Issue 23 Autumn 2008

SMarT News

The newsletter of the Sarah Matheson Trust

Contents

The Sarah Matheson Trust provides a support and information service to people with Multiple System Atrophy (MSA) and other autonomic disorders, their families and carers, health care professionals and social care teams. We also sponsor and support research into MSA

From the Office

Welcome to all our readers. This edition leads with a rather delicate issue. The SMT Nurses have been asked on many occasions about what research is being carried out on MSA, particularly relating to treatment options and the possibility of finding a cure. There have also been queries regarding how a definitive diagnosis of MSA can be made, with the sensitive issue of brain donation mentioned on a number of occasions. With these questions in mind, in this issue we have included a piece on important research work being carried out to further our understanding of MSA using donated brain tissue.

Natalie Fernandes is SMT's new Administrator, who took over from Linda Campbell, working three days a week. Natalie has a combined honours degree in English Literature and Psychology. Since graduating, she has worked in a GP surgery and at the prestigious Medical Research Council (MRC) as a Trials Assistant. In her spare time, Natalie also takes part in the Polychondritis Educational Society (PES) as Head of Public Awareness. Natalie is looking forward to assisting the nurses in making the SMT support network expand and grow. We wish Natalie all the best in her role as Administrator.

Samantha and Lee will be organising a number of awareness and support days, up and down the country, over the coming months. These days are an excellent way to connect with members and healthcare professionals, with whom we would only normally speak on the telephone. Please feel free to leave a message for us if we are not in the Office to answer your questions. The SMT always replies to telephone messages and emails.

We are looking forward to putting together and publishing the next SMarT News. The Sarah Matheson Trust warmly welcomes any contributions that you are able to send (by the 31st December 2008 for the next issue) and hope that the contents of this edition will be both helpful and informative.

Lee, Samantha and Natalie

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MSA and the Brain Bank

In the last issue we mentioned a £60,000 research grant made to the Queen Square Brain Bank. We have now extended that grant for a further three years. This is a subject that many members have asked about and so in this issue we look at the important work into MSA carried out within Brain Banks.

In the early part of 2008, the Trustees and SMT Nurse visited the Queen Square Brain Bank for Neurological Disorders in London. The visit was arranged for the Trustees to hear a presentation on the results of a £60K SMT grant, as described above and in the previous newsletter (Issue 22). The presentation provided a fascinating insight into an important area of neurological research, namely brain donation. Brain donation can play a vital role in the greater understanding of neurological conditions such as MSA and has the potential, in the near future, to help provide the basis for a possible cure.

Over the past nine months, there have been numerous enquiries to the Office on what constitutes a definitive MSA diagnosis, with occasional reference to issues related to brain donation and the research grant. While visiting the QSBB, and at a recent Trustee meeting, it was thought beneficial to provide information on these issues within this edition. In the Winter 2004/05 edition of SMarT News (issue 17) there was an excellent article on brain donation, written by members of the QSBB. The Trust, with QSBB approval, has re-visited this publication, summarised the main points and brought it up to date. We hope you find the following of interest.

This is a highly sensitive subject matter. We recognise that the nature of brain donation being what it is, examination can only be made after death.

Professor Tamas Revesz, the Neuropathologist Director, and Dr Janice Holton, Senior Lecturer/Consultant Neuropathologist at the Queen Square Brain Bank (QSBB), describe their interest in multiple system atrophy (MSA), a neurodegenerative disease affecting approximately 5 per 100,000 people in the UK.

"MSA is caused by loss of nerve cells in particular areas of the brain and spinal cord that control movements and the function of the autonomic nervous system. The nerve cell damage is associated with the accumulation of a protein called alpha-synuclein. Alpha-synuclein is a normal brain protein that is best known for its role in Parkinson's disease. In MSA abnormally folded alpha-synuclein forms inclusions termed 'glial cytoplasmic inclusions'.

At the Queen Square Brain Bank we have a large number of brains donated for research by people who suffered from MSA. We have used this valuable research resource to complete studies analysing the relationship between clinical symptoms and the distribution and amount of alpha-synuclein that has accumulated in the brain and also the structure of the gene that encodes the alpha-synuclein protein. We have recently been very fortunate to receive a grant from the Sara Matheson Trust to continue our work in MSA and this will enable us to begin a new study to try to understand the mechanisms underlying the formation of these unique glial cytoplasmic inclusions".

Professor Tamas Revesz & Dr Janice Holton

Brain donation for research

The QSBB has one of the world's largest collections of brain tissue, used for research into neurological disorders such as Parkinson's disease, progressive supranuclear palsy, dystonia and MSA. The centre receives around 80-100 donated brains per year. The QSBB is one of a dozen similar scientific facilities (not all specialising in MSA) involved in the diagnosis, treatment and research of neurological disorders by examining donated brain tissue after someone's death.

Brain donation tends to be quite a sensitive subject for many healthcare professionals. This sensitivity is felt because donation can only occur after death. However, Karen Shaw, the nurse specialist at QSBB who talks to patients, families, and members of the public about brain donation, tends towards a more pragmatic view point. Karen's experience leads her to consider that "donation… can offer patients and relatives the opportunity to salvage some meaning from an otherwise confusing situation".

What happens in a brain bank?

When a brain arrives at a brain bank it is either preserved in a fixative or rapidly frozen. The fixed brain tissue can then be examined under a microscope for any abnormalities. This process, termed histopathology, can take several months to determine whether any destructive changes have occurred because of a disease such as MSA. This examination process can then provide a definitive diagnosis. The next of kin at this stage may be informed, if they have expressed a wish to know. The tissue may then be used for research studies, to improve scientific understanding of cell change and damage determination.

Why do people donate?

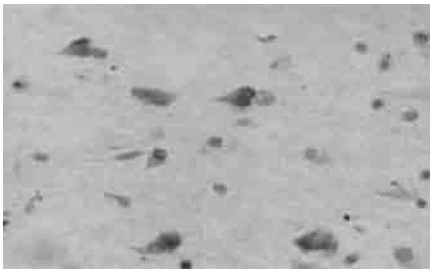
People with MSA often have to undergo a number of neurological investigations to rule out other causes for their symptoms. However, the only way to provide a definite diagnosis of MSA is by microscopic examination of brain tissue. So, to some people brain donation is viewed as a means of gaining a definitive diagnosis.

Some SMT members also donate to contribute to greater neurological understanding. Karen Shaw's experience has enabled her to suggest that "for families of deceased patients, benefits of brain donation include the comfort of certainty of diagnosis, contributing to the advancement of medical knowledge, and helping others in the future".

What is the link between a Brain Bank & MSA?

Brain bank research scientists carry out research into the manner in which glial inclusion bodies are formed. Such glial inclusion bodies are peculiar to MSA, and contain tangles of a protein called alpha synuclein. They appear under a microscope as comet shaped like structures. A picture of these comet-shaped glial inclusion bodies is shown in the figure below.

Research carried out on brain tissue must meet strict ethical and legal requirements. At the QSBB presentation (mentioned earlier), Professor Revesz of QSBB, emphasised that donors and their family need not worry about what will happen to the brain tissue, because the whole donation process has to meet stringent regulatory procedures.



Microscope picture: glial inclusion bodies

How does someone become a donor?

The potential donor first needs to garner as much information as possible, to help make an informed decision. This is not a fixed decision, as the potential donor is able to change his or her mind at any time. Family members, including next of kin, should also be involved so that they can be clear about a donor's wishes.

Not all brain banks will carry out research into MSA. If a donation is made with the intention of furthering research into MSA, then it is important to ensure that the brain bank chosen provides this facility. Most brain banks will provide the necessary forms and donor specific advice.

The most efficient way to provide a brain donation is to contact a brain bank early on, so that a system of checks and balances can be put swiftly into action. The brain bank can then register an intention to donate and will have all the relevant documentation to ensure a smooth donation process.

A donation is a very personal choice that only the donor can make. Many people will not want to consider donations; this personal choice will never affect any of the care anyone receives.

The QSBB, under the leadership of Professors Andrew Lees and Tamas Revesz, would also like to encourage people without a neurological condition to register with their donor scheme. People without neurological conditions are necessary because they play a vital role as the 'control group'. The control group is made up of healthy individuals who can provide scientists with an understanding of the normal appearance and function of the brain.

Being offered the opportunity of brain donation

Healthcare professionals, as indicated above, often find it difficult to communicate to patients and families that a relative is dying, while at the same time introducing a sensitive conversation about organ donation. There is a paucity of research examining how patients and relatives feel about being offered the opportunity to donate brain tissue. However, an interesting article on brain tissue donation and whether it is perceived as a positive opportunity has been published in a recent edition of the British Journal of Nursing.[1]

The article describes a 2-year pilot study, comprising an initial short postal questionnaire to gauge the level of distress when being approached about a brain tissue donation. The article highlighted that only a small minority of individuals actively themselves arranged in advance for a donation to be used for research. However, the results indicate that people were not further distressed by being offered a discussion on such issues, with a majority of respondents expressing the opinion that brain tissue donation for research purposes should be offered to family members.

Reference

1. Millar, T. *et al*, (2008) Post-mortem tissue donation for research: a positive opportunity? *British Journal of Nursing*, 17(10): 644-9.

A grateful thank you goes to QSBB members, Karen Shaw, Susan Stoneham & Dr Kingsbury, for producing the original article.

Karen and Susan are happy to talk to anyone interested in brain donation. They can be contacted on: 020 7837 8370 and via email: s.stoneham@ion.ucl.ac.uk.

If you would rather not speak directly to a member of a brain bank, then one of the SMT Nurses will also be happy to talk to anyone about the issues raised in this article.

Samantha Pavey – Specialist Nurse

Samantha is one of two nurses at the SMT. She works part-time for the Trust from home and we are very lucky to have her on the team. We thought you might be interested in Samantha's history.

I trained as a nurse at Addenbrooke's Hospital, qualifying in 1982. It was here that I first became interested in and inspired by neurology. I then worked at Atkinson Morley's Hospital as a Staff Nurse, undertaking further training at Addenbrooke's. I completed the neurology course and worked on neurology wards for a period before moving to Hertfordshire where I became a Ward Sister and then Ward Manager.

I also gained experience in the hospice setting, helping to care for patients with Motor Neuron Disease (MND). I then took up a post as a Parkinson's Disease Nurse Specialist (PDNS). This involved further study at London South Bank University. I enjoyed my 3 years in this PDNS role, and in January 2008 joined the SMT. I answer enquires from telephone calls and emails. I also take part in awareness and support days, give teaching sessions to the multi disciplinary team and run my own clinics. I split my time between the SMT, where I provide 20 hours of nursing support, and to the PSP (Progressive Supranuclear Palsy) Association, helping to support people living with PSP.

Samantha Pavey

Manchester Carers Day

The SMT Nurse took part in this year's Manchester Carers Day, which brings together a wide range of organisations that provide assistance to carers. The event was held on 12th June in Manchester's Town Hall. 14 flyers were sent out to SMT members within the Greater Manchester area. Among the members who came and spoke to the SMT Nurse, were Beryl and her partner, Alan Ross.

A happy John & Beryl

Eight years ago, Alan was diagnosed with MSA. Some time before his diagnosis he was the founding Chairman of Community Understanding, whose events have brought hundreds of people together from across the ethnic and religious divides. In recognition of his work a certificate, titled 'First among Equals in Community Understanding' was recently presented to him, with Ivan Lewis (Alan's MP) paying tribute to his "tremendous contribution to inter-community relations, being in particular a pioneer in building bridges between faiths".

MSA and travel insurance

One of the questions that the SMT Nurses are often asked concerns travel insurance for someone diagnosed with MSA, and we have had a small number of emails and telephone calls regarding members' experiences of travel cover. There are a number of insurance companies that deal with disorders such as MSA and we have attempted to get a real understanding of the insurance situation. Members can get insurance cover for MSA, and it does not necessarily have to be prohibitively expensive.

It appears that the best thing to do, as with all insurance cover, is to look around for the best deal. It is important to note that the travel insurance quotations can vary quite considerably in price. Most insurance companies will not have direct experience of dealing with MSA per se, but may have dealt with similar progressive neurological disorders.

The SMT does not necessarily endorse any of the agencies listed here. Agencies may not have MSA listed as a condition; if not try 'Parkinsonism' or 'Shy-Drager'. Feel free to give them our details if they wish to discuss this medical condition in more detail.

Age Concern Travel Insurance	0845 601 2234 www.ageconcern.org.uk/AgeConcern/travel_insurance.asp
CH Facilities	Tel: 0870 750 6711 www.ch-travel.co.uk
Free Spirit	Tel: 0845 230 5000 www.free-spirit.com/
Freedom Travel Insurance	Tel: 01223 454 290 www.freedominsure.co.uk
Lloyds TSB Travel Insurance	Tel: 0800 072 3321 www.insurance.co.uk
Rock Insurance	Tel: 0870 740 9260 www.24drtravel.com
Saga Holiday Insurance	Tel: 0800 056 5464 (for over 50s only) ww.saga.co.uk/insurance/travel-insurance/
Travelbility	Tel: 020 7446 7626 www.travelbility.co.uk/

PD drugs and compulsive gambling

During support days, awareness sessions and telephone calls, a number of similar questions have been put to the SMT Nurses. One frequently asked question has been a concern about the possible role that Parkinson's Disease (PD) medication (also used to treat people with MSA) might play in compulsive behaviour, particularly gambling. Compulsive behaviour can be defined as a person being unable to resist an impulse or temptation to partake in activities such as gambling, shopping or eating. It was thought beneficial to examine this issue briefly, with the intention of emphasising the extreme rarity of the condition and thereby alleviating people's fears. We hope you find the following short outline informative.

In 2005 an important research study was carried out to determine if there was a relationship between medical therapy for PD and pathological gambling.[1] The study found that there was indeed a very rare association with such drugs and 'reversible pathological gambling', or as it is now termed 'dopamine dysregulation syndrome'. A later article also tentatively argued the clinical case for a causal link between PD medication used by people diagnosed with MSA.[2] Recent clinical case studies have substantiated many of these findings.[3]

A leading article in a recent edition of Parkinson's News described two people with PD who brought a legal case against a pharmaceutical company, claiming that their medication turned them into compulsive gamblers.[4] They had been prescribed Mirapexin, a medication available since 1999, which belongs to a class of drug termed dopamine agonists. This type of drug works by mimicking the action of dopamine in the brain, which in turn helps to control the motor symptoms present in Parkinson's. Dopamine also stimulates the brain's pleasure and reward networks.

Those potentially at risk will have been either prescribed levadopa or a dopamine agonist, over a number of years and at a high enough dose. It mainly occurs in those aged under 50 and is estimated to affect between 3 and 4% of people prescribed these drugs. The Parkinson Disease Society (PDS) is investing £640,000 in a large scale research programme to investigate compulsive behaviours in people with PD who are taking dopamine agonist medication. The SMT will follow this study carefully and report the findings, once they have been made public.

When Samantha Pavey was a Parkinson's Disease Nurse Specialist, with more than 500 patients and over a three year period, she only ever encountered two cases of compulsive gambling.

It is important for doctors and other healthcare professionals to be vigilant for early symptoms. The good news is that, once diagnosed, the symptoms are reversible. Treatment to reverse the compulsive behaviour may involve reducing the daily amount taken, or introduction of other types of medication. The SMT, along with the PDS, strongly advises anyone who is worried about their medication or its side effects to speak to a Doctor or Specialist Nurse immediately.

If you need further information, you can contact either the SMT Nurse or the PDS free help line (0808 800 0303). You can also visit the PDS web site for a copy of their information sheet *Gambling and Parkinson's* www.parkinsons.org.uk/PDF/is_gambling_06.pdf.

Lee Potiphar
Autonomic Liaison Nurse

References

1. Dodd, M. *et al* (2005) Pathological gambling caused by drugs used to treat Parkinson's disease. Arch Neurol; 62(9): 1377-81.
2. McKeon, A. *et al* (2007) Unusual compulsive behaviors primarily related to dopamine agonist in Parkinson's disease and multiple system atrophy. Parkinsonism & related disorders; 13: 516-9.
3. Kimber, T. *et al* (2008) Resolution of dopamine dysregulation syndrome following cessation of dopamine agonist therapy in Parkinson's disease. *Journal of Clinical Neuroscience*; 15: 205-8.
4. Action launched against Parkinson's drug company. *Parkinson's News* (2008); 30: 1-3.

Fludrocortisone - changes to storage

If you are prescribed Florinef (Fludrocortisone Acetate) you may be aware that, fairly recently, the manner in which it is stored has changed. The tablets have also changed colour, from pink to white. The tablets will now need to be stored in a refrigerator, between 2 and 8° Celsius, and should not be frozen or kept at room temperature.

The SMT Nurse has been in contact with the manufacturer, Bristol-Myers Squibb Pharmaceuticals Limited, to enquire about how strictly people need to adhere to the changes in storage. After consulting the company's Medical Information Pharmacist, it was determined that they do not recommend the use of Florinef in any manner that is inconsistent with these storage instructions. There is at present a study being carried out to determine effects on the drug of different storage times outside a refrigerator environment. The SMT will update you when the findings are made available.

The table of regional support groups (published in issue 22) was very successful, leading to at least 8 new members joining local support groups. In view of this success, we have re-published a slightly updated version of the table. Further information on support groups can be found on the SMT web site (www.msaweb.co.uk/) under 'our services'

Region	Contact Point	Address
East Midlands Group Meets twice per year	Mrs Elizabeth Brackenbury Tel: 0115 933 3083 Or, Mr Ian Jones Tel: 0115 919 9294 i.jones5@ntlworld.com	Holme Pierrepont Hall Holme Pierrepont Notts NG12 2LD
Essex Group Meets twice per year	Mrs Laurelie Laurie Tel: 01206 210 410	The Old Rectory Little Tey, Colchester, Essex CO6 1JA
Yorkshire Group Meets twice per year	Ms Karen Walker Tel: 077103 12552 Or, 01274 861 947	In the first instance, please phone or email: karenwalker@BH-CC.co.uk
Lancashire & Merseyside Group Meets 4 times per year	Mrs Ann McLennan Tel: 01704 568 353 annandon@btinternet.com	72 Lyton Road Hillside, Southport PR8 3AP
Cornwall Group Meets 4 times per year	Mrs Jane Handy Tel: 01726 74792 Or, Ms Jan Pearce Tel: 01726 861361 Moonbeams@ymail.com	Address to be confirmed

These support groups are run entirely by members of the SMT, for the benefit of those whose lives have been impacted by a diagnosis of MSA. If you are interested in the possibility of running your own local support group, the SMT would warmly welcome your enquires and assist in providing relevant information and guidance on how to start one up.

East Midlands

The East Midland Support Group meets twice a year at Holme Pierrepont Hall (near Nottingham) which is my home as well as being a historic house our son runs as a business. We have adequate facilities to cope with people in wheelchairs

On Wednesday 30th April, we had a good gathering of old friends from Nottinghamshire, Derbyshire and South Yorkshire. Kirsty Rigg, from Sue Ryder Care, gave an excellent talk.

"This is an International Foundation which is devoted to the relief of suffering. Our work is a summons to seek out and face the reality of human suffering and do something about it". Sue Ryder (1953)

Sue Ryder served with the SOE during the war (Churchill's Special Operations Executive, also known as the 'Baker Street Irregulars') working behind enemy lines and at considerable risk to herself. The quote by Sue Ryder highlights her philosophy for the post war period, particularly in relation to Europe and Africa.

Today, the link with Sue Ryder is to Sue Ryder Care, which runs homes in the UK. Hickleton Hall near Doncaster specialises in neurological care, catering for respite and long term needs. Training programs are provided so that people can go out into the community and help people in their own homes. Sue Ryder Care seems to be developing this side of their work. All the care provided is free to the user. Further information can be found from: www.suerydercare.org or by telephone: 0845 050 1953.

We have found that meeting and sharing problems in a relaxed atmosphere, such as a support group, can be most beneficial. If anyone in our area would like to join us, please telephone Elizabeth Brackenbury on: 0115 9333 083 or Ian Jones on: 0115 9199 294.

Elizabeth Brackenbury,
SMT Trustee

Please note: unfortunately the Thoresby walk, advertised in the previous issue of this newsletter, has had to be cancelled this year.
The website was updated to this effect.

Devon & Cornwall

At our last meeting on 1st May, I demonstrated an internet messaging system. One important issue we also discussed was the support for carers. However, I am resigning from my position as Support Group Organiser. After a number of tests, I have been diagnosed as having Parkinson's disease without tremor, rather than MSA. Jan Pearce and Jane Hardy have agreed to take over the running of the group.

Peter Padmore

Jan and Jane wish Peter the very best with his future and would like to thank him for the huge amount of work he has done in promoting our group and keeping us together. We plan to hold our next meeting on 22nd October 2008 at Summercourt Village Hall (in mid Cornwall), from 11am to 2pm. Lee Potiphar, the SMT Nurse will also be present. To celebrate the occasion, Jane is going to bake a cake! Tea/coffee will be provided and you are invited to bring your own lunch.

Finding suitable venues to cover such a large area is challenging. So, if anyone would like a meeting nearer to where they live, or has any other ideas on staying in touch; please contact us so that we know where to focus our efforts. Contact Jane Hardy: 01726 74792 or Jan Pearce: 01726 861361, email: moonbeams@ymail.com.

Jan Pearce and Jane Hardy

We, at the SMT, are very happy with Peter's revised diagnosis and wish him all the best in his future endeavours. Peter's enthusiasm and stamina will be sadly missed. Thank you for all your hard work!

Essex

The next support group meeting will be held at Little Tey, in Colchester, on 27th October 2008. The two SMT Nurses will attend, providing a question and answer session (questions can be put on paper, to provide anonymity, if required).

Yorkshire

On 22nd July, we met at the Pinfold Lane Surgery in Leeds. An astounding 28 people turned up, with a good mixture from those with an MSA diagnoses, to carers and family members. It was great to see so many and I hope that the slight overcrowding did not spoil the visit. Despite the very warm and muggy day, everyone seemed to feel that it had been a worthwhile visit.

We were also delighted to welcome Lee, one of the SMT Nurses, who gave a short talk, followed after the coffee break by a question and answer session. I think everyone found the opportunity to ask questions very helpful.

One major factor for all those attending was to gain practical answers to the day-to-day element of living with MSA, particularly hearing how other people had tackled and then overcome similar problems. During the meeting, I agreed to prepare and circulate a list of contact details for those group members interested in contacting each other.

The next meeting will be held on Tuesday 25th November and we hope to ask someone from Sue Ryder charity to provide a presentation on respite care. I will endeavour to have the requested items from the SMT for the next meeting.

Karen Walker

Karen getting 28 people comfortable!

Lancashire and Merseyside

The latest meeting of the Lancashire and Merseyside Support Group was held on 12th June in Southport. Due to various other commitments, there were a few apologies but even so about fourteen of us were there to enjoy tea, coffee and homemade cakes. New members mingled well with those who had been before and new friendships were quickly formed.

There was a happy atmosphere and people were able to put the world to rights, discuss their problems with those suffering similar symptoms, laugh about what had gone according to plan and generally be very positive about life. Sadly, we have lost two friends since our last meeting – Arthur Holman and Susan Dupuy. Our thoughts are with their families. Everyone has booked the date for the next meeting (11th September) in their diaries when hopefully the SMT Nurses will be brave enough to venture to Southport to meet us all! [Please note: the meeting will take place when this newsletter already at the printers].

Ann McLennan, SMT Trustee

Ann has recently been made an SMT Trustee, after her years as a fundraiser and a Support Group Organiser. We offer our congratulations and welcome her to the board.

North East London – Enquiry as to interest

Michael Barrett, a Physiotherapist from St Joseph's Hospice in Hackney, is considering starting a support group in North East London for people diagnosed with MSA. He would like to know if there would be any interest in such a group being formed. If you would be interested in attending an MSA support group in this area, then please contact Michael Barrett on: 020 8525 6000 or email: m.barrett@stjh.org.uk.

We are always amazed and genuinely appreciative of the efforts that SMT members and their families make in fundraising. Here are some recent achievements.

Ladies' tennis tournament fundraiser

On a gloriously sunny 1st May (interrupted at times by inevitable showers) 32 ladies took part in a Ladies' Charity Tennis Tournament event, in aid of MSA. I had never heard of MSA until Susan, a close friend since school, was diagnosed with the disorder 3 years ago. I searched the internet to learn what such a diagnosis meant and this led to my desire to raise money for the SMT.

After all the activity, 40 ladies sat down to a hot buffet meal in either the conservatory or garden, at Mulberry House in Gloucester. Lee, one of the SMT Nurses, gave a brief presentation on MSA and why the Trust was created. I was delighted to present him with a cheque for £600. We all had fun, but at the same time were contributing to a very worthy cause about which not enough is known. **Jean Croft**

Susan and friends enjoying the sun

170 mile walk

In February 2007 Peter Dunkerley, who had been diagnosed with MSA, died. In May 2008 Chris and Anna, his son and daughter, went on a fundraising venture in his memory and also to raise funds for the SMT.

Peter had a 6-year battle with the symptoms of MSA, but remained stoical all through his illness. He was highly respected by his family and friends, volunteers and healthcare professionals alike for his humour, which he maintained throughout. He was a stalwart supporter of good causes. Following his death, we wanted to give something back, in memory of our father and to help support the SMT. So, we went on a 170 mile long walk along the Pilgrims Trail from Winchester to Portsmouth, and then continuing into France. One important reason for choosing the route was that there are strong family connections with the Normandy area, with our father's late mother, sister and brother-in-law having lived there.

Chris and Anna enter France

The walk took 9 days, beginning on 21st May at Winchester Cathedral and finishing on 29th May at the Abbaye de Mont St. Michel. Our French hosts were charming, with several sponsoring us. We are delighted to have raised £6,000 for the SMT, which will go to a project to help children to understand the condition, as it was particularly hard for Peter's grandchildren to come to terms with. We are working with Samantha Pavey (the SMT Specialist Nurse) on this project. If you would like to add to the funds or want to read more about the walk, please visit: http://www.justgiving.com/chrisandannadunkerley.

Chris & Anna Dunkerley

One mile swim

I wanted to raise money for research into MSA to find a cure for this disabling disease. My husband Peter Scott was diagnosed with MSA in August 2006 and had to give up work. He finds swimming at the gym and the steam room a relief for his symptoms. I and a friend, Marie, did a sponsored one-mile swim. Marie's mother Trish kindly counted the 123 lengths which made up the mile. We raised £280 for SMT! **Helena Scott**

A beaming Helena and Marie, with Trish

The 'golfing' footballers

Wes Brown's Golf Day

On 30th July in Manchester, a fundraising golf day organised by Wes Brown took place. Three of Manchester United's football players, Ryan Giggs, Paul Scholes and Edwin Van der Sar also took part. The day started off overcast, but soon became sunny once the golfers went on the green.

Rio Ferdinand & John O'Shea

In the afternoon everyone sat down to a good meal, followed by a fundraising auction at Manchester's 235 Casino. The auction consisted of a range of football memorabilia, with a number of Manchester United players present to offer support. The day was very successful, and the SMT will soon be presented with the cheque for the money raised.

The idea is something I thought about after losing my dad to the condition Multiple System Atrophy earlier this year. Most people have never heard of MSA and getting a diagnosis can leave people feeling very worried and alone.

My family and I were put in touch with the Sarah Matheson Trust which is dedicated to helping, not just the people who are living with the condition, but also their relatives and carers. We felt the golf day along with an evening fundraising event would be a great way to help the Trust.

Wes Brown

Please note: the fundraising day went so well that another Golf Day is planned for next year. A number of bookings have already been made, and the occasion is anticipated to be a considerably larger event.

A smiling Wes with his mum

Joan's book of poems – *Another Day is Dawning*

Those of us who have first hand knowledge of MSA are truly aware of its complexity, rapid deterioration and the distress it causes. My husband of over 40 years was diagnosed with MSA and I am now his full-time carer. We are so grateful to the Sarah Matheson Trust for assuring us that we are not alone in the things we have to face and especially for the help and support of the SMT Nurses.

We would like some good to come out of this situation and one way I have achieved this is by publishing a small book of poems, called *Another Day is Dawning*. I may not be able to take part in a sponsored marathon, but after entering a poetry competition and having my poem published in an anthology, I realised that I could write this book. All the money from the sale of the book of poems (£4.95 per copy) goes to SMT. It would be great if some of you could either buy or sell the book, for it will increase funds while also helping to raise awareness of MSA.

Joan Joyce

What am I?

Another day is dawning:
What will it bring?
As soon as I step out of bed
The things to do just fill my head.
Tablets, tea, toast on a tray;
Dressing takes nearly an hour.
And then to a reclining chair;
At least there's safety there
While I clear up, tidy up, wash up, shop;
Wash, iron, cook and serve
Elevenses first, then lunch and tea,
Is there any time for me?
We must go out to get the air
Walking with a frame at the pace of a snail
Back home, wipe wheels or there'll be a trail.
Appointments – doctor, nurse, hospital,
Physio, speech, are on the same days
It takes a good diary to sort out the maze
Eventually it's time for bed –
Tablets, nightcap, down to sleep
I collapse all in a heap
God give me patience to be
(Like to many others, the life you've given me)...
A CARER

Joan can be contacted on: jj.joyce@btinternet.com

Christmas Cards 2008

Now Available to Order!

Cards with our new design for 2008 "Decorating the Tree" are available in packs of 10 for £3.50 per pack plus postage.

The greeting inside the card reads: "With Best Wishes for Christmas and the New Year" .

"Decorating the Tree"

Number of packs	Total cost including postage
1	4.20
2	8.60
3	12.60
4	16.10
5	20.00
6	23.50
7	28.75
8	32.25
9	35.75
10	40.00

We also have a limited number of our old Christmas cards available, as shown below. Both cards are still available in packs of 10 (same prices as above) and are printed with the message: "With Best Wishes for Christmas and New Year"

"Starry Night"
(very limited supply)

To order, please send us the slip below, indicating which packs you would like, with a cheque made payable to "Sarah Matheson Trust" and post to:
Sarah Matheson Trust, Box 200,
St. Mary's Hospital, Praed Street,
London, W2 1NY.

Thank you for your support.

"Golden Tree"
(limited supply)

Either cut here or photocopy

Sarah Matheson Trust Christmas Card Order

Name ....

Address ....

....Postcode...

Telephone no. ....

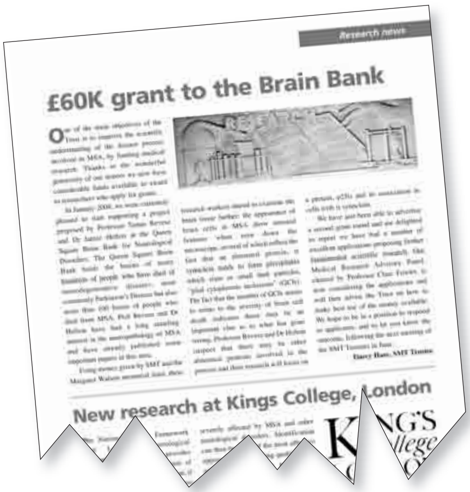
	No. of packs
Decorating the Tree	☐
Starry Night	☐
Golden Tree	☐

Total payment enclosed £ ....

The wide-ranging affects of MSA

Dear friends,
The diagnosis of MSA certainly affects not only those suffering from MSA but the entire family and circle of friends. Therefore, it is good to hear of the grant to the Brain Bank and the research at King's College London, for so little is known about Multiple System Atrophy… as pointed out in Karen Haigh's article [see Issue 22].

My daughter Trish was first diagnosed with Parkinson's disease but it gathered in momentum at such a rapid rate that finally a diagnosis of MSA was made. She was the mother of 6 children and had twenty grandchildren, with a wonderful bond of love that still exists, not least of all from her caring, loving and devoted husband George.


Research news

£60K grant to the Brain Bank

New research at Kings College, London

Although in my 80s I helped George nurse Trish. It is essential that those caring for someone with MSA have a break from the consent vigil of caring and by my being there he was able to have a game of golf twice a week. In her big adjustable chair he would take her on walks into the deer park, which was so peaceful and tranquil, and she loved him for it.

Trish died on 20th December 2004. The Church was packed for her Requiem Mass and donations in lieu of flowers amounted to £1,125; with a similar process for such additions as wreaths and 'talks on other things' given by me, another £996.00 was made. So, donations of over £2,000 have been given to SMT for research into MSA.

Yours sincerely,
Mrs Thora Beddard

You don't have to run...

Dear SMT,
Thank you for the mention of our card-making exploits in the Spring edition of *Smart News*. I thought you might like to know why we started them. My husband John was a keen wood turner until the symptoms of his illness made him unsafe handling the sharp tools and fast machinery.

We looked for something else he could do as a hobby. We tried several things from making chessmen with moulded resin to airbrush painting, until finally settling on encaustic wax art (a special wax applied to card using a low-powered iron).

John produced many pieces using this technique, and although we framed some, there were still quite a few left over. As you will notice, all our cards have some encaustic wax work on them and the result is very beautiful.

Unfortunately, John's MSA has progressed to a stage that he is no longer able to use the encaustic iron, so I now produce the waxes we need and card production has gone down somewhat. We now make them mainly to order. Our local florist, Julie of Arrochar Flowers buys and uses our cards for her bouquets, as well as selling cards for us in her shop, which she does without profit [cards can also be bought from the SMT Office].

I hope that you will mention some of this in your next SMarT News and that it encourages others diagnosed with MSA, who might be unable to run marathons, to show them that it is possible to do other things.

Yours sincerely,
Mrs Chris Fowler

Sadly, John died at his home, on 9th August. John was a shining example of how to stay positive throughout such a hard-to-live-with disease. Our condolences go out to his wife, Chris, family and friends.

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.

MSA
Sarah Matheson Trust for
Multiple System Atrophy

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

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

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

All correspondence and enquiries to:
Sarah Matheson Trust
Box 200
St Mary's Hospital
Praed Street
London W2 1NY
020 7886 1520
020 7886 1540 (fax)

www.msaweb.co.uk

The Trust is financed entirely by voluntary donations.

Registered Charity Number 1062308

Membership Numbers as of July 2008

Current MSA members	826
Other patient members	39
Relatives and carers	411
Professionals	1491
Others	162

Ways to support the SMT and help the Trust grow

• **Become a regular donor**
Donations by monthly or annual direct debit. Regardless of size, all donations help us maintain and improve upon our services. Don't forget to Gift Aid (see below) any donations to increase the value of the donation generously given.

• **Become a fundraiser**
Events such as coffee mornings, car boot sales and a wide variety of sponsorship opportunities bring the SMT valuable income every year. New ideas are always welcome.

• **Use our online fundraising/donation facility**
We have the facility for you to use an online fundraising package on: www.justgiving.com. This facility can be used for anything from a personal occasion to the dedication of a person's life.

• **Contribute to *SMarT News***
Sharing your experiences and tips with other members helps keep it your newsletter.

• **Form a local SMT group**
Link with the SMT office and independently run a group to provide local group support.

• **Raise awareness about MSA**
Share our information with family, friends and the health professionals you meet.

Don't forget: the SMT is your charity.

In Memory for 2008

This edition of SMarT News will cover the period from April 2008. If you have informed the SMT of a loved one's death and he or she does not appear below, please accept our apologies (we can always rectify this in a later edition). Some members passed away earlier than 2008 and these have the year in brackets.

- David Alan
- Norma Andriuskevicius
- Sandra Archer
- Nigel Blood (2007)
- Anthony Burbidge
- Maureen Colyer
- Margaret Conway
- Sylvia Dunwood (2007)
- Susan Dupuy
- Kenneth Easlea
- Roysten English
- Richard Evans
- Robin Falconer
- Heather Fisher
- John Fowler
- Ernst Garrard
- Victor Goodall
- Charles Halling
- Simon Harrison
- Richard Hodgson
- Arthur Holman
- Stanley Hopkins
- Sheila Jepps
- Robert Jukes
- Christina Leonard
- Bridget Lynch
- M. MacDonald
- Ann Martin
- Annaleen McCloy
- Cecil McVitty
- Ian Nimmo
- Barra O'Meara
- Vasundhara Ramachandran
- Edward Rogers
- Ramona Sharman
- Pamela Smith
- Hazel Sparks
- Robert Stringer
- Derek Todd
- Michael Waite
- Maureen Watkins
- Dolores Weisfeld
- Doreen Whitfeid (2007)
- Kevin Winder
- Alistair Young

Next issue

The next newsletter will be another interesting and informative edition. It will include practical MSA tips from Samantha Pavey (such as saliva control) and the use of Autonomic testing in an MSA diagnosis at the Pickering Unit and National Hospital for Neurological and Neurosurgery. We also intend to re-introduce the Carer's awards, after a period of 2 years absence.

The next edition (issue 24) is planned for posting to you by early February 2009. If applicable, please provide articles by 31st December 2008. All articles received after this date will appear in the following edition (issue 25).

All articles aim to provide as much information as possible. However, since some information involves personal judgement, its publication does not mean the Sarah Matheson Trust necessarily endorses them.

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