



SMT News

The newsletter of the Sarah Matheson Trust

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

From the Trustees

We are delighted to be able to announce the appointment of our new Executive Director, Nickie Roberts. She started with us in September on a three-day-a-week basis and brings with her extensive experience of working with and 'growing' small medical charities. This is a very exciting and positive move forward for the Trust and, together with Linda Campbell, our Administrator, and Samantha Pavey, our Specialist Nurse, we are confident that we now have in place a team which will enable us over time to extend the services we offer to our members.

With Nickie joining us, and the need for more space in the future, we felt this was also the right time to move our office out of St Mary's Hospital in Paddington. We are extraordinarily grateful to St Mary's and Imperial College Healthcare NHS Trust for their generosity in providing us with office accommodation for the last 12 years. The Trust now has its own friendly and affordable space in Southbank House, Black Prince Road, Vauxhall – just across the Thames from Westminster in London. We are printing in this issue the full details of our new postal address, telephone and fax numbers, and e-mail. Please see the box below. Our website remains the same.

So, it's a lot of change for the Trust – and change is always challenging. But we believe it is also going to be very rewarding and we are greatly looking forward to a period of innovation and growth and to improving the support and services we offer to you, our members. After all, that is what the Trust is all about.

Eileen Strathnaver, Chair of Trustees

SMT is moving offices

As from 1st November 2009
the SMT office contact details are:

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Southbank House, Black Prince Road,
London SE1 7SJ
Tel: 020 7940 4666 Fax: 020 7940 4664

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Samantha Pavey (Specialist Nurse)
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Linda Campbell (Administrator)
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Hot topics

– your queries answered

In recent months the Trust has received a number of requests for information relating to specific topics. In this issue Samantha answers queries on four of these: advanced care planning; coenzyme Q10; services available to those living with MSA; and stem cells.



Samantha Pavey

Advance Care Planning

Advance care planning means looking ahead at possible future options for health care, particularly at the end of life and expressing preferences. Thinking about end of life issues can feel uncomfortable or upsetting and it is important that you are able to have the time to discuss your feelings with family and/or carers; it may help to have the support of healthcare professionals in clarifying your thoughts and making decisions.

Unfortunately for people living with MSA, as the disease progresses, speech can deteriorate and it becomes more difficult to express wishes regarding care. It is a good idea, therefore, to discuss these issues earlier rather than later so that you can make your wishes known and ensure they are documented. Individual choice is paramount. It is extremely difficult for families to act as an advocate for the person living with MSA, if they do not know what your preferences are, and planning ahead can give peace of mind that your wishes will be taken into account.

Advance Statements and Advanced Directives

There are two means of making advance plans about medical care and treatment. These help to safeguard your choice in treatment decisions by recording your views and values, and can guide families and/or healthcare professionals acting for people who are unable to make decisions for themselves. There are two types of documents: Advance Statements and Advance Directives.

An Advance Statement is a general statement of your wishes and views. It is not legally binding but will assist medical staff to determine the best treatment for you. It may take one of the following forms:

- a signed document or card
- a witnessed oral statement
- a note of a discussion recorded in a patient's medical file.

An Advance Directive allows you to record your wish to refuse certain types of life-prolonging medical treatment. In England and Wales, such statements

can have legal force and are sometimes known as 'Advance Decisions'. Topics you might like to consider are: resuscitation, treatment with antibiotics for pneumonia, admission to hospital and artificial feeding. For example, a person may decide that they wish to refuse resuscitation, if their illness becomes such that they can no longer make their wishes known.

For an Advance Directive to be enforced when required, health professionals must be convinced that the person had capacity (was mentally competent) to make the directive and had accurately predicted their current situation. (See the notes at the end of this article relating to mental capacity.)

It is essential to find out about treatment options before drawing up an Advance Directive, so it may be advisable to discuss your intentions with a medical professional such as your GP, who can help you understand the consequences of different options. They can also help you to express your wishes clearly and confirm you were competent at the time you prepared and signed the document.

To make your Advance Directive you can either consult a solicitor, or download a form from one of the many website sources, but please ensure you are using a reputable company/organisation. The Alzheimer's Society website includes a form

Please note, the telephone number for Samantha Pavey (Specialist Nurse) has changed but her email address remains the same.

Her contact details are:

Samantha Pavey (Specialist Nurse) 020 3371 0003

Email: samantha.msa@googlemail.com

“Basic care and comfort must be provided and can never be withheld.”

(alzheimers.org.uk/advanceddecisionform)

The Advance Directive must be witnessed and you should give a copy to your GP, your lawyer and a close family member or friend. You can change your mind at any time, destroy the original Advanced Directive and make a new one. You must give copies of the new Advanced Directive to the people who previously received a copy.

Life-prolonging treatments

These include resuscitation, artificial feeding and hydration (administered by a tube which enters the body), ventilation (breathing by a machine) and intravenous medicine (by drip or injection).

Basic care

This includes nursing care, pain relief and relief of other symptoms, and the offer of food or drink by mouth.

The code of practice produced by the British Medical Association states that patients can refuse life-prolonging medical treatment but they cannot refuse basic care.

Planning for Choice in End-of-life Care

Currently in the UK it is recognised that where death is inevitable, life-prolonging treatments such as resuscitation, artificial ventilation, or artificial feeding may be withdrawn or withheld. In such cases the goal of medicine becomes the relief of symptoms. ‘Basic care’ and comfort must be provided and can never be withheld. Removing life-prolonging treatments is not euthanasia.

Palliative Care

One issue which should be discussed is palliative care. The philosophy behind palliative care is that people who are facing a serious illness should be able to expect privacy, dignity, a high standard of care in comfortable surroundings, adequate pain relief and appropriate support in keeping with their preferences.

Palliative care improves the quality of life of individuals (and their families) facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems – physical, psycho-

social and spiritual. The hospice or palliative care team are used to discussing end of life issues, so are another handy point of contact when considering advance care planning.

The Mental Capacity Act 2005 came into force during 2007 and applies to England and Wales. Scotland has separate legislation under the Adults with Incapacity (Scotland) Act 2001. In Northern Ireland, mental capacity issues are dealt with under common law. For a summary of the Mental Capacity Act see www.dh.gov.uk/PublicationsAndStatistics/Bulletins Other helpful websites are www.direct.gov.uk, www.alzheimers.org.uk and www.ageconcern.org.uk

Coenzyme Q10 – the basics

Anecdotal evidence and limited research findings indicate that Coenzyme Q10 may be of benefit to patients with neurological illnesses.

Coenzyme Q10 (CoQ10), also known as Ubiquinone, can best be described as a herbal supplement. It appears to work on the mitochondria of the cell (imagine the mitochondria as the battery of each cell) and therefore may help with energy levels.

CoQ10 was first isolated in 1957 by Dr Crane in Wisconsin and by Professor Morton in England. The role of CoQ10 in the energy production within mitochondria was better understood after the contribution of 1978 Nobel Prize winning scientist Peter Mitchell.

A lot of research has been carried out with interesting results. Changes in levels of CoQ10 in the cerebrospinal fluid of patients with Parkinson's disease have been found, but the clinical significance is unclear. There are some interesting reports suggesting possible therapeutic benefit of CoQ10 in Huntington's disease (HD). The suggestion is that the mitochondrial dysfunction found in HD may be improved with CoQ10 supplements. It has also been tried with apparent benefit in Friedreich's Ataxia. It is recommended in migraine prophylaxis.

CoQ10 may also have a role as an antioxidant and it undoubtedly has antioxidant activity.

There is insufficient data available to give a 'recommended' dose. Some patients taking doses varying between 100 and 600mg Coenzyme Q10 per day have reported improvements in their general well-being. Some people living with MSA have reported that they feel less tired during the day and as a consequence are sleeping better at night. There are no reported side effects from taking CoQ10 at this time. The longer-term effects of CoQ10 and whether it exerts any disease modifying or neuroprotective effects and at what doses and at what stage(s) in the disease are as yet unknown. Further research is required to provide the answers to these and other questions concerning the use of CoQ10 in the treatment of MSA.

Please note a possible interaction with some anticoagulants (blood thinning medication) has been reported at high doses.

Please speak to your GP if you are considering taking CoQ10.

Services available to those living with MSA

When living with MSA you may need a range of services to help support you. The National Service Framework (NSF) for Long Term Conditions states that people with such conditions are to be offered integrated assessment and planning of their health and social care needs. Many of these services will help maintain and improve your quality of life. It is therefore important for you to know how to access to them.

National Health Services

The NHS has Primary Care Trusts and NHS Trusts. Your Primary Care Trust is responsible for your general practitioner

(GP) and other staff, such as community nurses, operating from your GP's practice or health centre. Primary Care Trusts also run community rehabilitation services using physiotherapists, occupational therapists, and speech and language therapists. These therapists should review you regularly and, once you are under their care, you can contact them directly for follow-up advice or reassessment. Most therapists prefer to see you as early as possible after your diagnosis so they can offer appropriate advice about keeping yourself well.

The GP is seen as the gatekeeper for your care. You can access all of the services mentioned here via your GP.

"The NSF places emphasis on prompt access to specialist neurological expertise."

The NSF places emphasis on prompt access to specialist neurological expertise (as close to home as possible) for a person with a neurological condition. As well as primary care services, your NHS Trust will be linked to a number of Primary Care Trusts and also provides hospital-based services, including

Stem cells – the basics

Stem cells are a class of undifferentiated cells that can be induced to differentiate into specialised cell types. Commonly, stem cells come from two main sources: Adult stem cells and embryonic stem cells.

Adult stem cells

Adult stem cells have been found in tissues such as the brain, bone marrow, blood, blood vessels, skeletal muscles, skin, and the liver.

Embryonic stem cells

Embryonic stem cells are derived from a four- or five-day-old human embryo, usually extras that have been created in IVF (*in vitro* fertilisation) clinics where several eggs are fertilised in a test tube, but only one is implanted into a woman.

Research with stem cells

Scientists and researchers are interested in stem cells for several reasons. Although stem cells do not serve any one function, many have the capacity to serve any function after they are instructed to specialise. Every cell in the body, for example, is derived from the first few stem cells formed in the early stages of embryological development. Therefore, stem cells extracted from embryos can be induced to become any desired cell type. This property makes stem cells powerful enough to regenerate damaged tissue under the right conditions.

Brain disease treatment

Additionally, replacement cells and tissues may be used

to treat brain disease such as Parkinson's and Alzheimer's by replenishing damaged tissue, bringing back the specialised brain cells that keep un-needed muscles from moving. Embryonic stem cells have recently been directed to differentiate into these types of cells, and so treatments are promising.

This potential has given stem cell research a high profile and is leading to significant interest and investment in academic, medical and commercial research throughout the world.

Recent scientific advances have opened up the possibility of treating a much wider range of disorders by isolating and growing stem cells in the laboratory. In some cases it may be possible to administer stem cells directly to an individual in such a way that they would migrate to the correct site in the body and differentiate into the desired cell type in response to normal body signals. However, currently it seems more likely that stem cells will be grown and induced to differentiate into a defined cell type in the laboratory prior to implantation. In the longer term it may also be possible to induce stem cells to differentiate into several cell types, generating whole tissues, prior to implantation. For these approaches a much greater understanding of differentiation and developmental 'signals' will be required.



outpatient services. It is responsible for your local district hospital, neurology centre, neuro rehabilitation unit and neurosurgery centre.

Most neurologists will only be able to see you every 6 months. If you also access the services of your local Parkinsons Disease Nurse Specialist (PDNS) every 6 months and alternate your appointments you can be seen by a specialist every 3 months. The PDNS also looks after people living with MSA and is a good source of support and knowledge. The PDNS will know what services you can access locally. You can also liaise with Samantha Pavey, SMT's Specialist Nurse.

Social Services

Social services can provide:

- Help with personal care such as washing and dressing
- Meals on wheels
- Laundry services
- Equipment and aids to use in your home
- Free or subsidised travel on public transport.

You may have to meet certain criteria to be eligible for these services and you may have to pay for some of them. A community care assessment is undertaken by a social worker/care manager to find out your needs.

After your assessment your social worker/care manager will draw up a copy of a care plan, which summarises the services to be provided. You will be given a copy of this and it should be reviewed by social services every year. In some areas you may be under the care of a social worker from a specialist social services disability team.

The National Service Framework for Long Term Conditions focuses on the needs of people with neurological conditions calling for joint working across all agencies, including providers of transport, housing, employment, education, benefits and pensions, to support people to live independently.

Leaflet update

SMt has the following information leaflets, which are available from the office.

- Continence in MSA and other autonomic disorders
- Going into Hospital
- Holidays and Travel Insurance
- Living with Postural Hypotension
- Managing constipation in MSA and other autonomic disorders
- PEG feeding
- Saliva control
- Someone in my family has been diagnosed with MSA

There are also leaflets especially for children which, ideally, should be read as a package, but do ask for individual leaflets you think would be helpful.

- What is MSA

- What children understand about disability
- Gadgets – understanding disability for children
- Helping children with their grief

In addition we have some leaflets specifically for healthcare professionals, which are available on request from Linda at the new office address and telephone number.

If anybody feels that there is a need for a leaflet we do not have, please contact Linda with your ideas.

We would like to take this opportunity to thank INQ Design for their support for the Trust and particularly their kind donation of a print-run of 1,000 copies of the revised Gadgets leaflet.

EchoVoice machines available

The last *SMT News* advised members that the Trust loans lightwriters on the recommendation of their Speech and Language Therapist (S<). We now also have available for loan some EchoVoice machines, which

are amplifiers. If you think the loan of an EchoVoice machine might help you, please contact your S< who must send a letter of recommendation to Linda at the office. Don't forget to give your S< our new office address!

Sharing the caring

This is a new column that we hope to include in every issue of *SMT News* where readers can share tips and recommendations for making the caring of a loved one with MSA a little easier. It may be very simple such as plastic bags on car seats to aid turning to get in and out, or a successful holiday location. Please keep your contributions to not more than 100 words and send them to Linda at our new office address.

The summer issue of *SMT News* included a Holiday Directory as the main feature article. Vitalise was one of the organisations featured in the article. It was nice to receive feedback from David Waterman and Sheila Lucas of Herne Hill who holidayed with Vitalise at one of their five centres. This summer they went to Netley near Southampton. David has MSA and Sheila is his full-time carer and she wrote to *SMT News* to say they had a really good holiday and the impressive thing about the centre was the people who work there (who are on duty 24 hours a day) and the volunteers who will help with practically anything you ask for. The centre is very well equipped, trips out and evening entertainment are organised and three good meals a day are included. Sheila added that the costs are not low but their stay was well worth the money and in many cases Social Services will contribute. It's pleasing to know that our holiday directory has been of help and hope other readers have also found it useful.

Research update

Professor Tamas Revesz and Dr Janice Holton from the Queen Square Brain Bank report on the grant from the Trust that has facilitated the development of research into MSA and enabled a multidisciplinary approach, including collaboration with genetic investigations.

The award in 2008 of a one-year grant from the Sarah Matheson Trust enabled researchers at the Queen Square Brain Bank for Neurological Disorders (QSBB) to continue a programme of research into multiple system atrophy (MSA). The research utilises the considerable resource of brain tissue that has been generously donated to the QSBB by people who have died from MSA. The project was designed to further our understanding of the mechanism by which α -synuclein undergoes abnormal fibril formation and accumulates in oligodendrocytes to form glial cytoplasmic inclusions (GCIs) in

MSA. This is important because we have previously shown that the number of GCIs increases with the duration of disease and that increasing numbers of GCIs correlate with the degree of nerve cell loss.

The aim of this project had been to explore the role of several proteins that may play an important part in the formation of GCIs in MSA. The proteins chosen for study were LRRK2, parkin and parkin co-regulated gene (PACRG). These are thought to be important in the development of Parkinson's disease (PD) which has some similarities with MSA as in both diseases α -synuclein

accumulation is a key feature. We also wished to explore the role of astrocytic pathology in MSA. This is a neglected area although we know that astrocytic abnormalities are a fundamental part of the pathology of other parkinsonian diseases and our previous work had demonstrated that the astroglial response in MSA follows a similar pattern to that of GCI load. The award of this grant also enabled us to participate in projects aiming to establish the role of genetic factors in MSA; such projects often require the contribution of several centres.

In our study we showed that parkin is a component of some GCIs while LRRK2 can be identified in the majority of these glial inclusions and is also associated with degraded myelin sheaths which are thought to be an early pathological change in MSA. This may be important because LRRK2 is an enzyme that is able to add phosphate groups to proteins, possibly including α -synuclein, and phosphorylation of α -synuclein promotes the formation of abnormal insoluble fibrils of the type accumulating in GCIs. The question of whether astrocytes in MSA show increased expression of proteins implicated in the development of PD such as α -synuclein, parkin and PACRG had not been previously explored. Our results show that reactive astrocytosis in MSA is most severe in the pons (a region of the brain) and that increased GCI load in



One of the main objectives of the Trust is to improve the scientific understanding of MSA by funding medical research. I am delighted that this issue of *SMarT News* includes an article by Dr Janice Holton and Professor Tamas Revesz on the results of a one-year research project, funded by the Trust, which they carried out in 2008. This is an excellent example of the important work that we are able to fund thanks to the wonderful generosity of our donors.

I am also very happy to report that we have been able to advertise again recently, inviting applications for a further research project grant. This is in addition to the two three-year projects which we are currently funding – one by Dr Henry Houlden and one by Dr Holton and Professor Revesz which builds on their earlier work funded by the Trust. Our Research Advisory Panel will review the applications that we receive for the latest grant and advise us on how to respond. We will let you know the outcome in a future issue of *SMarT News*.

Darcy Hare, Trustee

“The new grant has enabled the appointment of a post-doctoral research fellow, Dr Zeshan Ahmed.”

the pons is related to an increase in astrocytosis in the putamen, an area of the brain that is often severely affected in MSA. We confirmed that there is no accumulation of α -synuclein in reactive astrocytes. PACRG could be demonstrated in approximately 80% of astrocytes in controls but there was only a mild increase in the number of PACRG immunoreactive astrocytes in the putamen in MSA despite considerable astrocytosis indicating that a sub-set of PACRG-negative astrocytes is selectively involved in the astrocytic response to disease.

In a genetic study the contribution of the glucocerebrosidase (GBA) gene to MSA was explored. Mutation of the GBA gene may sometimes be important in pre-disposing towards Parkinson's disease but our study has shown that

this is not the case for MSA. It has also been possible to contribute to a multi-centre study in which variants of the gene encoding α -synuclein which are associated with the development of PD were also shown to be associated with an increased risk of MSA.

This grant has provided resources for neuropathological studies in MSA resulting in a number of publications in high impact medical journals. The support of the Sarah Matheson Trust has been acknowledged in these publications. The grant has facilitated the development of research into MSA at the QSBB and importantly this has enabled a multidisciplinary approach including collaboration with genetic investigations. It also gave us the opportunity to establish collaboration with the Sydney Brain Bank, Australia, which is a centre with considerable reputation for research into parkinsonian disorders.

The work undertaken and the development of collaborations has paved the way for our on-going research in MSA and these studies have now been secured by the award of a further 3 year research grant by the Sarah Matheson Trust. The new grant

has enabled the appointment of a post-doctoral research fellow, Dr Zeshan Ahmed, who has considerable experience in neuropathological research into parkinsonian disorders and we look forward to providing further reports into this ongoing research programme in the future.

The QSBB is now a centre recognised for its contribution to neuropathological research into MSA and as a result of this Dr Janice Holton was recently invited to teach about the pathology of MSA at a course in Uppsala, Sweden. The purpose of the course, organised by BrainNet Europe and funded by the European Commission, was to promote the harmonisation of diagnostic approaches in neurodegenerative diseases including MSA and it attracted neuropathologists from across Europe.

**Professor Tamas Revesz,
Neuropathologist Director
and Dr Janice Holton,
Senior Lecturer/Consultant,
Queen Square Brain Bank, London**

A list of papers published or submitted for publication are available from the SMT office – call Linda on 020 7940 4666

Request for volunteers with MSA-P to take part in a London research study

The National Hospital for Neurology and Neurosurgery, Queen Square, London are looking to recruit patients with MSA-P to an MRI study.

They are currently investigating how new MRI techniques may help in diagnosing Parkinson's Disease (PD), Progressive Supranuclear Palsy (PSP) and Multiple System Atrophy (MSA). When patients first experience symptoms it can sometimes be difficult to make an accurate diagnosis. At the current time MRI scanning is useful for ruling out other problems (for example, strokes or tumours). Sometimes abnormalities are seen on scans that are helpful as they are very specific for one of the illnesses but this is not always the case.

New MRI scanning techniques include the use of stronger magnetic fields (3T rather than 1.5T) and looking at the brain in different ways, including so-called diffusion tensor imaging that measures how the structure of the brain is affected by disease.

They have been looking at these techniques in PD, PSP and controls and are looking to recruit 5-10 participants with Multiple System Atrophy with predominant parkinsonian features (MSA-P). The aim is to see if they can find new ways of reliably getting a diagnosis using MRI, and also to see if they can monitor the disease using MRI scans.

Participation would be entirely voluntary and would involve coming up to the National Hospital for Neurology and Neurosurgery in Queen Square, London for a morning where a scan could be performed. There would also be a clinical assessment. They would be able to reimburse travel expenses or arrange transport by taxi. It would be most suitable for those living within 60-90 minutes by car of central London.

Further details are available from Luke Massey (l.massey@ion.ucl.ac.uk). Those interested would need to be referred by their GP or local neurologist.

Pioneering new study uses innovative techniques to diagnose autonomic nervous system damage in overlapping disorders of Multiple System Atrophy, Parkinsons Disease, Lewy Body Disease and Pure Autonomic Failure

Dr Valeria Iodice recently joined the Neurovascular and Autonomic Medicine Unit (NAMU) as the first Sir Roger Bannister Clinical Research Fellow at Imperial College London. Dr Iodice has previously worked at the Mayo Clinic, USA, where she trained in neurodegenerative disorders associated with generalised autonomic failure, such as Multiple Systems Atrophy (MSA), peripheral autonomic neuropathies and focal or target-specific autonomic syndromes.

Dr Iodice will be working with other NAMU colleagues, Dr David Low and SMT Patron, Professor Christopher J Mathias. They will be using a combination of unique and innovative techniques to determine the early damage to the central and peripheral nervous systems to improve diagnosis of MSA, Parkinsons Disease (PD), Lewy Body Disease (LBD) and Pure Autonomic Failure (PAF), which all share similar symptomatology. MSA is mainly a preganglionic central disorder, while PD, LBD and PAF all have a postganglionic autonomic pathology, particularly at the start of the illness. The prognosis and various treatment strategies for MSA are different from PAF and PD so it is

especially important to improve the diagnostic accuracy in consideration of supportive and preventative aspects of care for the patients and their symptoms and for their relatives.

“The differential diagnosis between MSA and PD can be particularly complex and often only made a year or more from clinical presentation.”

The differential diagnosis between MSA and PD can be particularly complex and often only made a year or more from clinical presentation. A further complicating factor of MSA is that, in its early stages, it also shares similar symptoms with PAF. However,

by combining a battery of unique autonomic tests, Dr Iodice and her colleagues are to be able make a more accurate diagnosis earlier than previously possible. The team will examine the peripheral as well as the central autonomic pathways using a skin biopsy no more painful than a pin prick and several autonomic function tests.

This study will permit the delineation of pre- and post-ganglionic nerve damage and, moreover, will define novel biological markers to help make diagnosis in Multiple System Atrophy, Parkinsons disease, Lewy Body Disease and Pure Autonomic Failure at an earlier stage. This will help treatment and possibly, in due course, also our understanding of these disorders, especially Multiple System Atrophy.

Andrew Owens
Clinical Research Coordinator,
Imperial College London/Imperial
College Healthcare Trust

For further information about our studies or autonomic and neurovascular medicine, please visit:
<http://www1.imperial.ac.uk/medicine/about/divisions/neuro/npmdepts/clinneuroscience/neurovascular/> and
<http://www1.imperial.ac.uk/medicine/people/c.mathias/>.
 Or contact Andrew Owens at a.owens@imperial.ac.uk or Neurovascular and Autonomic Medicine (Pickering) Unit, 2nd Floor QEOM Wing, Imperial College London, St Mary's Hospital, South Wharf Road, London, W2 1NY

New office address

As from 1st November 2009 the SMT office contact details are:

Sarah Matheson Trust, Southbank House, Black Prince Road, London SE1 7SJ

Tel: 020 7940 4666 Fax: 020 7940 4664 Email: office@msaweb.co.uk

Request for volunteers take part in RESULT, a Birmingham research study

The RESULT study is looking at service provision for people with rare long-term neurological conditions. 'RESULT' stands for Review of Epidemiology and Service Use in Rare Long Term Neurological Conditions. People with rarer progressive neurological conditions have complex needs requiring specialist expertise and resources, yet little is known about the incidence, prevalence, course of disease and burden to patients, families, health and social services. People with conditions such as motor neurone disease and Huntington's disease report variations in services. Little is known about continuity of care and how diversity (ethnicity, gender, age) influences care. The findings of the study will provide the information required to assist service planning and inform the implementation and audit of the National Service Framework for Long-Term Neurological Conditions. Specifically, the study will be focussing on people with Motor Neurone Disease (ALS), Huntington's Disease, Multiple System Atrophy, dominantly inherited ataxias, Progressive Supranuclear Palsy, Post Polio Syndrome, and Charcot Marie Tooth Disease. This study aims to investigate the current provisions of care and treatment and how they need to change.

Why get involved in the Reference Panel?

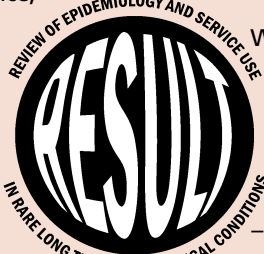
It is important that any health care research is done in partnership with people who either have direct experience of the health condition/the health or social care services or who cares for someone who does. This helps us ensure the research is relevant to the people who use those services and that new information can be quickly shared with the wider community.

We are inviting people with long-term neurological conditions or people who care for someone with

long-term neurological conditions to work with us on this project.

How do I get involved in the Reference Panel?

There are a number of ways you can get involved and the amount you get involved is up to you – there is no right or wrong way.



We want to set up a national panel of patients and carers who will work with us in different ways across the whole project. About 10 people will be invited to be part of this panel. The panel will exist as a 'virtual' group which means anyone from across the country can be part of it – location doesn't matter. We will set up an email or telephone link (it depends upon who is taking part) so we can talk to each other.

The Reference Panel will play an important role in this project. It will support a number of different activities as the project develops. For instance people have already helped us to draw up participant information leaflets that have been used to guide people through Phase I of the project. A main role of the panel will be to look at the information coming from the project to see how we can share it usefully with other patients and carers.

Before you agree to be part of the panel, we will talk with you about how you can get involved. You can take part in some or all of the activities – you tell us what and when you want to take part.

We are able to pay you for your time and travel costs whilst working on this project.

Are you interested? Do you want to know more?

Then please contact: Sonal Shah, Primary Care Clinical Sciences, University of Birmingham, Edgbaston, B15 2TT. Tel: 0121 414 8585. Email: s.shah.1@bham.ac.uk

In Memory for 2009

This edition of *SMarT News* covers the period until 30 September 2009. If you have informed the SMT of a loved one's death and their name does not appear below, please accept our apologies. Let us know and we will rectify this in the next edition. Some members passed away earlier than 2009 and the corresponding year is shown in brackets next to their name.

- | | | | |
|-------------------------|---------------------------|------------------|-------------------------|
| • Hilary Anderson | • David Haight (2008) | • Malcolm Payne | • Kenneth Spencer |
| • William Bailey (2008) | • Robert Hale | • Alan Ramsden | • Syd Stephenson |
| • Graham Bartlett | • Terry Layton | • Susan Rowley | • Joy Trigg |
| • Christopher Bourne | • Errol Litherland (2007) | • David Simpkins | • Harry Wilcocks (2008) |
| • Peter Brannan (2006) | • Valerie McCullum (2006) | • Bruce Shepherd | • Robert Youd (2008) |
| • Cornelia Coughlin | • Robert Mettam | | |
| • Michael Cox | • Roy Moore (2007) | | |
| • Margaret Crossman | • Clive Morgan | | |
| • Gerry Cusack | • Mark Mortimer | | |
| • Malcolm Done | • David Newman | | |
| • Celia East | • Wayne Norris (2008) | | |
| • Paul Edwards (2005) | • Nessa Oldershaw | | |
| • John Gould (2008) | • Mike Owens | | |

muchloved.com

muchloved.com is a website dedicated to offering personalised website tributes in memory of a loved one. MuchLoved is a UK registered charity set up to help with grieving and healing. The website can be used without charge or obligation. To visit the website go to www.muchloved.com

Continuing regional support

Regional Support Groups provide a fantastic service to SMT members, are generally run by volunteer members and are greatly appreciated by those able to attend. We are very grateful to those members

who put in so much time and hard work in organising and running the eight existing groups, all of which go from strength to strength. We would very much like to expand the coverage of local groups – it would be fantastic

if everyone in the UK had the option to attend a group without having to travel too far.

If you are interested in setting up your own local support group please contact Linda on 020 7940 4666 for

Regional Support Group Contacts

Further information on support groups can be found on the SMT website (www.msaweb.co.uk/) under 'our services'.

Region	Contact point	Contact details
Cornwall Group Meets 4 times per year	Mrs Jane Handy Tel: 01726 74792 Or, Ms Jan Pearce Tel: 01726 861361	In the first instance, please phone or email Moonbeams@ymail.com
Devon Group Meets 4 times per year	Dennis Westrip Tel: 01271 378273	In the first instance, please phone
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	Lady Laurelie Laurie Tel: 01206 210 410	The Old Rectory, Little Tey, Colchester, Essex CO6 1JA
Gloucester Group Meets (possibly) twice per year	Ms Janice Davies Tel: 01242 224617 www.thehewlett.co.uk/index.htm	The Hewlett, Harp Hill Cheltenham, Gloucester GL52 6QG
Greater Manchester Group Meets (possibly) 3 times per year	Samantha Pavey Tel: 020 3371 0003 Samantha.msa@googlemail.com	In the first instance, please phone or email
Lancashire & Merseyside Group Meets 4 times per year	Mrs Ann McLennan Tel: 01704 568 353 annandon@btinternet.com	72 Lynton Road Hillside, Southport PR8 3AP
Yorkshire & Humber 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

relevant information and guidance on how to start one up.

This summer saw the inaugural meetings of the Devon Group and the Greater Manchester Joint Support Group. Both were very well attended and obviously a great success. Many

thanks to Dennis and Betty Westrip for starting up this much needed group in Devon and saving members a long drive to Cornwall.

Also many thanks to Samantha Pavey, Patsy Cotton and Maggie Rose for setting up and attending the

Greater Manchester meeting. A number of groups have meetings arranged for October, by which time this newsletter will be at the printers. There will be lots to report on regional group meetings in the Spring 2010 issue!

Devon

The Devon support group held their first meeting on Friday 24th July 2009 at Tomlin Hall in Bickington, North Devon. We had a great start with 11 people attending. It was a pleasure to welcome Samantha Pavey, the SMT's Nurse Specialist, who gave everyone a very informative talk and slide show and then answered questions about MSA,

which was appreciated by all the members present.

As we only had two hours there was not a lot of time to discuss any other issues. I am sure we can make up for this at the next meeting.

A big thank you to Jan and Jane from the Cornwall support group who came all the way up from Cornwall to give us support and help; thank you to

Jane who baked a cake. Tea and coffee with snacks were available to welcome everyone to the meeting. It was agreed we would hold meetings about four times a year with the next one to be held at Cullompton at the Baptist Church, High Street, Cullompton, EX15 1AJ on Friday 6th November 2009 at 2.30pm. We hope to see everyone there next time.

Dennis Westrip

Cornwall

In July we went to the inaugural meeting of the North Devon Group, set up by Dennis and Betty Westrip, and were delighted to meet them again, along with Samantha Pavey, SMT's Nurse Specialist, and the other MSA families who came along. We wish the new group continued success.

We now feel we can focus on people in Cornwall, and the Devon people who are nearer to us than they are to

Barnstaple. As usual, it's the phone calls and emails that keep our group going, as although Cornwall looks small on the map, it's 100 miles from end to end, with a very scattered population.

We feel fortunate to have befriended two Parkinson's Nurses, who are very interested in what we are doing, and have the medical expertise that we do not. However they are learning from having MSA patients within their remit, and from the various experiences that

each of our group has to tell.

We are currently researching where best to hold our next meeting, probably in October/November, and will write to all within our catchment area when arranged. However, we would be delighted to receive any enquiries from anyone from outside of Cornwall who may be visiting – please use the usual contacts. We would be delighted to hear from you.

Jan Pearce & Jane Handy

Greater Manchester

The first Greater Manchester Joint Support Group meeting took place on 11th September at BASIC, 554 Eccles New Road, Salford, M5 5AP. This was instigated by Patsy Cotton, Advanced Nurse Practitioner, who works with people living with Parkinsons disease, MSA and PSP. We are very grateful for her hard work in setting this up. I attended as did Maggie Rose, Nurse Specialist from the PSP Association. In the morning local professionals were invited to a study session where each of the nurses spoke about their speciality and Dr Dick, Consultant

Neurologist, gave an overview of MSA and PSP. We were treated to a nice buffet lunch followed by the afternoon support group. We welcomed 19 people with MSA and their families and feedback was positive. We are aiming to repeat the

support group meeting on the afternoon of 2nd December at the same venue. Contact the office/Samantha for more details nearer the time. Depending on demand we would aim to run this group meeting three times a year.

Samantha Pavey

Area contact scheme re-established

In the last issue of *SMarT News* we reported that we have re-launched the contact scheme and it is now up and running. The scheme is telephone and/or email based and is open to all members, their families and carers. If you would like to be put in touch with someone in your area, please contact Linda in the office on 020 7940 4666 to request a registration form and leaflet that explains the working of the contact scheme.

Thanks to everyone who has raised funds for us. We are always amazed and genuinely appreciative of the wide-ranging efforts that SMT members and their families make in fundraising. Here are some recent achievements.

Sophie cycles for her Granddad

Last year, Sophie MacInnes sadly lost her Granddad, Don MacInnes, to MSA. Sophie, who is nine, decided to organise a sponsored cycle run by herself for her and her friend, Rebeka. She compiled the sponsor forms on the computer and managed to raise a brilliant £350. Sophie was very close to her Granddad and wanted to do something to mark his memory. Thank you Sophie!



Sophie MacInnes (left) and Rebeka

North Curry Community Coffee Shop – call in for a coffee!

North Curry Community Coffee Shop is run for the benefit of the community by volunteers who nominate a charity or local organisation that they wish to receive a cash benefit in proportion to the time they spend working for the coffee shop. Three volunteers designated the Trust and we received a cheque for £72.30. A huge thanks to the coffee shop for their generosity. Do call in for a coffee if you are in the area (North Curry is near Taunton in Somerset) and tell them you read about their support in *SMarT News*.

Laura's Fancy Dress Party

Laura Fergusson's Dad suffers from MSA. When she recently celebrated her 40th birthday with a fancy dress party, she asked for donations to the Trust to show her family's appreciation for all the help given by SMT. She sent us a

Car boot sale for SMT

Nicola Davison's mum, Wendy Horniman, passed away in January 2009. On 5th July Nicola, her son and daughter, aunt and a friend ran a stall at a car boot sale and raised an impressive £212.59 for the Trust. Wendy writes that her mum would have been proud of them all and, as they had so much fun at the car boot sale, they are going to do it again next year. A big thanks to you all and good luck for next year!



Nicola and family at the sale



Guests at Laura Fergusson's party

very generous cheque for £178.45 and some great photos. It looks like it was a terrific party and we chose to print the one above of some very jolly pirates! Many thanks to Laura and all the partygoers for your wonderful donation.

Francesca Abseils for the Trust

In July, Francesca Alcock did the MEGA Ipswich Hospital abseil in aid of the Trust and raised £112 – the

picture below proves it! Francesca chose to give the money to the Trust as her aunt had passed away from MSA earlier in the year and she wished to contribute to the support given to sufferers and their families. Well done Francesca – looks very scary!



Francesca Alcock

Les & Joyce Ward organise yet another event!

Les and Joyce Ward have organised another event to raise funds for the Trust in memory of their daughter Linda Stone. On 25th July Elaine Gibbs hosted a coffee morning and was supported by members of the Croft Singers choir. They raised a wonderful £221.69. A huge thanks to everyone who helped make the morning such a success.



Jean Beales, Molly Booth, Les Ward, Elaine Gibbs and Joyce Ward

Keira and friends run the Belfast Marathon

Keira Davidson's Dad, Joe, was diagnosed with MSA in 2003 and she, her family and friends wanted to do something to support the work of the Trust. In May 2009 Keira and her work colleagues Jenny Neil, Patrick Dewar, and Angela and Peter Boucher from ASM Horwath Chartered Accountants successfully ran the Belfast marathon as a relay team. They raised a fantastic £1,486.50 plus Gift Aid. A special thanks to all involved and especially the runners.



Keira and colleagues

Great Scottish Run – a busy weekend for the Troy family

Again this year the Troy family have raised money to support the Trust. On Saturday 5th September Matthew, Kelly and Holly were joined by their cousins, Sarah, Corrie and Robbie, on the Junior 3k Great Scottish Run in memory of their grandmother who died from MSA. The next day their mother, Anne, ran the half marathon in the pouring rain. Together they raised a terrific £225 – a big 'thank you' to the sponsors and especially the runners. Sadly, no photo of Anne as she felt the drowned rat look does not make a good picture!



The Troy family left to right Corrie, Holly, Matthew, Kelly, Sarah and Robbie

Line Dancing in Inverkeithing!

Jean Croly, whose husband John died five years ago of MSA, nominated The Sarah Matheson Trust to the Inverkeithing Tuesday Line Dance Club as one of their chosen charities to receive a donation raised from social evenings and raffles. The Club has sent us a very generous cheque for £250 to help support research and awareness of MSA. A very big thank you to Jean and all the members of the Tuesday Club.

Cycle2cannes

On Thursday 17th September cycle2cannes launched the 2010 ride that will start in London on 11th March and finish at MIPIM (a major property world exhibition) in Cannes on 16th March. The launch included the first of

four Rollapaluza evenings where two cyclists battle it out on a pair of custom rollers connected to a huge dial over a simulated distance of 500m at speeds in excess of 50mph. Readers will remember from the last issue that cycle2cannes generously gave us £20,000 from the 2009 ride and they will again be raising money for SMT in 2010 – along with four other charities.



Rollapaluza in action!

Walking the Illuminations

The HASSRA Fylde Rambling Club has chosen the Sarah Matheson Trust as its charity of the year and is supporting Jas Hans, who has MSA. Jas and his wife, Jo, attend the meetings of the Lancashire & Mersyside Support Group in Southport.

So far they have organised a tombola stall at a local fun day that raised £146 and on the 17 September a group took part in a sponsored walk through the Blackpool Illuminations. Jas was able to take part on his mobility scooter and asked people to sponsor him instead of giving him gifts for his 65th birthday in August. The final total raised is not yet known, but it should be over £600. What a great achievement!

Two further events are in the pipeline one of which is an 'Olympic Games', so everyone is in training! A massive 'Thank You' to Jas, Jo and all the members of the Club for their fantastic support.



Waitrose Community Matters

Waitrose Community Matters is a scheme by which branches donate £1,000 between three local good causes each month. When customers pay for their goods at the checkout, they are given a token. They then choose which one of the three good causes they wish to support. At the end of the month, each cause receives a proportion of the £1,000. In August, the office put forward the Trust as a good cause at the Edgware Road branch of Waitrose in London. We received £306 – many thanks to

Waitrose! If any of you want to nominate the Trust at your local branch, pick up a nomination form in store.

Fundraising down under!

Jessica Kelly, age 11 years, lives in Carnegie, Australia, and wanted to raise money to help people with MSA. At her school pupils had to choose a charity for a project with the title 'Making a Difference in the Community'. Jessica and her friend, Mathilda, baked cakes for a student market and raised \$90. She could not find an appropriate organisation in Australia and her mother, Janet, suggested she donated the money raised to the hospital where her dad, Graeme, stayed for the eight months before he died from MSA. Jessica spoke to the head nurse at the Bethlehem Hospital who suggested the money be used to purchase a DVD player and some DVDs for the common room. To help raise awareness of MSA her teacher organised for her to be interviewed by the local paper about why she wanted to raise the money. Well done Jessica and Mathilda. It's good to hear of events in Australia and thanks to her mother, Janet, for keeping in touch with us.



Jessica Kelly and Mathilda

We are very grateful for all your fundraising activities.
The Treasurer puts in a small plea however. Could any cheques be made payable to 'Sarah Matheson Trust' (not MSA).

Posters for fundraising events

And remember, the Trust has produced an A3 size MSA/SMT poster for anyone wishing to use it for fundraising. We send them out in protective cardboard tubes. The posters have been welcomed by those who have requested a display that describes MSA and the work of the Trust. Please feel free to phone the office, if you would like one: 020 7940 4666.



...and don't forget we have boxes and badges available too.

Christmas Cards 2009

Now Available to Order!



Moonlit Night



Parcels Under the Tree

This year we have two new designs – “Moonlit Night” and “Parcels Under the Tree”. They are available in packs of 10 for £3.50 plus postage. The greeting inside reads “With Best Wishes for Christmas and the New Year”

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,
Southbank House,
Black Prince Road, London SE1 7SJ

Thank you for your support.

Number of packs	Total cost including postage
1	£4.25
2	£8.85
3	£12.35
4	£16.25
5	£20.20
6	£23.70
7	£28.90
8	£32.40
9	£35.90
10	£39.40

Either cut here or photocopy

Sarah Matheson Trust Christmas Card Order

Name

Address

.....Postcode.....

Telephone no.

Moonlit Night

No. of packs

Total payment enclosed £

Parcels Under the Tree



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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Mrs Ann McLennan
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Karen Walker

SMarT News Editor:

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Tel: 020 7940 4666

Fax: 020 7940 4664

www.msaweb.co.uk

The Trust is financed entirely by voluntary donations.

Registered Charity Number 1062308

**Membership Numbers
as of September 2009**

Current MSA members	825
Other patient members	38
Relatives and carers	464
Professionals	1465
Others	174
Total	2966

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 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 an *in memorium* for 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.

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. 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.

Don't forget: the SMT is your charity.

Donate now!

If you would like to make a donation to the Sarah Matheson Trust please complete the form below and send to the office. If you are a UK taxpayer we can increase the value of your donation by 28% by reclaiming the tax as Gift Aid.

Name _____

Address _____

_____ Post code _____

Signature _____ Date _____

☐ I would like to make a regular donation by standing order.
Please send me the appropriate form.

☐ I would like to make a donation of £ _____
and enclose a cheque made payable to 'Sarah Matheson Trust'.

☐ I am a UK taxpayer and wish all gifts of money that I have made in the past 6 years and all future gifts of money that I make from the date of this declaration, until I notify you otherwise, to be treated as Gift Aid donations.

PLEASE MAKE ALL CHEQUES PAYABLE TO 'SARAH MATHESON TRUST'

Next issue All articles to be received by the office by 15th January 2010

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