



SMarT News

The newsletter of the Sarah Matheson Trust

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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, both old and new. This edition is slightly different, in that it has been prepared by the newly appointed Autonomic Liaison Nurse, Lee Potiphar and Linda Campbell, SMT's present administrator. The lead article is on providing care, a subject close to the hearts of many SMT members.

There have been a few staff changes over the past year. In December 2007, Linda Campbell kindly took over the position of administrator at the SMT Office. Linda, a former SMT Trustee, has provided invaluable support over the last 6 months, often taking messages from callers when Lee has been unavailable. Linda plans to step down once a permanent administrator has been found. She will be sadly missed.

You may have had a call from Samantha Pavey. Samantha, an experienced specialist nurse, has been helping Lee with calls while he grows in his position as an Autonomic Liaison Nurse. Samantha and Lee will also be taking part in support and awareness days over the coming months. With Lee and Samantha at SMT, the team is back to full strength.

Lee, who joined the SMT in January 2008, was a special needs teacher of children with autism, before he decided to embark upon a career in healthcare. Graduating with a degree in nursing, he then worked as a Staff Nurse on a gastrointestinal unit. Lee considers that providing dedicated and personalised nursing care is an essential nursing function and that the role of Autonomic Liaison Nurse allows him the opportunity to channel this passionately held feeling.

Diagnosis can be very distressing and significantly affect the every day life for those diagnosed with Multiple System Atrophy (MSA), their family and carers. The Autonomic Liaison Nurse's role is to ease the burden of a MSA diagnoses by providing personalised care and support to individual patients, carers and family members. The SMT Nurse will also assist primary care clinicians to gain a better understanding of how best to help those diagnosed with MSA. Lee will add to the role by including a clinical research component at Imperial College.

Catherine Best, the Autonomic Nurse Specialist, has left the Trust and is now based full-time at the National Hospital for Neurology and Neurosurgery. However, Lee will still see Catherine, informally each Tuesday, at her clinic.

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 end of August for the next issue) and hopes that the contents of this edition will be both helpful and informative.

Lee, Samantha and Linda

SMT's New Address!

Please note, the SMT has a slightly altered address:

The Sarah Matheson Trust
Box 200, St Mary's Hospital, Praed Street
London, W2 1NY

The dedicated helpline numbers to use are
Lee: 020 7886 1520 or **Samantha:** 020 8150 6250

Supporting a carer's

The term 'carer' is generally used to describe anyone who provides practical and emotional support to a partner, relative or friend requiring help because they are ill, aged or disabled. This feature looks at the various aspects of the role, and support available to carers.

Providing care is a very individual experience. The degree to which a carer's life is affected and the role that incorporates will depend on many factors, including:

- The particular health problems of the person being cared for;
- The type and extent of the help they need;
- The relationship between carer and the cared for;
- The carer's own health and circumstances;
- The resources available, including care support services.

Feelings about the term 'carer' can vary enormously. Some people say it is hard to identify with this term, because they feel the support provided becomes part of a complex relationship (parent, child, relative, partner or friend) between carer and cared for. Others say

“Caring can be viewed as extremely difficult, especially where the carer feels that they have had little choice in the matter.”

that having a word to describe this role can help highlight the needs of carers and assist them to separate the task of caring from the myriad of variables that make up the relationship they have with the person they care for. In recent years, carers have been provided with the potential for a higher profile, via the development of Carers Acts. These Acts include:

- The Carers (Recognition and Services) Act 1995 – giving carers the right to ask for their own needs to be included within an assessment;
- The Carer's and Children's Act 2000 – enabling a carer to an assessment in their own right, even if the person they care for refuses to be assessed;
- The Carers (Equal Opportunities) Act 2004 – promoting greater opportunities for carers in employment, education and leisure.

In 1999, the UK government published *Caring about Carers: a national strategy for carers* to acknowledge the value of carers in the community and develop information and support services for them. As a result, many statutory bodies, such as primary care trusts and social service departments, are developing services, centres and workers specifically catering for carers' needs. The social services department, GP surgery or Citizens Advice Bureau should be able to provide advice on what is available within a local area.

Acknowledging the importance of a carer's needs

Many carers desperately want to care for the person they support and, despite an array of challenges, find it a very rewarding experience. However, caring can also be viewed as extremely difficult, especially where the carer feels they have had little choice in the matter. Carers can often feel isolated and struggle to make ends meet. For some, being a carer means caring when they are themselves over 60 or 70 years of age and may have their own health needs. Therefore, it is important to acknowledge the carer's needs, as well as those of the person being cared for.

Research carried out on those providing care, including for illnesses such as MSA, has identified several key points that are essential for a carer's well-being. These include:

- Information and education;
- Access to services to help with care (including financial benefits);
- Ensuring the carer's continued health and well-being;
- Having a say in the provision of services provided;
- Meeting others in a similar position.

There may not always be a definitive solution to every issue a carer might face. However, considerable information and support can often be found if someone knows where and how to look for it. How easy it is to access support often depends on what is available in

needs

the local area and how effective communication is between carer and the health/social care professionals they are in contact with. It is important to note that provision can be variable.

A carer's assessment

One of the main ways carers can access information on available support is through a carer's assessment that they are now entitled to as a result of the Carers Acts, described earlier. The local social service department is responsible for arranging support services for people who require help to live independently in the community, because of their age, illness or disability. Social services must assess anyone who appears to fit these categories, thereby determining what services should be provided.

The services that might be available will largely depend upon the area where the person being cared for lives and can include support in the home to help with caring tasks or housework, day care or respite care services (mentioned later), equipment/ alterations to the home or opportunities for social contacts and leisure. Assessments can be determined by contacting local social services; the phone number will be listed in the local telephone directory under 'local authority' or 'GP surgery'.

Two examples of relevant voluntary organisations

Many voluntary organisations, especially those helping people with specific health conditions or circumstances (including the SMT), have recognised the needs of carers and family members. These organisations provide services specifically for carers, and are often involved in campaigning and awareness raising activities

A nurse's perspective on the impact of caring

Over the past 3 months, I have taken part in an awareness day, support days and answered many calls at the SMT office. This experience has proved to be invaluable in my understanding of MSA. One thing that particularly impressed me has been the enormous amount of care provided by carers. It was for this reason that I have decided to dedicate this, my first newsletter, to all the carers who provide support to those with a diagnoses of MSA.

Interestingly, I recently read an article in the British Journal of Nursing (Taylor, 2008, vol. 17(4): 226-30) which describes the carer of someone with a long term chronic illness as feeling that they can never give, or do anything well enough. The article emphasised the manner in which a carer has to constantly juggle the every day basics of life, prioritising the care they provide. With this in mind, we are printing an article from Bridget McCall on caring, based upon her book, *The Complete Carer's Guide*. I hope you find the following, abridged article, informative.

Lee Potiphar – Autonomic Liaison Nurse

Please note: I am available to discuss anything regarding this or any other article within *SMarT News*. My number is 020 7886 1520.

focused specifically on carer issues.

Two dedicated voluntary organisations in the UK that provide a focus on carers' issues are: Carers UK and Princess Royal Trust for Carers.

Carers UK: In 1965, a voluntary organisation called Carers UK was formed to provide carers with a voice to fight for the recognition and support that they require. It aims to:

- Transform the understanding of caring so that carers are free from discrimination;
- Mobilise carers, decision-makers and the public to bring about changes that make a real difference to carers' lives;
- Inform carers of their rights and how to challenge injustice;
- Provide a free advice service – CarersLine (0808 808 7777);
- Production of a magazine *Caring*.

For further information, contact: Carers

UK, 20-25 Glasshouse Yard, London EC1A 4JT. Tel: 020 7490 8818 or via the website: www.carersuk.org.

Princess Royal Trust for Carers: This Trust is the largest provider of comprehensive carer's support services in the UK. Through its network of 118 Carers' Centres, the Trust provides information, advice and support to over 180,000 carers. In general, the services offered includes:

- Information on any aspect of caring
- Publications – produced by the Trust and other organisations
- Carer's courses
- Research, development and consultation

To find your local Carers Centre, see the website (www.carers.org) or contact their national office at 142 Minories, London EC3N 1LB, tel: 020 7480 7788.

The relevance of respite care

Having regular breaks, often called respite care, can help carers cope with caring and give them the time to recharge their batteries. Respite care also allows carers the opportunity to pursue their own interests. Respite care can take many forms, from a few hours a week so they can have lunch with friends to a longer break that will allow the carer to go on holiday. The person cared for might have their care provided by somewhere outside the home such as a day centre or other respite care facilities. The local social services, Carers UK and Princess Royal Trust for Carers are available to provide practical advice.

There is also a voluntary organisation dedicated to providing respite care for carers, called Crossroads – Caring for Carers. This scheme is available in most parts of England and Wales, offers a range of

A Carer Checklist

- Make sure you have all the information and services you require
- Get a 'care assessment' for you and the person you are caring for
- Arm yourself with self-management strategies
- Check what financial benefits you may be entitled to
- Accept your feelings and talk about what you are doing
- Be clear about what you are willing and unwilling to do
- Have contact with other carers for information, ideas and support
- Maintain your own health and set some time aside for yourself
- Try to avoid making caring the sole focus of your life
- Try to keep your sense of humour!

services to meet local needs and may include additional services such as care for people who are terminally ill. More information is available from: Crossroads – Caring for Carers, 10 Regent Place, Rugby, Warwickshire CV21 2PN. Tel: 0845 450 0350. The website is available at: www.crossroads.org.uk.

- City & Guilds are one of the UK's leading providers of vocational qualifications. They have developed an online learning resource for carers, called Learning for Living, leading to a recognised qualification. More information is available via the website: www.learning-for-living.co.uk;
- The Expert Patients Programme is the government's NHS-based training initiative. The course aims to help carers look after themselves. More information can be obtained from their enquiry line: 0845 606 6040 or via the website address: www.expertpatients.nhs.uk.

“Why is respite care relevant? Because caring can be exhausting!”

Examples of courses for carers

Some carers may find taking a course helps them to understand more about caring and what it involves. Two relevant courses are provided by City & Guilds and The Expert Patients Programme.

Some healthcare professionals may also provide courses of relevance to carers. In particular, physiotherapists sometimes run courses on moving and handling for those caring for people who have physical disabilities.

A recent Campaign for Carers by the PDS

The Spring issue of *Parkinson's News* (2008, 30: 10) describes a focus group study carried out by the Parkinson's Disease Society (PDS). The study, which was recently completed, provided a forum for carers to discuss their views on a number of caring and care support issues. The initial findings are as follows:

- A low awareness of entitlements to benefits and carer's assessments
- Many carers not seeking support in the early stages of caring
- Worries regarding eligibility criteria
- Poor-quality respite care
- Poor financial support for carers.

This is a very interesting research study, of direct relevance to many members of the SMT. Therefore, we will follow the study carefully to see what the final results are. Please read further issues of *SMT News* for updates.

This précised article was based upon the information contained in *The Complete Carer's Guide* by Bridget McCall, published in 2007 (Sheldon Press, £7.99 ISBN: 0 85969 995 1).

The SMT thanks Bridget for providing this informative and helpful article.

£60K grant to the Brain Bank

One of the main objectives of the Trust is to improve the scientific understanding of the disease process involved in MSA, by funding medical research. Thanks to the wonderful generosity of our donors we now have considerable funds available to award to researchers who apply for grants.

In January 2008, we were extremely pleased to start supporting a project proposed by Professor Tamas Revesz and Dr Janice Holton at the Queen Square Brain Bank for Neurological Disorders. The Queen Square Brain Bank holds the brains of many hundreds of people who have died of neurodegenerative diseases, most commonly Parkinson's Disease but also more than 100 brains of people who died from MSA. Prof Revesz and Dr Holton have had a long standing interest in the neuropathology of MSA and have already published some important papers in this area.

Using money given by SMT and the Margaret Watson memorial fund, these



research workers intend to examine the brain tissue further: the appearance of brain cells in MSA show unusual features when seen down the microscope, several of which reflect the fact that an abnormal protein, α synuclein tends to form precipitates which stain as small dark particles, “glial cytoplasmic inclusions” (GCIs). The fact that the number of GCIs seems to relate to the severity of brain cell death indicates these may be an important clue as to what has gone wrong. Professor Revesz and Dr Holton suspect that there may be other abnormal proteins involved in the process and their research will focus on

a protein, p25 α and its association in cells with α synuclein.

We have just been able to advertise a second grant round and are delighted to report we have had a number of excellent applications proposing further fundamental scientific research. Our Medical Research Advisory Panel, chaired by Professor Clare Fowler, is now considering the applications and will then advise the Trust on how to make best use of the money available. We hope to be in a position to respond to applicants, and to let you know the outcome, following the next meeting of the SMT Trustees in June.

Darcy Hare, SMT Trustee

New research at Kings College, London

The National Service Framework for Long-term Neurological Conditions (NSF for LTNC) provides the NHS with goals in the form of quality requirements for services that, if achieved, could substantially improve the quality of life of individuals with neurological conditions and their carers. The Department of Clinical Neuroscience, Kings College, London is carrying out research to “define palliative care needs of people with late stage Parkinson's disease, Multiple System Atrophy and Progressive Supranuclear Palsy”.

The research sets out to understand the experiences and needs of people

severely affected by MSA and other neurological disorders. Identification can then be made of the most effective approaches to enhancing quality of life and how to provide personalised support through healthcare and social services.

Dr Tariq Saleem began the project in June 2007. The research programme consists of two parts (quantitative and qualitative) which are designed to complement each other within a longitudinal study. Research participants have been identified, with interviewing continuing over a number of months. Participants are being followed up at four-monthly intervals.

KING'S
College
LONDON

University of London

Further details of the study can be found at: <http://www.kcl.ac.uk/palliative>.

We will keep you informed on the progress of, what appears to be, a highly promising research project.

NNIPPS: Positive lessons from a negative drug trial

Calls have been received at the SMT office regarding what results were derived from a MSA related drug trial. Professor Leigh (Kings College, London) describes the results, so far, on how the drug trial might help those with MSA.

The NNIPPS (Neuroprotection and Natural History in Parkinson Plus Syndromes) recruited 403 patients with MSA, alongside 763 patients with Progressive Supranuclear Palsy (PSP). Although many people do not like the term ‘Parkinson’s Plus’, we used it because we wanted to recruit patients in whom the diagnosis of MSA or PSP might not yet be clear. We were keen to study MSA patients as early as possible in the evolution of their disease

We were hoping that Riluzole would delay the progression of MSA and PSP. Sadly it did not but we have a clear result which allows no doubt. NNIPPS used survival as the main measure of the effectiveness (or otherwise)

of Riluzole, and there was no difference in survival at the end of three years between MSA patients who took Riluzole compared to those who took the placebo (dummy).

What did we learn from NNIPPS?

We learned a great deal about the nature of MSA and PSP. We developed a new clinical outcome measure (the Parkinson’s Plus Scale) which can be used to measure changes in day-to-day function over time. We also showed that simple criteria for the diagnosis of MSA can be used with high accuracy.

We acquired new insights into the clinical course of MSA. We also have unique information from MRI scans

collected over the course of the study and on psychological changes experienced by some patients. We have a wealth of information on the cost of providing care for people with MSA, and on quality of life of patients and care-givers.

We also collected DNA samples from most of our MSA patients. We have a unique tissue resource, through brain donation, for further research on the basic mechanisms of the disease. We are currently working hard to finalise all the analyses relating to these different aspects of the study and to publish them.

Finally, we have started new projects using the DNA and brain tissue. We intend that the NNIPPS resource will continue to generate exciting and important new research. We are inviting colleagues in the UK and abroad to use the NNIPPS resource to advance understanding of MSA.

**Professor Nigel Leigh,
Kings College, London**

Government petition update

In the previous edition of *SMarT News* (issue 21) we ran an article on the e-petition created by Chris and Karen Haigh. Here, Karen tells us of its progress.

In April 2007, I set up a petition on the 10 Downing St. website to encourage the UK Government to create awareness about the debilitating disease Multiple System Atrophy. Chris and I were delighted at the sudden flurry of signatures that appeared over the relatively short time after publishing details of the petition in *SMarT News*. We were keen to get at least 200 signatures, because this guarantees that the petition will be looked at by the Government. I am very happy to say that we finished with a total of 704 signatures!

I set the petition up mainly to create an awareness of the illness in GP surgeries and hospitals countrywide. I



already feel we have, at the very least, created awareness because of the response to the petition and those who will now look at it. It is impossible to tell from the signatures who has signed the petition from reading about it in the newsletter and who signed after

perusing the petition online. We hope that all those who signed the petition will receive a positive response, sometime in the future.

It is the lack of knowledge about this illness that has always struck me as one of the toughest hurdles that we have to face. I think it is fair to say that we can ask anyone on the street about Parkinson's and they would know what we were talking about but with MSA, very few people have ever heard of it. I believe that creating awareness is one of the most important things we can do to help everyone who has been touched by a degenerative neurological disorder, such as MSA.

Thank you all so much from the bottom of my heart for supporting my efforts. If we have made even a few more people aware of MSA, then it has all been worthwhile.

Karen Haigh



I have a medical condition called Multiple System Atrophy (MSA)

For more information about MSA please go to www.msaweb.co.uk

This means that:

- I have difficulty talking but can understand everything you say
- I have difficulty walking
- It may take me a little while to answer
- I may need to sit or lie down
- I am not drunk
- I may need to use the toilet

In an emergency please contact:

New MSA help cards available

Some time ago, Catherine Best initiated the concept of a 'Help Card' for all those with MSA. With Catherine and Peter Padmore's assistance (Peter already uses his own home-made card), the SMT has created a MSA Help Card. SMT's gratitude goes out to both Catherine and Peter for

their support in producing the cards. We hope you find the cards useful.

If you are on our database as a person living with MSA you will have found a Help Card included with this newsletter – if it was missing, please contact the office.

School project highlights Sarah Matheson Trust

In September 2007, Roseanne Blaze of John Roan School contacted the SMT office. She enquired about devising a logo and other material for her Year 11 Graphic Design coursework. Six months on, Roseanne has completed her coursework and visited the SMT office with the results.

"For my GCSE Graphic Design coursework, I was asked to create promotional material for a charity. I chose to design promotional material for the Sarah Matheson Trust", says Roseanne. "I chose the charity for two reasons. Firstly, because they kindly helped my uncle who suffered from MSA and sadly passed away 2 years ago.

"Secondly, I know through experience that the Trust is only small which means that very few people know about them and what they do. I wanted to create promotional materials that emphasised the SMT so that more people would know about MSA."

We were all considerably impressed

with the professionalism of Roseanne's badge, booklet, flyer, donation box and poster. Below is a picture of a proud Roseanne, displaying her coursework.

The SMT thanks Roseanne for all her hard work. Well done!



Badges

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

Contact the office for more information.



Collection boxes

Flat pack cardboard collecting boxes are available on request. Collections/donations however small are always appreciated by SMT and help us to continue our services free of charge.



One question often asked at the SMT office is what local support groups there are for those living with the impact of a MSA diagnosis. This question has arisen so frequently that it was thought beneficial to provide 'at a glance' details of all five regional support groups. Further information 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
Devon & Cornwall Group Meets 4 times per year	Mr Peter Padmore Tel: 01822 870 642 Zen70184@zen.co.uk	9 Venn Hill, Milton Abbot, Tavistock, Devon P119 ONY

These support groups are run entirely by members of the SMT, for the benefit of those whose lives have been impacted by MSA. In the previous edition of *SMarT News* (issue 21, page 8), Laurelie and Bay Laurie (Essex Group Organisers) provided an excellent description of how to start up a support group. 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 Midlands Support Group has been in existence for about 4 years and our area covers Nottinghamshire, Derbyshire, Leicestershire and Lincolnshire. We also have two members from South Yorkshire. The Group meets twice a year at Holme Pierrepont Hall (near Nottingham) which is my home as well as being an historic house our son runs as a business. We cater for wedding receptions most weekends of the year and therefore have adequate facilities to cope with people in wheelchairs.

Our Group has a spring meeting in early April/May, with a further September/October meeting. We meet from 2pm to about 4.30pm and cater for tea, cake and gossip. Our last meeting was on 30th April, when we had a guest speaker, the regional fund raiser for Sue Ryder Homes. It was interesting to hear how Sue Ryder Homes can help people with neurological conditions.

We have found that meeting and sharing problems in a relaxed atmosphere, such as a support group, can be most beneficial. If anyone in this area would like to join us, please

telephone Elizabeth Brackenbury on: 0115 9333 083 or Ian Jones on: 0115 9199 294.

The annual Thoresby Walk will take place on Sunday 14th September. Members can either be sponsored, or (on the day) make a donation to the event. This is a fabulous walk, led by Hugh Matheson, through the Private Park including the remains of the ancient Sherwood Forest. Anyone interested please ring the office on: 020 7886 1520 for further information.

Elizabeth Brackenbury,
SMT Trustee

Devon & Cornwall

The group hosted a very successful Awareness Day near Plymouth last Autumn with a large room full of healthcare professionals for Catherine Best's excellent presentation, *How MSA rules our life*. Peter Padmore gave Catherine a well earned break with a ten minute talk on the disease with a dynamic mix of questions, answers and general discussion.

Since then, the group has held a number of local meetings, but the attendance has been disappointing mainly because of the travelling distances involved. As a result of this, our next meeting in May was devoted to



Smiles all round

a discussion about alternative means for discussing our problems, notably the internet. A live trial of one system will start soon after the meeting in co-operation with the American 'SDS/MSA' support group. Anyone who is interested in exchanging messages with other people with the disease, or carers wanting to talk to other carers, please email me for the joining instructions.

Our meeting was on 1st May in the Tavistock area to talk about how we can communicate better without the travelling. Then we are planning a normal meeting in mid September in the Exeter area. For further details of these meetings, please phone (01822 870642) or email me on: zen70184@zen.co.uk.

Peter Padmore



Samantha and Lee's presentation

Essex

We met on 31st March in Great Tey Village Hall on a beautiful sunny day. To make the meeting even better we were able to welcome several new members to join the regulars with the added bonus of the MSA Specialist Nurse Samantha, and Lee (SMT Nurse) coming from London to meet the group.

When everyone had arrived, 24 of us sat down to a good chat over lunch. Lee and Samantha went around the hall and 'table-hopped'. This enabled all the members of the group an opportunity to discuss any issues with them. After lunch they gave excellent presentations and answered a number of written questions which had been submitted beforehand. We are so grateful to them

Lancashire and Merseyside

The second meeting of the Lancashire and Merseyside Support Group took place on 8th March 2008, in Southport. Twenty seven people came to drink tea and coffee, eat homemade cakes, talk, share problems (and solutions to problems), relax for a while and smile!

It was lovely to see familiar faces, but very exciting and rewarding to meet new people for the first time. At the moment, the group seems to be going from strength to strength and hopefully this will continue.

It is so evident that this is what has been so desperately needed in this area



Tea and cake all round

and hope they will come again.

The time went all too fast but it seemed that everyone left feeling that it had been an informative and enjoyable get-together. We are looking forward to the next meeting in October.

Bay and Laurelie Laurie

Note from Lee: *This was my first time at a support group. Bay and Laurelie made me feel very welcome, with good food and quite a few cups of coffee. I really enjoyed the day, and hope that everyone got something worthwhile out of it. It left me with the feeling - this is why I became a nurse! I will definitely go again. Samantha and I would like to offer our thanks for a great day at Great Tey.*

of Britain - a place where patients, friends, family and carers can come and talk. If you are able to, please come and join us at our next meeting on Thursday, 12th June 2008.

Ann McLennan



The group relaxes, sits and chats

The regional support groups clearly play an important part in reducing the isolation felt by having an unusual disorder like MSA. If you would like further details of any of the local groups or would be interested in setting up a group in your area please contact the office. We can provide information, practical help and financial support to start new groups.

The trust is amazed, astounded and always appreciative of the efforts of our members and their families in fundraising. Here are some of their achievements.

Cycle2cannes

Cycle2cannes is the brainchild of Peter Murray, a former Trustee of the SMT. Peter's eldest brother, John, died from MSA in 2000. Peter's first cycle ride to raise funds for SMT was from Land's End to John O'Groats. After that, he undertook a series of solo charity rides and believed that a cycling event at the time of the MIPIIM Property Fair (the world's premier real estate summit held annually in Cannes) could tap into the generosity of the property industry and raise significant amounts for good causes. Cycle2cannes was registered in January 2008 as a charity in its own right and will continue to make charitable grants.

The first ride in 2006 had just 17 riders supported by a double decker bus with bunks. The weather was cold and at times the riders faced blizzard conditions. But all arrived safely, having enjoyed the experience of a lifetime and raising £110,000. In 2007, there were 52 riders including the majority of those from the previous year. This time there was a rolling road closure, riders stayed in hotels and the weather was rather milder, yet the experience was just as exhilarating. The ride raised £270,000.

In 2008, there were 115 riders from London and a further 15 from Barcelona taking part in the 5-day



A group of happy (and very fit) riders arrive in Cannes; Peter Murray hands the c2c baton to Peter Rhodes of MIPIIM

1500km cycling endurance event suitable for fit commuters as well as cyclosporive riders. The logistics of moving 130 riders and £200,000 of bikes over the 5 days required 32 support staff, 12 motorbike outriders, 3 mechanics, C2C executive coaches with luggage trailers, mechanic's vans, 2 lead cars and support vehicles, in excess of a year's preparation and the support and effort of hundreds of people.

This year the British riders left Greenwich on Thursday 6th March and on arriving at Folkestone caught the Euro Star to Calais, where they stayed overnight. They each rode a minimum of 100 miles a day in two sessions. With the rolling road closure they averaged a speed of 15/17mph and arrived in Cannes on Tuesday 11th March. On arriving in Cannes and meeting up with riders from Barcelona, the group rode along the Croisette before turning into the forecourt of the Palais de Festival where Peter Rhodes of MIPIIM presented all the riders with medals.

Later they changed out of their lycra into their business suits to take part in the Property Fair! Peter Murray and Mike Evans, a current Trustee of the SMT, both took part this year. Mike's mother died from MSA. Since the inception cycle2cannes has assisted four charities: Sarah Matheson Trust, LandAid, The Tom ap Rhys Pryce Memorial Trust and Architects for Aid (A4A). This year cycle2cannes are also supporting the Duke of Edinburgh Award Scheme.

So far cycle2cannes 2008 has raised £350,000 and Peter hopes the final figure will be some £400,000. He anticipates that SMT will receive a cheque for at least £40,000. This is a fantastic effort and we are all very grateful to cycle2cannes and all the

riders and their sponsors for their hard work, energy, commitment and support that raised such an impressive sum of money for SMT and the other charities.

**Geoffrey Murray and Michael Evans,
SMT Trustees**

Scottish Madness Night

On 1st March 2008, the McLennan family held another night of Scottish Madness To remember Donald. The



Two happy tartan hat wearers...

venue was once again held in Southport, the same band agreed to be there, the buffet served was as good as last year, and everyone wore tartan in some way or another. On the night, over £3,500 was raised for the Sarah Matheson Trust.

From the moment the band started, people were dancing (or at least trying to) and laughing at their attempts to master the Scottish reels. Friends and family travelled from all over the country to be there and the evening was made more special by the fact that Fraser (Donald's eleven-month-old grandson) joined the party for a while. From the feedback received it looks as though it won't be too long before another such evening is being planned!

Ann McLennan

Tall Ships Race

Since 1982, Malcolm Noble had operated as a volunteer and a Mate on voyages aboard the Ocean Youth Club fleet of sail training ketches. As a First

Mate, he had logged over 30 voyages aboard the North East boat, James Cook, a boat built as a training scheme for unemployed youngsters largely funded locally. In 1995, Malcolm was given the chance to sail in the Tall Ships Race to the Baltic visiting 14 changes of country in nine weeks, involving five crews covering 3,600 miles. He subsequently ran the office covering the North East of England for the Ocean Youth Trust and continued to sail as First Mate, logging over 21,000 miles.

When Malcolm was diagnosed, about 5 years ago, with Parkinson's disease and subsequently with MSA, it became rapidly apparent that he was undergoing loss of muscle power and balance. This became obvious through dingy sailing, which became increasingly difficult. He gave up the Commercial Endorsement to his Yachtmaster Certificate which includes a Doctor's examination and Sea Survival Course. Malcolm was facing the prospect of never being able to sail again.

In 2005, the Tall Ships Race came to Newcastle and Gateshead and as part of the Education work around the event, Malcolm had taken a party of young people to see Tenacious, the Jubilee Sailing Trust's (JST) latest sail training vessel. JST promotes the integration of men and women of all physical abilities together with able-bodied sailors, providing a buddy system for those who need specific support. The Mate of Tenacious suggested that he should consider joining one of their trips. And so, Malcolm signed up to join the Tall Ships race in the Baltic to celebrate his 60th birthday!

The race started in Finland, with planning how to get there initially proving difficult. However, solving this problem and anticipating further foreseeable challenges, became part of the very positive experiences of Malcolm's trip.

Each person is assigned a carer or



Malcolm 'learning the ropes'

'Buddy' throughout the voyage. The crew is 50% disabled and 50% able-bodied, and thus the Lord Nelson carries a large number (43) of permanent crew. Many experiences ensued, including an opportunity to go up the mast. For those who were apprehensive, you can have supervision which Malcolm took advantage of as he has a tendency to fall backwards – not advisable half way up a mast!

The trip proved a fantastic opportunity to sail again when Malcolm thought that this was 'all in the past'. It was good to experience the Baltic again as well as seeing the boat and harbours as a passenger rather than First Mate

The 2008 London Marathon

The day proved to have a mixture of weather, with one minute sunshine and the next pouring rain. However, conditions were better than the heat of last year! Four of the runners and their families and friends joined us for some refreshment at The Warwick pub nearby afterwards and the attached pictures show them grinning in triumph and relief.

We did have seven supporters lined up to run, but unfortunately two had to withdraw with injuries. However, Allan Comette, who was unable to run, did manage to join us at our reception afterwards.

The times of our runners were as follows:

- Michael Gill 3:33:55
- Andrew Ladd 4:21:11
- Andrew McCormick 4:27:58
- Gina Grasso 5:42:08
- Mark Steel 3:46:46

Andrew McCormick and Gina Grasso both ran carrying injuries. So, well done for finishing! We will give you a further update on their marvellous efforts in our next *SMarT News*.

If people would like to run for the Trust in 2009, please log onto the London Marathon website (www.london-marathon.co.uk) and apply for a place in the ballot. We would be grateful if you would let the office know later in the year if you have been successful. We do have a small amount of Golden Bond places which can be shared between some of the unsuccessful applicants, though we cannot guarantee a place for everyone.

A big thank you goes to all our runners who have yet again raised funds for the Trust.

Linda Campbell – SMT Administrator



Mark Steel



Michael Gill



Andrew McCormick



Andrew Ladd

with all its responsibilities. For more information on JST, please visit: www.jst.org.uk

Malcolm Noble

Card Makers

In the previous issue, we mentioned that Christine Fowler, who has been hand-making cards for the Trust over the last few years, raised £400. This figure has now increased to over £2,000. Christine does not charge for the materials involved or for making the cards and is grateful to Julie, from Arrochar Flowers in Argyll, who sells the cards in her shop without taking any profit. Some of our members may have seen Christine's cards on awareness days and know how professional, beautiful and unique they are. We thank Christine and her husband John, for their unfailing support.



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

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The Trust is financed entirely by voluntary donations.

Registered Charity Number 1062308

Membership Numbers as of April 2008

Current MSA members	821
Other patient members	41
Relatives and carers	407
Professionals	1495
Others	155

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.

Gift Aid It!

Did you know that if you are a UK tax payer, we can increase the value of any donations made to the SMT by 28% This Gift Aid could raise the SMT's income by as much as £20,000 extra per year. We have Gift Aid forms available at the SMT office.

In Memory for 2008

This edition of *SMarT News* will cover the period from January 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).

- | | | |
|-----------------------|------------------|-------------------|
| • Janette Armstrong | • Ruth Curtis | • Brian McCormick |
| • Angela Barton-Smith | • James Davies | • John Moir |
| • David Blair | • John Duncan | • Sally Pollock |
| • Henry Boyd | • Ray Edwards | • Lewis Roper |
| • Andrea Breen | • Margaret Grace | • Francis Sharp |
| • Maureen Burt | • Michael Harden | • Charles Simons |
| • Aubrey Cahill | • Terry Jackson | • Valerie Spacie |
| • Pamela Cole | • Morag Mackle | • Robert Turner |

MSA and travel insurance – next issue

One of the many enquires that come into the SMT office is on how to get travel insurance cover for MSA. The SMT Nurse is, at present, gaining a greater understanding of the insurance situation. A table of insurance companies providing MSA cover will be published in the next edition of *SMarT News*. Please contact Lee to discuss either good or bad experiences that you have encountered.

The next edition (issue 23) is planned for posting to you by the middle of October 2008. If applicable, please provide articles by the end of August. All articles received after this date will appear in the following edition (issue 24).

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