage of urine (see figure 1).

The bladder can hold about 1pint (500mls) of urine. The first sensation of needing to go to the toilet happens once the bladder is about half full. The stretched muscles of the bladder sending messages up the spinal cord to the brain cause this sensation. If it is convenient to go to the toilet the brain then sends messages to the valve to open and the bladder muscle to squeeze so that urine is released down the urethra. It is normal to go to the toilet to pass urine between 4-7 times during the day and once at night.The brain can delay this process until the time or place is convenient.

This may sound straightforward but it is a very complex process and needs the bladder, the brain and all the nerves between them to be working in co-ordination. Being able to control this process is also known as being 'continent'.

Figure 1. The urinary system



What goes wrong?

Bladder problems are very common in people with autonomic conditions and often occur as one of the first symptoms. However because bladder problems can occur to men and women for other reasons, it is also important to think about other possible causes and not assume it is all down to MSA. This information concentrates on the common problems in MSA.

In MSA the areas of the brain that control bladder emptying and the nerve pathways from the bladder to the brain can be affected; this causes bladder symptoms. Here are some of the potential problems:

- Hesitancy, difficulty starting to pass urine.
- Urgency, needing to go to the toilet suddenly and quickly. If this is not possible you may leak urine.
- Frequency, going to the toilet a lot (more than 8 times in 24hours) but only passing small amounts of urine.
- Feeling the need to go to the toilet again immediately after passing urine, as if your bladder was not completely empty.
- Urine infections, especially if you have incomplete bladder emptying.
- Accidental leakage of urine, sometimes called Urge incontinence.

Other problems with going to the toilet can also be affected by other MSA symptoms:

- Passing lots of urine during the night, this usually happens in people who also have postural hypotension as a symptom.
- Accidental leakage because of difficulty or slowness getting to the toilet or adjusting clothing in time.
- Being constipated can put pressure on the bladder causing dribbling, especially after going to the toilet.

MSA

It is important to realise that you may not develop all of the symptoms described here.

What investigations might be done?

The first concern is to identify exactly what the problem is, to ensure appropriate treament can be started. When you see a nurse or a doctor they will ask you questions about: your general health, how much fluid you drink, the colour or smell of your urine and your bladder problems, including whether you have had any accidental leakage or incontinence.

You may be asked to produce a sample of urine to test for a variety of things including signs of a urine infection. This can either be sent to a laboratory for detailed testing or tested then and there with special urine testing strips. A urine infection can change your symptoms and will require treatment.

Measuring the volume and frequency of urine can help determine what the exact problem is. You may be asked to keep a diary for a few days, recording everything you drink and how often you pass urine. The other useful investigation is checking how much urine is left in your bladder after you have passed urine, using either a small ultrasound machine or a catheter. This is called a post-micturition residual urine volume.

All these tests can be done at your home or GP surgery. If more detailed testing is needed to decide exactly what the problem is, you will be referred for urodynamics. Urodynamics are a range of procedures that tests how well your bladder fills and empties.

Treatment for bladder problems can involve surgery. This is unlikely to help people with MSA or PAF and more detailed testing of urodynamics can help to determine this.

Who can help?

Continence Advisors are nurses who have specialist training and experience in managing bladder and bowel problems. Continence advisors work in hospitals, health centres and in the community. Many accept self-referrals over the telephone although some may ask that your GP write to them. The Continence Foundation helpline will have details of your nearest advisor (see ‘Where to get more help’).

Your GP or Specialist will also be able to help.

The Nurses at the Sarah Matheson Trust are also available to discuss bladder problems and treatment.

What treatment is available?

Advice: Sensible advice about fluid, toilet habits or diet is often very useful in preventing problems and managing symptoms.

Maintaining a healthy bladder means drinking plenty of fluid (about 8 large cups each day). Drinking too little fluid can irritate your bladder and cause problems.

One glass each day of fruit drinks such as cranberry juice or lemon barley appear to help prevent infections.

Avoid going to the toilet ‘just in case’, only go when you need to.

Be comfortable on the toilet, especially in public lavatories. Ladies should sit rather than hover (carry some wipes with you) and men should use cubicles which provide privacy.

Some people find bending forward or pressing the bladder at the end of the flow helps to squeeze out any urine left in the bladder.

Choosing clothes that make it easier to get to the toilet (for example, Velcro fastenings rather than a zip) saves time which may prevent accidental leakages.

Medication: Medication called anticholinergic drugs allows the bladder to relax and fill to capacity before needing to empty. This can prevent urgency and frequency.

DDAVP or desmopressin is a hormone that prevents urine production for several hours after it has been taken. Taken at night it can help stop the need to get up to the toilet, which improves sleep. It can only be used once a day and comes in a tablet and nasal spray. It is particularly useful for people who have postural hypotension as a symptom.

Regular or daily laxatives may be required if constipation is causing bladder problems.

Urine infections often make people feel very unwell and can have an affect on other symptoms, for example they may worsen postural hypotension. Although there is a general need to reduce the use of antibiotic in the general public, the early use of antibiotics to treat urine infections is very important for people with MSA.

A doctor should prescribe all these medications.

Equipment: An occupational therapist can help to make it easier to use the toilet at home. Adjusting the height of the toilet, adding grab rails or even creating a downstairs toilet are all worth thinking about.

Community nurses can provide urinals or commodes to reduce the number of journeys needed to the bathroom. Some commodes look like regular house furniture when not in use making them more acceptable.

Catheters: These are small plastic tubes that drain urine. Although no one likes the idea of using a catheter many people are surprised how easy they are to use and how they can improve the affect that bladder problems have on everyday life.

Intermittent catheters are inserted along the urethra into the bladder, the urine is drained (which only takes a few minutes) and then removed. The continence advisor will teach people how to do this themselves, which helps to fit the catheter more conveniently into their life. This is called intermittent catheterisation.

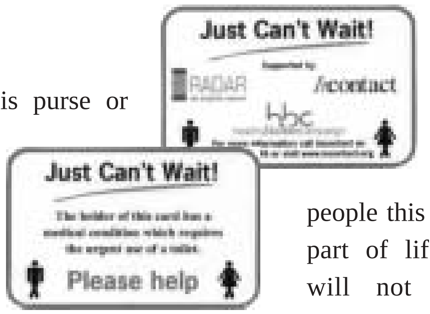
Indwelling catheters are also inserted via the urethra or through the abdomen (a supra pubic catheter). The catheter drains urine either into a drainage bag or has a valve that allows the bladder to be drained at regular intervals.

Both types of catheter can be discreet and can give people more freedom from needing to use the toilet. However, for many people the decision to use any kind of catheter needs to be given plenty of thought and discussion.

Clothing: For people who do not like the other treatment options, underwear that accommodates continence pads may be preferable. There are a wide variety of disposable pads with variable absorbency, for day or night use and for men and women. Some are available on prescription and the continence nurse or community nurse can arrange to supply them to you.

Other help

Can't wait card: This purse or wallet sized card can be shown discretely to gain easy access to toilets when you are away from home. It is free and available from the SMT office.



The National Key Scheme: Initiated by RADAR this offers independent access for disabled people into over 4000 locked public toilets around Britain. Ideally all accessible toilets should be kept unlocked. However, the scheme is used where it is necessary to lock the toilets, to maintain their cleanliness and to protect them from vandalism and misuse. The cost of a key is less than £5 (see 'Where to get more help').

Social Services: In some cases financial assistance towards laundry equipment e.g. a washing machine or laundry services may be available. A social worker or benefit advisor can provide more details.

Sexual Activity

Bladder problems don't mean the end of intimate or sexual relationships. Some treatment options may be more suitable to people who are sexually active. There are often practical solutions to overcome the problems that can affect this issue.

Most continence advisors are experienced in offering advice or treatment to enable sexual activity to be maintained. They recognise that for some people this is a very important part of life. Therefore, they will not be surprised or embarrassed if you want to talk about this with them. During a visit they may even ask you directly if you are experiencing any problems with sexual function; so you may want to prepare your reply.

Key points

- **Bladder problems are common for men and women who have MSA and other autonomic disorders.**
- **Don't reduce how much you drink to manage bladder problems.**
- **Don't be embarrassed about asking for help.**
- **Get immediate treatment for urine infections.**
- **Be positive, with the range of treatments available, bladder control is possible.**
- **Talk to your neurologist if bladder surgery is offered as a treatment.**

Where to get more help

- **Continence Foundation**
  The Continence Foundation provides information, advice and expertise to anyone with bladder and bowel problems
  Helpline 0845 345 0165
  Monday to Friday, 9:30am to1:00pm
  The Helpline Nurse
  The Continence Foundation
  307 Hatton Square
  16 Baldwins Gardens
  London ECIN 7RJ
  www.continence-foundation.org.uk

- **Incontact**
  Incontact provide support and information and represent the interests of people with continence problems.
  United House
  North Road
  London N7 9DP
  Tel 0870 770 3246
  Fax 0870 770 3249
  Email - info@incontact.org
  www.incontact.org

- **RADAR**
  National key scheme for locked toilets
  12 City Forum
  250 City Road
  London EC1V 8AF
  0207 250 3222
  www.radar.org.uk

- **Disabled Living Foundation**
  This is a national charity providing equipment advice and information for disabled people.
  380-384 Harrow Road
  London W9 2HU
  Helpline 0870 603 9177
  (10am - 1pm)
  www.dlf.org.uk

- **Constipation Information**
  A leaflet on prevention and management of constipation is available from the SMT office.

Meet the new Trustees

We are pleased to welcome on board two new Trustees: Alexander Loehnis and Michael Evans. The trustees feel that an injection of new blood will strengthen the board and initiate the further development of the SMT for the future.

Clockwise, top left: Michael Evans, Alex Loehnis, Michael Cook, Val Fleming, Eileen Strathnaver, Harriot Tennant

Alex Loehnis is 35 and is currently a director of a company providing corporate websites having previously worked as a chef and a City analyst. His interests include cooking, bridge and travel – he is also a keen Arsenal fan. His mother Jenny was a founding Trustee of the SMT and Sarah Matheson was his godmother. “Sarah was a very special and brave person and all her qualities live on through the work of the Trust. I have been so impressed with the dedication and commitment of everyone who is involved and feel honoured to have been asked to become a Trustee. I hope I can help the Trust build on its success in raising awareness of MSA and providing support and help for sufferers of the illness and those who love and care for them.”

Michael Evans was one of our marathon runners in 2002 raising over £10,000 for the Trust. He got involved after the death of his mum, Catherine, from MSA in 2001. During her illness the SMT provided information, comfort and support which were helpful to both Catherine and her family. Michael is honoured to be a Trustee and to give something back. He is a chartered accountant and a director of a London based property consultancy. He hopes to continue the excellent work of the Trust and is particularly interested in raising its profile and strengthening fundraising efforts. Michael lives in Battersea, although originally from Middlesbrough and still manages to get up there regularly to see his Dad ...and the football team!

From the treasurer

As some readers may already know the trust now has a part time administrator. Niki Ranade works alongside Alison in the office at St Mary’s Hospital and has taken on a range of tasks, thereby relieving the ever-increasing workload of the nurses. One of Niki’s tasks concerns the receipt, recording and the logging of the wonderful donations which we are so fortunate to receive. This in turn has allowed Peter Filby, the assistant treasurer for the last few years, to gracefully retire. His work behind the scenes made possible the production of monthly financial statements for the Trustees and annual figures for the Auditor. His output needless to say has been meticulous.

But the Filby link with the Trust remains firmly in place. His daughter, Linda, now also works with Alison as a volunteer, one day a week. This is a splendid and generous gesture and along with the arrival of Niki has greatly strengthened the team.

Val Fleming, Treasurer

(l-r) Niki, Catherine, Cilla & Alison

Whilst in Europe in May for conferences and a holiday Cilla Barkuizen visited the SMT office. Cilla works in New Zealand supporting people with neurological conditions in the community, including people with MSA. It was a great opportunity to share experiences and swap information in an informal setting.We welcome visitors to our offices to discuss any issues around living with and caring for MSA.

A new face at SMT: Niki Ranade

We are pleased to welcome our new administrative assistant, Nikita Ranade, to the SMT team. Niki joined us at the beginning of May and works two days a week, Wednesday & Thursday, in the SMT office. Her administrative support and organisational skills will free Catherine and Alison to devote more time to the services for members, particularly telephone support and more MSA Awareness Days across the UK.

Niki is the proud mother of a young daughter, Saskia and comes from a medical family – her mother is a GP and her father a Practice Manager. She has previously worked in marketing and is currently studying Psychology. She lives in London with her musician partner, Ian, Saskia and Lottie their chocolate Labrador.

She is looking forward to meeting and speaking with our members.

Report: 2nd International Meeting on Multiple System Atrophy Rome, Italy, June 17-18 2004

This event was held as a satellite meeting of the 8th International Congress of Parkinson's diseases and Movement Disorders. **Tim Young**, Sarah Matheson Trust Clinical Research Fellow, summarises the key presentations made during the meeting.*

Introduction: Etiopathogenesis of MSA

by Professor Nick Wood

In this talk Prof Wood summarised the current situation on genetics and MSA. Of course, at present, to make a clinical diagnosis of MSA requires the exclusion of a family history. However, this does not mean that genetic factors are unimportant in MSA.

A few conditions in medicine follow simple genetic patterns (e.g. with the condition cystic fibrosis, if both parents are carriers of the faulty gene, you would expect that, on average, 1 in four of their children would be likely to develop cystic fibrosis). However, other conditions are more complex (e.g. "X"-linked disorders where males are more prone to develop disorders). Most medical conditions have even more complex genetic components, for example susceptibility to coronary heart disease may be influenced by many different genes which influence cholesterol levels, blood pressure etc.

> **"To make a clinical diagnosis of MSA requires the exclusion of a family history"**

The protein α-synuclein has been implicated in both Parkinson's disease and MSA as it is found to build up in the damaged brain areas in these conditions. That excessive α-synuclein itself is likely to be important has recently been shown by the discovery of a family with an inherited form of Parkinson's disease where there are too many genes coding for α-synuclein, resulting in excess of the protein. However, inherited forms of Parkinson's only seem to make up 5-10% of all cases of Parkinson's disease, and α-synuclein gene disorders have not yet been associated with MSA.

There has been recent interest in the newly described condition FXTAS (Fragile X associated Tremor/Ataxia Syndrome). This condition is caused by a trinucleotide repeat. It is essentially a problem in the same part of the DNA which leads to the condition Fragile X syndrome in children/young adults, but FXTAS has fewer repeats of the trinucleotide. The syndrome was noticed when it was noted that the grandfathers of some children with Fragile-X syndrome were noted to have a tremor and ataxia (FXTAS). It was initially claimed that FXTAS had many similarities with MSA. However, FXTAS also tends to produce a peripheral neuropathy (not associated with MSA) and autonomic failure is not a prominent feature, unlike MSA. Finally the inclusion bodies are α-synuclein negative in FXTAS, and are found in the nerve cells themselves rather than in the nerve support cells (oligodendroglia) seen in MSA.

The FXTAS story does at least show that candidate genetic areas or genes can emerge which can then be tested for in MSA subjects. The improvement of existing MSA DNA banks should help the search for such candidate gene defects as and when they are discovered in the future.

During subsequent questions it was agreed that 2 areas might help target the search for candidate genes:

- Possible investigations of the 5% of MSA subjects who develop symptoms at a young age (40 years or younger); a similar approach helped in the discoveries of inherited Parkinson's disease.
- In Europe/USA the ratio of MSA-P (Predominantly parkinsonian) to MSA-C (predominantly cerebellar) is 2:1. In Japan this ratio is 1:2. Racial differences in genes occur between Caucasian and Japanese populations and may thus provide clues to possible candidate genes.

Clinical Skills

by Professor Niall Quinn

Prof Quinn discussed some of the findings from the history and

---

* I have omitted my own contributions to the meeting (presenting work on improving diagnosis of MSA with the laser Doppler and the effects of water ingestion as I have reported these in previous editions of *SMarT News*). ***Tim Young***

examination, which can point to a possible diagnosis of MSA. In particular he emphasised a few points which are not always widely utilised:

- In the history it is important to ask about sleep disturbance-this may be present but not appreciated by the patient and so asking the partner about this is important. Specifically, REM Behaviour Disturbance ("acting out dreams") may be common in MSA, sometimes pre-dating the diagnosis of MSA
- On examination, classical "pill-rolling" tremor in the hands is only seen in 9% of MSA, being much more common in Parkinson's disease.
- 50% of MSA patients have pyramidal signs on examination (including brisk reflexes elicited with a tendon hammer). These findings are also commonly seen in stroke patients, but in MSA these findings are NOT associated with significant weakness.

Autonomic Testing
by Professor Mathias

Prof Mathias outlined many of the autonomic tests which are routinely used to help diagnose MSA, which have previously been discussed in *SMarT News.*

Single Photon Emission Tomography (SPECT) & Positron Emission Tomography
by Dr Sid Gilman & Dr Angelo Antonini

Angelo & Dr Gilman discussed various aspects of these imaging techniques, which use short-lived radioactive injections to highlight certain areas in the brain. The specific areas usually looked at include the dopamine producing nerves and the receptors upon which they act. Whilst the dopamine producing nerves are affected in both MSA and PD, the dopamine receptors are especially depleted in MSA. SPECT cannot only help differentiate MSA and PD, but can help monitor progression in both conditions. It therefore provides a means to monitor progression in MSA when designing therapeutic trials.

Dr Gilman also discussed MIBG and 11CHED tracers used in SPECT studies of the heart. Recently there has been a lot of interest in imaging the heart in PD, as there seems to be selective loss of the small sympathetic nerves supplying the heart. Whilst the clinical implications of this are not fully understood, diagnostically this is useful as this may help differentiate from MSA where these small nerves are thought to be preserved. These scans are expensive however, are not widely available, and some MSA subjects may also show similar changes to those seen in PD (Dr.Gilman is currently investigating this aspect).

Sphincter EMG
by Dr David Vodusek

David has several decades of experience in the use of sphincter EMG, which can be used to help distinguish MSA from PD and other disorders. The rationale behind the test is that Onuff's nucleus, a small group of nerves near the base of the spine, which innervates the anal and urethral sphincters, is specifically targeted in MSA. The resulting damage to the sphincters results in specific changes in the muscles of both sphincters as assessed with a very small needle.

Some of the key points made:

- Other disorders including PD and previous haemorrhoid/prostate surgery can also result in abnormal results
- Even if the test is initially normal, it can become abnormal within the following 2 years in MSA. Therefore re-testing is sometimes required after a normal test. If a second test, performed 2 years after their first, is also normal then a diagnosis of MSA would be unlikely.
- Sphincter EMG testing is now standardised allowing better correlation between different centres for this highly specialist test.
- Interestingly an abnormal EMG result does NOT necessarily mean that the patient will have any symptoms related to the anal or urethral sphincters

Natural History of MSA: Prospective Studies The European Multiple System Atrophy Study Group-EMSA-SG
by Professor Gregor Wenning

Gregor described the recent validation of the MSA rating scale. Both a firm diagnosis and understanding of severity of MSA are clearly essential to allow interpretation of any studies of treatment of MSA.

It is important to know that one is including true MSA patients and have a way to decide if the treatment has led to an improvement, or at least a slowing of, deterioration. For this reason the validation of the MSA rating scale has provided an important tool to help assess study results. It is highly likely that any treatment for MSA would be most effective if started as early as possible.

For this reason improved techniques to confidently improve early MSA diagnosis are needed. The rate of deterioration in MSA has also been studied. This is important to know for therapeutic studies so that it can be seen if the intervention results in a slowing of deterioration in MSA. An additional element of the European MSA study group has been the setting up of an MSA DNA bank.

There are currently 4 major on-going studies of possible therapeutic intervention in MSA, all of which are nearing completion:

- Neuroprotection and Natural History in Parkinson Plus Syndromes (NNIPPS). This study is looking at the effects of riluzole. Riluzole is a drug which has been recently shown to slightly improve

Continued overleaf

Research news

prognosis in Motor Neuron Disease. It has many actions including blocking the release of the neurotransmitter glutamate. It has been shown in rat models of PD to protect against neuronal damage. About 400 patients with MSA and 400 with PSP (another Parkinsons plus syndrome) have been recruited and given even riluzole or placebo.

- Growth Hormone Study: Looking at the effects of Growth Hormone (GH) injections in a smaller number of MSA patients. The scientific background is not as powerful as for riluzole, but results are still awaited.

- Minocycline is an antibiotic which also has antioxidant and neuro-protective effects in animal models. This study is looking at the effects of minocycline for 48 weeks in MSA, using the Unified MSA rating scale as an end-point

- GDNF is a nerve growth factor which is being studied in MSA after having shown improvements in PD. HOWEVER, this treatment requires the drug to be infused via a small tube directly into the brain. The trial design is that patients receive GDNF or placebo for 0-6 months and then all patients receive GDNF for the remaining 6 months.

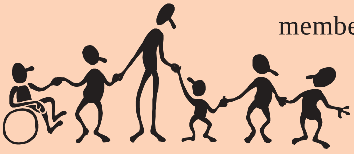
The above studies are still on going and so results have NOT been reported yet. Results should start to become available in about a year. Even if these results do not show an improvement, these studies represent an important and exciting step forward in MSA research as they provide the framework for future therapeutic studies to be performed.

Future research will not only focus on developing new agents to try in studies, but also better ways to differentiate MSA from other related conditions at an earlier stage.

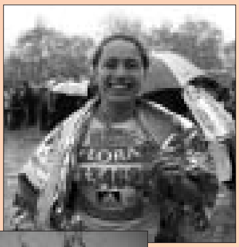
Dr Tim Young,
Neurovascular Medicine
(Pickering Unit),
Imperial College London,
St Mary's Hospital
London

Fundraising

Fun Walk – Sunday 12th September 2004 A date for your diaries! Once again, for the third year running, Hampton Court has graciously agreed to host our Fun Walk. We will have two walks: a long one and a shorter chair friendly one. The event will culminate in a communal picnic lunch. Entry for the walk is by donation to the SMT on the day, although sponsored walkers are welcome and sponsorship packs are available from Alison and Niki. All members and their families and friends are welcome to register for the event and join us for the picnic.



London Marathon 2004 Sunday 18th April saw six runners set off on the London Marathon 2004 in SMT colours. All six made it safely home over the finish line in some very respectable times. Ron Newman, whose cousin Robert Milton suffered from MSA, completed in our fastest time this year – 3hours 46 minutes. Pam Parsons, neighbour of our member Chris Jones, completed in 4H 05. Two of our runners, Darcy Hare and Miguel Bracamontes were closely matched with Darcy coming in at 4H 31 and Miguel 4H 34. Faye Stammers, whose father Mike has MSA, completed in 5hours and our stalwart of the Marathon, Allan Comette, completed in 5H 23. Miguel has since returned home to his family and work in Mexico but intends to keep raising funds for the SMT. We will update you on the final total raised by all our runners in the next *SMarT News*.



Faye Stammers, and with her proud Dad, Mike Stammers

Other fundraising events The late Brian Abra had been promised £649 in sponsorship for his supreme effort in getting to church on Sunday. A big thank you to the congregation and supporters who fulfilled their sponsorship promises.

When Scottish members David & June Edge's son Derek got married recently he and his bride Suzie asked for donations to the SMT instead of having a wedding list. They were surprised and gratified to see a total of £370 come in from right around the world. And to commemorate a much longer union, their Golden Wedding, Tony & Eileen Green also asked for donations in lieu of gifts to mark the occasion. Generous family and friends donated a total of £462. A further £300 was raised for Christine Millsted's 40th Birthday – her cousin Linda Stone is one of our members.

Peter Visagie, who lives and works in Cyprus, was a member of the Curium Music Society which when it was dissolved recently donated £1000 towards the work of the SMT. Orwell Connection, a community choir in Felixstowe raised £136 at their Summer Concert. Gale Watson, one of our SMT members, sings in the choir. A collection after a small concert by Lyn & Andrew Parkyns and William Morton for Ealing's town twinning group, the Friends of Mac en Baroeul, raised £127 for the SMT.

St Andrew's quilters rose over £200 auctioning the quilting materials, books and equipment of

Local action

Support around the country

Sarah Matheson Trust Essex Support Group

Monday 17th May saw a small gathering at the home of Bay & Laurelie Laurie in Great Tey. A mix of past & present carers and a member recently diagnosed with MSA joined the Lauries, Alison and Linda Campbell.

Over a scrumptious spread of tea and cakes in the sun soaked garden, views and experiences were exchanged and plans made for a further meeting later this year.

If you would be interested in attending the next meeting please contact Alison or Linda at the SMT office.

West Berkshire News

MSA is one of the half dozen rare neurology conditions that a new West Berkshire community based nurse post, planned for the end 2004, will be supporting. The nurse will be funded for two years by the local voluntary sector, and the audit results used to push for NHS funding for the future. The West Berkshire Neurological Alliance is an umbrella group for 14 local charities and 20 neurological conditions. They currently have no members with MSA and would like to invite people with MSA in the local area to get involved, both to strengthen their involvement with raising the profile of MSA and also to increase the awareness and use of the new nurse post.

For further information contact the West Berkshire Neurological Alliance Secretary, John Holt on 01635 33582.

Anyone looking to establish an SMT Group in their area should contact Alison 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.

South East Region Neurological Alliance (SERNA)

Although MSA is a rare disorder, estimated at around 50 people per million in the UK, did you know that:

- 8 million people in the UK are affected by neurological conditions
- 1 million people are disabled by neurological conditions
- 350,000 people require help for most of their daily activities

On 23rd January Professionals, Carers and Neurological Condition Sufferers came together in The Queen Elizabeth Centre in Dartford to form a Regional Neurological Alliance. There were 15 regional neurological alliances in Great Britain but none in the South East so interest was high. Over 50 people came to the meeting and a further 20 gave apologies and asked to be kept informed of future meetings. An interim committee was formed and the

---

Letters

In praise of the Contact Scheme

When I was told about the Sarah Matheson Trust and heard of the “Contact” scheme, and about the possibility of being linked with someone with a similar background and interests to mine, I immediately joined. I needed to realise I was not alone with MSA. I wanted to know other sufferers, be able to share and understand feelings of loss and anger. To exchange experiences and gain any useful tips for coping with everyday living. But more importantly, to compare life experiences and continue an interest in the arts and crafts, to still be creative and be of value! I wanted to be mentally stretched and not use the link as an easy outlet to moan about my losses and harp on too much about health issues.

Quite a tall order! I hoped Alison would find someone suitable. Well, after a few disappointing starts and me moaning to Alison, I’m in contact with someone with a similar outlook to mine and, surprisingly similar work experiences. Yes, we sometimes moan about having MSA, but we can always write of other things. She lives far away, at the opposite end of the country, I doubt we will ever meet but is good to know there is somebody out there who understands.

I’ve also been linked in with someone nearer home. She went to Art School like me! And she knows of my home town! But she is dogged by ill health which has hampered us exchanging but a few letters.

I must admit I miss the challenges my work gave me and also my recent exploits into ceramics but hope I have found someone who will offer me more than a good moan about MSA!

So you see, it is worth trying the “Contact” scheme. You may have success immediately, you may not. But persevere and work with Alison and you may eventually come up trumps!

Maureen Watkins, Gloucestershire

Are you a textphone user (not a mobile phone user who “texts”) who would like to take part in the Contact Scheme? If so, please contact Alison in the SMT office as we have an interested participant.

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

Carers Award 2003

"Carer, helper, enabler – call us what you will but in the long run it just means you do what you can, in the best way you can for the one you love." *Dave Kirby – caring for a partner with Parkinson's disease (From the PDS Carers Update 2004)*

We are pleased to announce the nominees for our annual Carers Awards.

Keith Roberts in the Isle of Lewis nominated his wife and partner **Pauline** for her tireless work in caring, supporting and fighting for his rights and needs. She gave up her job so they could relocate to the Outer Hebrides where he is now happily settled with Pauline and the support of the local community and palliative care services.

Sheila Lord nominated her hairdressers, **"Vanessa' Classic Styles" of Crewkerene**, for their kindness, thoughtfulness and care. They are happy to make allowances for her "bad days" and will rearrange appointments as needed – they are even learning some basic sign language as Sheila is deaf. Sheila also nominated her aromatherapist/masseuse **Bethan Harris** who makes a "fantastic difference" to her life and eases her aches and pains.

Michael Siddle, who lovingly cared for his wife Rita, was nominated by their friend **Sylvia Howarth**. After forty-six years of happily married life he willingly took on the role of sole carer for Rita. Rita's continual cheerfulness and humour was his biggest tribute. They drew strength from this wonderful quotation by Mother Theresa of Calcutta "We can do not great things, only small things with great love"

Carol Young nominated her sister **Denise Halliday** who has supported her along her road to diagnosis and has remained a close and supportive carer; particularly through the recent loss of their mother.

All those nominated have received a token of thanks and certificate of appreciation from the Trust.

our late member – Maureen Bell. Crystal Palace Radio & Electronics Club raised £500 by the sale of the equipment of our late member, Geoffrey Stone, one of their founder members.

A Charity Bring & Buy, organised by Mary Dickinson in Henley on Thames, raised £120. Mary's husband Malcolm had MSA and she is keen to see the work of the SMT continue. A Charity Raffle organised by Charlotte Brackenbury, daughter-in-law of our Trustee Elizabeth, raised us £111. Sue Fairlie along with family and friends in Oxfordshire raised £456.50 for the SMT from a tombola stall and a car boot sale. Sue's dad, Stanley Hartley, is a member of the SMT.

Thanks to the stalwart efforts of Allan Comette, and blatant advertising of his Marathon Medal, we raised £1900 at Wembley Arena when we were nominated as the official collectors at a series of Duran Duran concerts. Allan was joined on various occasions by Harriot Tennant, one of our Trustees, Catherine, Alison and Alison's partner Andrew. The excited crowds gave very generously and even offered us tickets to join them at the concert.

Thank you all for your efforts and kind thoughts, we couldn't do what we do without your support and encouragement.

Christmas Cards Following the sell out of our bespoke Christmas card last year we now have on order a new design. Cards will come in packs of 10 costing £3.50 per pack, and will be available at meetings and by post. For orders, and postal charges, please contact Niki or Alison in the SMT office.

Badges We have had many requests for enamel lapel badges that members could wear or sell to raise awareness and funds. The Sarah Matheson Trust badges are now being made and will available in a few weeks. They will come mounted on a card with information about MSA and the Trust. They will be available to individual members and for fundraisers – we suggest a minimum donation of £1 per badge.

We will be bringing them with us to the awareness days but any enquiries can be made to Niki or Alison in the SMT office

Forthcoming sponsored events include:

- Becky Bate, Sponsored Parachute Jump, 2nd June
- Kate Fairfoull, Norwich Half Marathon, 13th June
- Mark Butler, Blackpool Marathon, 20th June
- Vincent O'Reilly & Eamon Flanagan, BorderTrek 04, cycling Enniskillen to Sligo and back June 26-27
- Sarah Hawker, London 10K Run, 1st August
- Sponsored Odd Walk – Daventry Country Park – August/September (for more information or to take part contact SMT)
- Peter & Nick Dukes, Walking from Cardiff to Falkirk, starting 4th September
- Anna & Sarah Folan, Flora Light Challenge, 5th September
- Owen Keating, Dublin City Marathon, 25th October

We will publish any reports and photos in the Winter edition of *SMarT News*. Please do let us know of any fund-raising events taking place so that we can let the SMT membership know.

membership agreed an ambitious programme of work to see aims, objectives, and mechanisms for election of a more permanent committee. The second open meeting on 18th June was similarly well attended with the presence of local MPs raising SERNA's political profile.

SERNA's aims are to:-

- Raise awareness of neurological conditions and the impact on individuals, their families, carers and society
- Inform and influence policy makers about the needs of people with neurological conditions and their carers
- Secure the highest standards of service and improved care for people with neurological conditions
- Promote research and the dissemination of information about neurological conditions

For further information please contact the Secretary Jackie Weeden
20 Seaton Road, Dartford DA1 3LB
Tel 01322 226958 or email at serna@serna.org.uk A website is under development see www.serna.org.uk for the latest developments and news.

We need more lightwriters...

Some of our members may be aware of the lightwriter loan scheme that the Trust runs. A lightwriter is a small communication aid that can display a typed message on its screen or with its voice synthesiser can repeat the message aloud. They are useful for members who have difficulty producing strong voice sounds or whose clarity of speech fluctuates. They can store prepared messages and some can print them. This enables your needs, instructions or wishes to be known. They also fascinate children, grandchildren and technophiles alike who can often find interesting new uses for them!

The downside of these wonderful machines is that they are expensive (over £2000 each) and unlike other disability equipment they are not readily available in all areas of the country. The Trust currently has 13 lightwriters; some we have bought and others have been donated. All are out on loan and we have a growing waiting list. We issue each one to a Speech Therapist who can show someone how to use one, make adjustments whilst in use and return it to us when no longer required. It can then go to the next person on the waiting list.

The initial cost of the lightwriter makes this an expensive service to offer but the need to communicate is so vital that the Trust feels that the loan scheme is an important area where we can provide direct help. We are very grateful to everyone who has donated a lightwriter to us and would welcome any future donations. The Trust would also be happy to purchase the lightwriters from anyone who no longer found it useful.

Should anyone wish to purchase a lightwriter directly from the manufacturer rather than join the loan scheme, we would be delighted to organise the transaction on your behalf. As frequent customers we may be able to secure a discount.

Please contact Catherine to discuss any of these matters further.

Letters

Spreading the word...

On Wednesday 10 March Margaret and I attended a Neurological Charities Talk show in Long Eaton. This was run as a result of an "After Dementia Millennium award". All those who had applied for the award were families who had contact with a background of Neurological conditions. Present were three eminent speakers from the Queens Medical Centre here in Nottingham and "SRING"

MSA was not amongst the list of conditions mentioned. This was quickly rectified by yours truly who presented each of the speakers with one of our brochures, explaining who we were and what we are about.

***Ian Jones**, secretary of the SMT East Midlands Support Group*

If you would like to be put in touch with the SMT East Midlands Support Group which welcomes members from Nottinghamshire, Lincolnshire, Leicestershire, Derbyshire and beyond then please contact Alison or Niki at the SMT office.

A restful experience

I am writing in response to the excellent Q&A item in the last *SMarT News*. As a grateful recipient of hospice respite care from time to time over a period of a few years I can fully endorse the high standard of care they achieve, be it medical, nursing, emotional or whatever. Rightly or wrongly, I cannot envisage the same level of person-to-person care being accessible in a bustling general hospital ward. In this regard I also have the enormous extra worry of being totally deaf. Many deaf people, like so may Parkinson's patients, dread going into hospital because of previous bad experiences. In the hospice, with a high ratio of staff to patients, nothing was ever too much trouble for the staff, indeed they actively sought out things they could do to ease your stay and I used to say I thought they must all have been hand picked for their smiling faces as well as their TLC. Consequently I always found a week's respite care a truly stress-relieving experience. Most of all, I quickly found their welcoming caring attitude dispelled any fears one might have of being in a different environment and away from one's own careful home-based routines.

Sheila Lord, Somerset

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

All correspondence and enquiries to:
Alison Abery (Nurse)
Catherine Best (Nurse)
Nikita Ranade (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

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.

Banking moves

We have moved our main banking to a CAF Account. If you donate by direct debit or standing order and have not received the new banking details – or wish to become a regular donor to the SMT – then please contact Niki for a mandate form.

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.

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!

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.

Free to a good home

Essex: Minivator curved stair lift. Will require professional installation. Must collect (Ongar, Essex). Available free of charge, donation to SMT suggested by previous owner. If you are interested, please contact Alison at the SMT

Items are offered or sold in good faith. Before obtaining disability equipment SMT suggests that you take advice from a therapist. The Sarah Matheson Trust cannot accept responsibility for the goods or transactions entered into from this feature.

Future Awareness Days for your diary

- Liverpool (16th September) Glaxo Neurological Centre
- Sheffield (23rd September) Centre in the Park, Norfolk Heritage Park
- Bristol (2nd November) Frenchay Hospital
- Edinburgh (9th November) Scottish Health Service Centre
- Kent (24th November) Ashford
- Lymington (29th November)

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

In Memory

Donations received with gratitude in memory of:

- Derek Balson
- AE (Eddie) Bell
- May Callaghan
- John Croly
- Ronald Cushion
- Jennifer Daniel
- Betty Fairman
- Patrick Folan
- Lee Grant
- Peter Hassall
- Lesley Hewitson-Brown
- Dewi Enoch Jones
- Jean Joslyn
- Joan Larsen
- Urie Marks
- Malcolm McKinney
- Jean Rowles
- Rita Siddle
- Sarah Stadler
- Brian Toase
- Dina Udani
- Brian Walker
- Matthew Woollacott
- Patricia Worden
- Joan Young

Designed, laid out and printed by INQ Design. Call Martin on 020 8688 8773