Issue 21 Winter 2007

SMarT News

The newsletter of the Sarah Matheson Trust

Contents

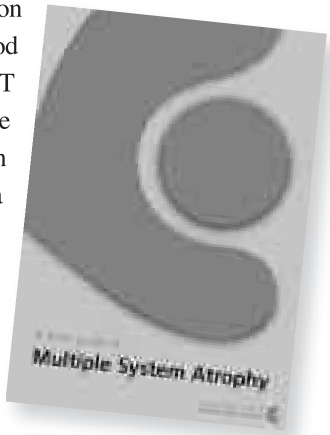
The Sarah Matheson Trust provides a support and information service to people with Multiple System Atrophy (MSA) and other autonomic disorders, their families and carers, health care professionals and social care teams.
We also sponsor and support research into MSA

From the Office

Welcome to the long awaited SMarT news. I am told that an apology is not the best way to engage readers however I offer one here for the delay in getting the newsletter to you, in the hope that the content will make the wait worthwhile. There have been several staff changes in the office which have contributed to the delay. This is unavoidable with an office in the centre of London but is resolving even as you read.

This edition has a focus on health and disability information. Information is important in helping people learn about, cope and adapt to any medical diagnosis but the advent of the internet means that people can experience ‘information overload’. Our feature article, Finding Information, written by Bridget McCall a health journalist and long time supporter of the Trust, looks at sources of information useful to our readers and suggests ways to tell if its valid, good quality or reliable information. You can reread the SMT information with Bridget’s advice in mind and see how we measure up. If you have any suggestions, comments or even criticism about the information let us know as feedback is a good way to improve our service.

The blue and orange booklet a ‘Guide to MSA’ was originally written for people with MSA and their families but health professionals really appear to like it. It seems that even health professionals are at risk of ‘information overload’ and the guide helps prevent this. It does contain a lot of information but it is easy to access and can be read in sections. Informed health professionals provide better care which is what we all want. With this in mind the guide is available to all health professionals free of charge. Encourage anyone involved in your care to have a copy. They can contact the SMT office to get the guide and other information free of charge or you can request extra copies to give out.



Catherine Best, Nurse Specialist

Government Petition

My husband Christopher was diagnosed with MSA in Dec. 2005 having first been diagnosed with PD in Feb 2005. Through a meeting in Liverpool recently organised by Catherine Best we were able to meet up with one or two other people with MSA.

Being able to talk to others affected by this dreadful illness has helped enormously but one thing that frequently crops up in conversation is how rare this illness is and more importantly the lack of knowledge that hospitals and GP surgeries have about it. I'm sure you know that it is distressing for families that a loved one has to be admitted to hospital to be met with blank faces and little support.

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I have set up an E-Petition on the 10 Downing St website which is petitioning the Prime Minister to create awareness in all hospitals and GP surgeries about MSA. The petition is running until April 2008. The petition which reads, 'We the undersigned petition the Prime Minister to Create awareness in all NHS hospitals and GP surgeries about the debilitating neurological disease Multiple System Atrophy' can be found at: http://petitions.pm.gov.uk/Neurological/

Our own GP Rob Caudwell has signed it. I have contacted my local MP John Pugh and he has agreed to sign it. Chris's daughter Catherine has been in touch with her MP Mike Wood and he in turn has written to the Secretary of State. If we get enough signatures we might be heard!

We do feel that support is growing and I would be delighted if Sarah Matheson Trust members sign the petition. You all know about this illness and how debilitating it is and how difficult it is for families who are directly affected by it.

Christopher and I can't make a difference on our own but we both feel that this is the best way we can create awareness about it. Thanking you all in anticipation.

Karen Haigh

Message from the Trustees

To All Our Readers: We apologise for the long delay in getting out this latest edition of SMarT news. We have had a number of staff changes in the office in recent months and this has resulted in some disruption to the normal level of service we try to provide to all of you.

We greatly regret this and hope to be back up to speed soon. Sadly we are losing our long serving Nurse Specialist Catherine Best, who is moving on to a post in full time patient care at the National Hospital for Neurology. Catherine's contribution to the Trust has been invaluable and she will be much missed. We are in the process of recruiting a replacement. In the meantime the office will be manned, part-time but very ably, by Linda Campbell, a long time friend and supporter who has served as our office administrator in the past. We welcome her back and thank you for all your patience and understanding as we rebuild our team.

Eileen Strathnaver,
Chair of Trustees Carers

Our sympathies

The Trust is deeply saddened by the death of one of our Medical Advisor Panel members Professor John Michael Newsom-Davis in a road accident in August.

Professor Newsom-Davis was a respected neurologist and pioneer of neuroimmunology. He was Professor of clinical neurology at Oxford (1987-98) and one of the most distinguished clinical neurologists and medical scientists of his generation. He was best known for his work on myasthenia gravis and related diseases but became involved in the Sarah Matheson Trust when a family member was diagnosed with MSA. His great neurological knowledge and experience coupled with his enthusiasm for research were a wonderful combination to the advisory panel and will be greatly missed.

Our deepest sympathies are extended to John's family.

A Strange Experience

Have any of you been to Geneva lately? There is a good reason for asking this seemingly strange question. My wonderful husband Donald died in June 2006 after being in palliative care for almost two years and as a family we are very strong supporters of the Trust and I always try to wear the Sarah Matheson Trust (SMT) badge.

In December 2006 I went to Geneva with two friends for a weekend break. On our last morning we went into the main store, Globus, and decided to start at the top and work our way down. On the last escalator I felt something under my foot. When we got to the top we examined what I felt under my shoe. It was a SMT lapel badge!

As we all know SMT is a relatively small organization so what were the odds of me stepping on that particular step, on that particular escalator and finding a SMT badge in a store in Switzerland exactly six months since Donald had died? Needless to say we were all quite emotional and had to have some moments to come to terms with what we found. I like to think that Donald was with me in the store thinking 'what is she going to buy now!'

So if you have been to Geneva and lost your badge, rest assured that it has been found. It is good to know that other people are wearing badges and supporting what is a fantastic charity.

Ann McLennan

New Deal for Carers

The government has announced a £33 million package of support and services for carers in England as part of a commitment to updating and extending the National Carers Strategy. The package, which has been labeled the 'New Deal for Carers', consists of three parts:

- £25 million for local authorities to spend on providing short-term home based respite care for carers in crisis or emergency situations;
- £3 million to set up a national helpline for carers;
- £5 million for an Expert Carers Programme to provide training for carers in how to better manage both their own health and that of the people they care for.

Welfare Reform

Part of the government's welfare reforms planned for November 2008 involves changes to Incapacity Benefit and Income Support (for incapacity for work). As many carers receive these benefits in their own right you may have concerns about the changes. The following information may answer some of your questions but if you find you need further help please see the 'How to find out more' section at the end of this article.

I already get Incapacity Benefit. What will happen to me in 2008?

Those already getting Incapacity Benefit and or Income Support (for incapacity) will remain on those benefits. However, it looks as if existing claimants will eventually be transferred onto a new allowance called Employment and Support Allowance. The time scales for when this will happen have not been announced yet.

Employment and Support Allowance (ESA)

ESA is the new benefit which will replace Incapacity Benefit and Income Support (for incapacity) for new claims from November 2008. It will have contributory and means tested parts. People will be able to claim on the basis of their National Insurance contributions, on low income grounds or both. Currently, in order to claim a benefit through the 'incapacity route' a claimant must satisfy the Dept for Work and Pensions that s/he is incapable of working. Most people have to do this by satisfying either the Own Occupation test or the Personal Capability Assessment.

How will the ESA work?

All new claimants from November 2008 will have to apply for ESA instead of Incapacity Benefit or Income Support (for incapacity). The basic rate of the allowance, which is equivalent to Job Seekers Allowance, will be paid for up to 13 weeks. During this time the claimant will attend a work-focused interview and go through a revised version of the Personal Capability Assessment. Claimants assessed as being capable of 'work related activity' will then receive an additional component as long as they comply with certain conditions. Some people with severe disabilities will get a different additional component with no conditions attached. Some claimants will get extra amounts paid with their ESA if they get Disability Living Allowance or Attendance Allowance.

What is the revised Personal Capability Assessment (PCA)?

The new PCA has been redesigned to look more at what a person can do and what 'interventions' would help a person back to work. The mental health part of the assessment has been extensively revised to make it more like the physical health assessment. The claimant will need to score 15 points on either physical health or mental health grounds in order to be found incapable of work. There are a few circumstances where a claimant will be treated as having limited capability for work, but there are no plans to exempt people from the new PCA. The second part of the new PCA assesses whether a claimant has "limited capability for work related activity" due to "a severe level of functional limitation". Some claimants will be treated as falling into this group because of their condition.

Claimants who pass this part of the new PCA will get the additional support component. Claimants who are assessed as being capable of work related activity will get ESA with the work related activity component. Claimants aged 18+ in this group are also subject to the third part of the new PCA which is the requirement to attend a work focused health related assessment.

Warning! In all cases, failure to attend an assessment without good cause may lead to benefit being stopped or reduced.

This information was written by Newcastle Welfare Rights Service and was included in the Autumn Carers Newsletter produced by the Newcastle Carers Center. To find out more about the center, its range of services or to get a copy of their newsletter please contact:
Carers Centre Newcastle, 6 Saville Place, Newcastle upon Tyne NE1 8DQ.
Telephone 0191 260 3030
Fax 0191 230 150
Email:CarersCentreNewcastle@btconnect.com
Web:www.newcastlecarers.org.uk
For other information about the New Deal for Carers or benefit changes please contact www.direct.gov.uk or the National Benefits helpline 0800 882200

Finding and Assessing

Bridget McCall highlights some general health and disability information sources and discuss the issue of medical information in the media and how you can best identify valid materials.

When you are living with MSA, having appropriate information on areas of health and care that affect you can make a big difference to you ability to cope. This might include resources on:

- The nature of MSA, its treatment and management
- Services available to help you
- Self-help strategies
- Useful organisations
- Family support
- Research.

Finding the right resources is often a matter of identifying what you need, what is available from where and how to access it. Although we hope that the Sarah Matheson Trust has in the last ten years made the search for MSA information less difficult, locating materials on wider health and care issues tends to be very variable. Sometimes it isn't that there is a dearth of information, especially now the Internet has made huge amounts of material available to anyone with access to a computer. Instead the problem is sifting through it and determining what is accurate, up-to-date, evidence-based information and what is suspect.

General sources of information

Healthcare

The NHS has an information service for patients in England, Northern Ireland and Wales called ***NHS Direct***. If you are a member of your family fall ill or you want some general information about health services or conditions, you can phone their 24-hour nurse-led telephone information service for advice. Local rate charges apply. If you live in Scotland, there is a similar service, ***NHS24***. The NHS Direct website is also a useful resource for information on health conditions and issues – www.nhsdirect.co.uk.

On a local level, all primary care trusts have Patient Advice and Liaison Services (PALS). These aim to:

- Provide you with help and information on local health care services and support agencies
- Offer practical advice to help resolve difficulties that you may have when using any NHS services or if you don't know how to access them
- Give you a say in your own care and how your local services operate.

Your local primary care trust, GP surgery or hospital should be able to provide you with contact details for your local PALS.

Voluntary organisations

The Sarah Matheson Trust is one of an enormous number of UK voluntary organisations that cater for a very broad range of need and interests. They usually operate independently from government or business on a self-governing, self-funding (through donations and fundraising initiatives) and not-for-profit basis. Although many have paid staff, they often rely heavily on volunteers to help them run their activities.

It is worth remembering that as well of those that concentrate on specific medical conditions, there are many that focus more generally on health and disability that may be able to provide you with the support and advice you need. Examples include those concerned with:

- **Ageing**, such as Age Concern (www.ace.org.uk), Help the Aged (www.helptheaged.org.uk), Counsel & Care (www.counselandcare.org.uk)
- **Disability** issues such as equipment and rehabilitation, including the Disabled Living Foundation (www.dlf.org.uk) and the Royal Association for Disability and Rehabilitation (RADAR – www.radar.org.uk)
- **Carers organisations** like Carers UK (www.carersuk.org), Princess Royal Trust for Carers (www.carers.org) and Crossroads – Caring for Carers (www.crossroads.org.uk).

Citizens Advice help people resolve their legal, financial and other problems by providing information and advice free of charge. They can also signpost you to other sources of local and national help. They provide independent advice from over 3,000 locations including bureaux, GP surgeries, hospitals, colleges, prisons and courts. This can provided face-to-face or by telephone. Most also offer home visits where necessary and some also have email services. They also have an Internet advice guide (www.adviceguide.org.uk), which

Information

includes frequently asked questions in a number of community languages. The number of your local bureau should be in the phone directory or available from your library. You can also find them on the Citizens Advice website – www.citizensadvice.org.uk.

If you want to locate voluntary organisations that may be able to help you with particular needs, the National Council for Voluntary Organisations publishes the Voluntary Agencies Directory, an annual reference guide to over 2000 national charities and organisations connected to the voluntary sector (see www.ncvo-vol.org.uk). See also Charity Choice published annually by Waterlow Professional Publishing or available online at www.charitychoice.co.uk.

Patient UK is useful online resource produced by Drs Tim and Beverley Kenny, two GPs who work in Tyne and Wear in England. This evidence-based website provides a wealth of information on health conditions, maintaining a healthy lifestyle and contact details for many voluntary organisations. See www.patient.co.uk

Health information and the media

Health and science articles are extremely popular media items. As wonderful as it is to have so much information at your fingertips, this availability has created a new problem in its wake. Although lots of publications and websites provide excellent material, many others contain questionable material or make dubious, but persuasive, claims.

This situation is exacerbated by the fact that we now live in a 'new age' that has resulted in a huge interest in complementary therapies. This interesting area of health has many genuine practitioners and valid disciplines, but also attracts people peddling all sorts of "miracle cures". Many of these are marketed in a way that makes them seem more credible than they are, often making claims that "research has proved their efficacy". Even if this is true, there are different levels of research and sometimes the 'proof' is based on very flimsy or questionable standards. Providing a long list of references is no guarantee of quality!

Tips for assessing medical/health information you find

You may find it helpful to use the following checklist when assessing any information you find on the Internet or anywhere else.

- **Who produced the information and why?**
  Does the website clearly state its aims and objectives; who produces the information with details of their expertise and qualifications; charity number (where appropriate); and contact details? Do they subscribe to any codes of practice such as HON or DISCERN.
- **How current is the information?**
  Is there a date provided so you can ensure the information is up-to-date?
- **What sort of language is used?**
  Is the information balanced and unbiased or is it sensational and emotional?
- **What is the purpose of the information?**
  Is it aimed at simply providing you with information or does the purpose seem to be to encourage you to buy a product or service? Is the website sponsored by particular commercial organisations. If so, does it seem biased in favour of their merchandise?
- **What evidence is it based on and does it clearly state this?**
  For scientific research double-blinded randomised controlled trials are the gold standard. They should also be published in peer-reviewed journals (i.e. where the quality of the research has been assessed before publication).

  Personal (sometimes called anecdotal) experience can be very valuable especially in providing opportunities for exchanging ideas and providing mutual support but should not be used by itself as 'proof' that a product works. It is important that websites make it clear when information is based solely on this. Remember that medical conditions often affect people differently so your experience may be very different from someone else's.
- **Is the information from the UK or abroad?**
  Information from other countries can be very interesting but may not be relevant to the UK. Drug names and other details may also differ.
- **Check anything you are concerned about with your doctor.**
  If you want to try a complementary therapy, check with them that there are no contraindications between this and any treatments that you are already receiving.

A study by Dr Katja Schmidt and Professor Edzard Ernst at the Peninsula School of Medicine at Exeter University demonstrated how faulty the advice and claims made for some products can be. They analysed 32 popular websites that give advice and information on various complementary therapies used to treat cancer and found that a significant amount of these were a risk to people with the condition. Out of 118 cancer 'cures' of a complementary therapy nature that were recommended on these sites, none could be demonstrated to cure cancer and some of the advice offered was potentially harmful. However, two sources of excellent information on complementary therapy research were identified – ***Bandolier*** and ***Quackwatch***.

Bandolier is an independent journal and website about evidence-based healthcare written by Oxford scientists. On their website, they say that "the impetus behind Bandolier was to find information about evidence of effectiveness (or lack of it), and put the results forward as simple bullet points of those that worked and those that did not: a bandolier with bullets". For more information see www.jr2.ox.ac.uk/bandolier

Quackwatch is a non-profit organisation, run by Stephen Barrett who is a retired doctor. Based in the USA, it has an international focus and attempts to "combat health-related frauds, myths, fads, and fallacies". See www.quackwatch.org

See the panel for more information about complementary therapies.

Other guides to medical information in the media

In recent years the issue of medical information and the media has attracted considerable concern from a number of organisations and individuals who have developed resources to help the general public.

The British Medical Association (BMA) publishes a guide to 'Finding reliable health information on the internet' on its website – see www.bma.org.uk/ap.nsf/Content/healthinfonet. This provides some guidelines and references to other sources that provide guidance on searching for health information. These include the Health on the Net Foundation (HON), a not-for-profit organisation, based in Switzerland, which seeks to help lay people and healthcare professionals to find reliable online health information. Many health websites carry the HON quality mark given to sites that follow their guidelines – see www.hon.ch.

The British Medical Journal (BMJ) has also recently launched a website called Best Treatments that aims to provide evidence-based information to lay people – see www.besttreatments.co.uk

Contact a Family is a UK voluntary

What are complementary therapies?

Complementary therapies are non-conventional health treatments, often based on ancient systems, which may be used in addition to conventional medicine. Examples include acupuncture, the Alexander technique, aromatherapy, ayurveda, creative therapies (involving art, music, dance or drama), chiropractic, conductive education, herbal medicine, homeopathy, osteopathy, Pilates, reflexology, tai chi, and yoga.

Why are they so popular?

Complementary therapies are particularly popular among people who have long-term conditions, such as MSA and Parkinson's disease. This is partly because although conventional medicine can provide good symptom relief, it does not always provide all the answer. Most people want to do all they can to help themselves and turn to complementary therapies as a possible solution to their difficulties.

Sometimes people also become disillusioned with mainstream medicine, while others are simply reluctant to take drugs and view complementary therapies, especially herbal medicines, as a more 'natural' option. This latter point is debatable as many conventional medications are plant-based. Even when they are synthetic, this does not mean that they are inferior. The problem with many herbal medicines is that they have not been subject to rigorous scientific research and are not at present subject to any government medical control, although regulation of the profession is now in progress. Herbal medicines are commonly marketed in a variety of formulations that will have different types and amounts of active ingredients. A licensed drug, on the other hand, has to go through an extensive series of trials before it will be given its licence to ensure that it is safe and effective and to ascertain what side-effects there may be. The drug will be quality controlled in the sense that the exact active agents and amounts of these will be specified so that ingredients of a drug are known.

Another reason for the popularity of complementary therapies is that people like the holistic approach many adopt, i.e. one that treats patients as a whole, not only treating the disease but also taking into account the person's physical and mental state as well as their social background.

What do 'conventional' medical practitioners think of them?

The division between orthodox medicine and complementary therapies has become more blurred over the past few years. Some complementary therapies now have well established uses in mainstream medicine – for instance various therapies are used for pain relief and creative therapies are often employed in psychiatry. Some conventional health practitioners also train in complementary therapy techniques. As a result of this crossover between the two, the term 'integrated medicine' is increasingly used to mean, 'conventional and complementary approaches form parts of the one process'.

In general doctors are more open to the idea of complementary medicine that they used to be, especially if it is 'integrated'. However many still have reservations because few of the therapies used have been the subject of rigorous scientific research and only two (chiropractic and osteopathy) are regulated through government legislation. However, a recent House of Lords Science & Technology Committee report recommended that several others should also be regulated, especially acupuncture and herbal medicine. The regulation of these two therapies is now in progress and it is likely that other forms will follow suit.

Complementary therapies should always be used in addition to conventional medicine not instead of it. If you are thinking of trying complementary therapies, discuss this further with your doctor. Make sure the therapist you use is properly trained and affiliated to a recognised regulating professional body for the complementary therapy discipline in question.

What research is available for their effectiveness with MSA?

Although some people with MSA can provide anecdotal accounts of the use of complementary therapies, we are not aware of any research evidence specifically about their use with people with MSA. There has been some limited research in Parkinson's disease – see the Parkinson's Disease Society booklet Complementary Therapies and Parkinson's (see www.parkinsons.org.uk).

Where can I find more information?

Organisations such as the Institute for Complementary Therapies (www.i-c-m.org.uk) and the British Complementary Medicine Association (www.bcma.co.uk) can provide you with more information and details of professional organisations for the different types of complementary therapies. Your GP surgery may also be able to provide you with details of local practitioners. The Research Council for Complementary Medicine (www.rccm.org.uk) can also provide you with more information on research into complementary therapies in general.

Recommended reading

- A good general book on this subject is *The Patient's Internet Handbook* by Robert Kiley and Elizabeth Graham, 2001, Royal Society of Medicine

  (ISBN: 978-1853154980)
- People who are interested in reading research papers may also be interested in *How to read a paper: the basics of evidence-based medicine* (3rd revised edition) by Trisha Greenhalgh, 2006, Blackwell Publishing

  (ISBN: 978-1405139762).

organisation that helps families with disabled children. It has produced a good article on 'Medical Information on the Internet; Seeking Quality'. See www.cafamily.org.uk/info.html

Sense About Science is an independent charitable trust promoting good science and evidence in public debates publishes a useful leaflet, I don't know what to believe…making sense of science stories, which explains how scientists present and judge research and how you can ask questions of the science information presented to you. See www.senseaboutscience.org

Bad Science is an entertaining and illuminating weekly column, published in the Guardian newspaper, written by Ben Goldacre – a medical doctor working in the NHS. This focuses on debunking scientific inaccuracy, quackery and pseudoscience. You can read the columns on The Guardian's website (www.guardian.co.uk) or his own website, www.badscience.net A book Bad Science will be published in June 2007 by Fourth Estate (ISBN: 978-000724019).

DISCERN is "a brief questionnaire which has been developed to provide users of health information with a valid and reliable way of assessing the quality of written information on treatment choices for a health problem. It can also be used by authors and publishers of information on treatment choices as a guide to the standard which users are entitled to expect". An Internet version is also being developed. The project is based in Division of Public Health and Primary Health Care, Institute of Health Sciences, University of Oxford. See www.discern.org.uk for more information.

REFERENCES

1. Schmidt K, Ernst E. Assessing websites on complementary and alternative medicine for cancer. *Ann of Oncol* 2004; **15**(5): 733-42.
2. Definition taken from DISCERN website, www.discern.org.uk

Acknowledgement

This checklist has been compiled using information in Finding medical information on the internet by Contact a Family and Making Sense of Science Stories by Sense About Science.

Essex

Monday April 2nd 2007 was a beautiful, sunny, spring day as we travelled from our home in Harlow to the SMT Essex Support Group meeting in Little Tey, Colchester. The day became even better when we arrived at the village hall and were welcomed by two very special people, Laurelie and Bay Laurie who run the Essex Group.

My husband, David, has MSA and when we were first invited to attend the meeting two years ago we were very apprehensive. We had never met anyone else who had MSA and were, if we are honest, a little afraid. Our fears were unfounded, everyone was so kind and it was really good to share experiences, exchange ideas and find out how MSA affected other people's lives. The meetings are very informal, more of a "get together". As they are only twice yearly there is always a lot of catching up to do. We have a lovely lunch and some friends from the village tend to our every need. You share time with people who know exactly what living with MSA really entails. No one is embarrassed; if you have a problem speaking clearly probably the person sitting next to you does too.

At this meeting we were lucky to have Catherine Best, the SMT nurse specialist at our meeting. She talked to us abut MSA and the research that is being carried out, answered our questions and asked us our opinions on the support group meetings. It was so interesting that the meeting overran by an hour. It is such a pity that more of these groups are not set up around the country, we would encourage anyone to attend them.

The best part of the meeting (apart from Sue's meringues) - WE LAUGH! It is good to know that with all the trials that MSA brings we all still have a sense of humour.

Christine Mead

To anyone thinking of starting a support group – DO IT

Our connection with SMT was through my sister Juliet Price who died in 1997 just as the Trust was being set up. However it was not until 2004 before we were approached and asked if we would be prepared to organise an Essex Support Group on the lines of the one which Elizabeth Brackenbury, Sarah Matheson's sister started in Nottingham and which has proved a great success.

Our first meeting was with only 8 people including Alison and Linda from the London office and as it was a lovely day, we had tea in our garden. We have grown since then and we now have about 20 people twice a year in our village hall. The benefit to all far outweighs the time spent by us with 2 or 3 wonderful helpers to provide a simple lunch and plenty of tea and coffee.

We are now a group of FRIENDS with new ones joining at every get together. Talk is of problems, specialists, grandchildren, holidays etc. but most of all it is to meet people with similar problems and to exchange experiences.

The group is well supported by the SMT and the last time we met Catherine came down from London and it was a great opportunity for us to meet her. At the moment, I believe that there are only 3 or 4 other Support groups in the UK and that is not enough. They are so appreciated by all who come that I would strongly recommend other areas to start a group. They fill a great need and give a lot of satisfaction to all concerned.

Laurelie and Bay Laurie –
Essex Group Organisers

Nottingham

The Nottingham Support Group was our first regional group and was set up by Sarah Matheson's sister, Elizabeth Brackenbury, although it is a family affair with Elizabeth's husband Robin and son Robert both very involved. Sarah lived in London when she was diagnosed with MSA but came to live with Elizabeth in Nottingham. This means that Elizabeth has first hand experience caring for someone and understands how MSA can affect a person and family. This experience and her warm nature mean that everyone who comes to the Nottingham group gets a wonderful welcome from Elizabeth and is soon at ease. Members of this group become friends as they chat and listen to each other. New members can look forward to this and are always welcome.

Cornwall & Devon

Our First Meeting Report

The Cornwall and Devon Support Group was formed in October 2006 at an open meeting hosted by Catherine Best from SMT. After a number of telephone discussions, we arranged our first independent meeting near Tavistock, West Devon on 8th February 2007 and 8 SMT members attended with a further 3 phoning in their apologies because of the snow which arrived that morning.

The meeting was a lively unstructured discussion around MSA, its diagnosis and the people responsible for making that diagnosis. A number of key issues were discussed in depth:

- We believe there may be some form of early trigger which starts a patient down the MSA route many years before diagnosis. All those sufferers present reported one or more symptoms which started in a minor way with a memorable event earlier in the sufferer's life and developed into one of the standard symptoms of MSA. This idea is suggested as the basis of some research amongst a wider population of sufferers.
- We suggest to all carers and professionals that they should keep saying "Stand up STRAIGHT" or "Sit UP" to remind their sufferers of the need to maintain a good posture. **(Ed** - *do this with caution if you have postural hypotension*)
- The free NHS Expert Patients Programme should be promoted to sufferers at every opportunity. This is a programme of six 2-hour sessions which teaches the patient how to set (and try to keep) daily objectives within their capabilities and to think positively. Regular daily exercise, such as dog walking, was also highly recommended by all present as one of the best treatments to keep MSA under control.
- The standard of knowledge of healthcare professionals about MSA and related neurological disorders is very variable. We were pleased to note that many professionals, even at consultant level, admit their lack of knowledge and in some cases allowed the sufferer to lead the discussions. We were not so pleased to note that some neurology consultants in our area refused to admit the existence of MSA.
- Cornwall and Devon is a very big area which means our meetings will always involve long travelling distances. Whilst we would keep the 2 counties approach, we would like to split into much smaller areas for informal meetings. To be successful we do therefore need more members, so would ask everyone reading this to promote our group to your friends and colleagues.

Early in May we had our second meeting, this time in the New Memorial Hall in Summercourt, near Bodmin. Despite the weather (heavy mist and rain this time), 6 people attended including 2 new faces to our group.

There was some talk about the (American) National Institute of Neurological Disorders web page and similar web pages. We will be making a commented list of all the web sites we can find and seem to be useful. This will be circulated to our local members, if anyone else would like a copy, please email or phone me (Peter Padmore, zen70184@zen.co.uk or 01822 870642).

Peter Padmore –
Cornwall and Devon Organiser

Ed *Since these meetings Peter had been very active in organising further meetings with the help of his harem of helpers Liz, Jan and Jane. He has also been writing and producing several local newsletters and journal articles and speaking to groups of health professionals about the diagnosis and impact of MSA including those at the SMT awareness day in September.*

Yorkshire

Just thought I would let you know how things went at the first Yorkshire support group meeting.

We had three couples who came along and one who had hoped to come, but when I arrived home, she had sent an email to apologise that the day had been a bad one and she just hadn't been able to face it. Another couple who had hoped to come had put on the bottom of their reply that they were awaiting news of their first grandchild and that might prevent them from coming along, so I am assuming they became grandparents on or around that day and couldn't come. So not too bad a start for the group.

Everyone seemed very keen to meet again and I have said I will try to find a venue that is perhaps a little more accessible (e.g. just off the A1), travelling into Bradford proved a little arduous for some, and to set a date in early November.

Karen Walker,
Yorkshire Group Organiser

Ed *Since then Yorkshire have had another successful meeting which will be in the next SMarT news.*

Merseyside

Ann McLennan arranged the very first meeting of this group for Dec 6th. Held at the SMT office we know it was a success and send Ann and her helpers all our best wishes and look forward to getting a report on the day.

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.

Card makers

Christine Fowler has been hand making cards for the Trust for several years now and has raised over £400. Christine is grateful to Julie at 'Arrochar Flowers' in Argyll who sells the cards in her shop and does not take any profit. Some of our members will have seen Christine's cards at awareness days and will know how beautiful they are.

Catherine Griffiths-Carroll exceeded her target of making 100 cards which raised £125. She says that 'It has really helped me to focus on my father's death. Good luck with all your work.'

A Hairy Story

Sharon & Nicola Foulis who live Ramsey in the Isle of Man decided that a dramatic approach was needed for their fundraising activities and decided on a hair style with a difference. Both girls shaved their heads! Local hairdressers Carl and Alison from KD hair Salon agreeds Kai, to wield their scissors and the Ellan Vannin pub on the quayside in Ramsey turned the deed into an event by letting the girls have their head shaves in front of an audience.

Sharon & Nicola

The sisters, who's Mum Maggie has MSA, decided to shave their shoulder length hair to raise funds and awareness for MSA. They raised an impressive £3100. Catherine Best, nurse specialist travelled to the Isle of Man to meet Val and the Parkinson's disease Nurse Specialist for the island and was able to collect the cheque from Sharon and Nicola and to congratulate and thank these wonderful daughters in person. Catherine also had the opportunity to catch up with Diane Collister. Nearly 10 years ago Helen who was a social worker bought a lady with MSA to London where they met Catherine.

Sharon, Val, Catherine, Nicole & Family

Margaret's Dinner

Margaret Watson suffered from MSA which took her life but as the generous lady she was, she donated her brain and spinal cord for medical research in the full knowledge no benefit would accrue to her but with the strong belief it might benefit others. A statement which I found impressive and thought provoking!

Some years before she died I was made to promise I would raise money for SMT, specifically for research into MSA, as she wished to do something for the benefit of others. This was a challenge I accepted gladly, because it gave me an opportunity to do something for the Trust to and at the same time say, in my own way, a big thank you to her for all the generosity she displayed during our marriage.

So it was on Friday 20th April I held Margaret's Dinner, a night of entertainment and fun in Edinburgh with the specific purpose of raising money for the Trust, to conduct the research as she wished. The dinner was different in that the only speech was mine in opening the proceedings but was otherwise to be a night of fun. It was well attended, principally by people in the property, legal and architectural professions and was a great success, raising more than £50,000 on the night. People were most generous in their giving in praise of the artists, the Katzenjammer piano duo, and Rebecca Carrington, a cellist with a difference. It is fair to say that, had Margaret been there, she too would have had a great time!

Personally I am very pleased to have been given the opportunity to support the Trust in this way and it is my hope, as it was Margaret's that some good research will be done which may lead to a much netter understanding of the condition, benefiting others in the future. **Michael Watson**

Margaret Watson

Runners and Riders

Paul Stephens (below) completed the Bath half marathon and raised over £2000 which is an amazing amount.

Simon Prower (left) on the London to Brighton Bike ride

Simon Prower raised over £400 in 2 cycle rides in June. He wanted to say….

'A huge THANK YOU to all of you who sponsored me for my 2 bike rides. The 54-mile London-Brighton bike ride (plus another 6 miles to and from the start and finish) with 3 of my former colleagues from Etihad, and another 35 miles the following week on the Horsham cycle. We had a great time amongst a great crowd of fellow competitors, in a fantastic and fun atmosphere.'

Simon is the stepson of Ian Welsh who is a SMT member. Both Ian & Sue Welsh are quite overcome and proud that he chose to raise money for the SMT.

A Huge Thank You to all our London Marathon Runners!

Yet again, our London Marathon runners have managed to raise a wonderful amount of money for the Trust. This year, the total amount raised so far (with more still finding it's way to us) is over £20,000. We are very grateful to all those sore feet! After the long day in very hot conditions, most of the runners managed to find their way to The Warwick pub nearby where a space had been reserved for the Trust. Hopefully the odd glass of liquid refreshment along with some delicious snacks went some way to ease the pain. The runners were joined by friends and family as well as some of the Trustees and Catherine. It proved to be a lovely afternoon and enabled the Trust to give a little back to all our supporters who do so much for us.

One of our runners, **Ian Filby**, was injured just a couple of weeks before the event, but signed up for the Nottingham marathon in September so that the money raised would still come to us.

Runners' times:

Allan Comette	**5 hours 07 minutes**
Michael Gill	**4 hours 40 minutes**
Gina Grasso	**6 hours 06 minutes**
Jeremy McGivern	**4 hours 16 minutes**

For anybody interested in running for the Sarah Matheson Trust next year, the Flora London Marathon takes place on Sunday 13th April 2008. Please let the office know whether you have been successful in obtaining a place – all entrants will be informed in early December. We also have a small amount of Golden Bond places which can be shared between some of the unsuccessful applicants, though we cannot guarantee everyone a place.

Thank you again and we look forward to another fun day in 2008!

Donna Marcelle (left) from Essex ran the Brentwood Mother half marathon in support of her Mum, Doreen Ellis, a SMT member. As well as raising money through sponsorship Donna made use of a scheme at her work and her employers matched her total which meant Donna raised over £1500

Charity Concert

The Isle of Man has been very busy fundraising and making sure that all the family get involved. Earlier readers learnt about Val's daughters shaving their heads and Maggie's husband David organised a variety concert which raised £400. The whole island must have heard about MSA now, well done.

Scottish Madness

Ann McLennan and her children Ross and Sally incorporated the SMT initials into their night of Scottish Madness To remember Donald. Held in a hotel in Southport, this energetic evening of great Scottish traditions like eating drinking and dancing raised over £2500. It was such a success that the McLennan's are doing it all again next march. This is one kind of madness that everyone should have.

SMT in Schools

A huge cheque from Northampton

Several schools who have a pupil or staff member that know someone with MSA have raised money for the Trust. **Urshuline College London** raised £800 and **Northampton School for Girls** who collected £400. Our thanks to everyone involved at each school.

Cycle to Cannes

A distance of 1500km and four days of grueling, round the clock exercise - this is the challenge completed by a group of architects and property professionals who cycled from London to MIPIM in Cannes.

Peter Murray, an ex SMT trustee initiated the ride in 2006 and its success meant that it was repeated in 2007 but in a bigger better fashion. The challenge has been organised in aid of the several charities; National Hospital for Neurology and Neurosurgery, Architects for Aid, Tom ap Rhys Pryce Memorial Trust and the Sarah Matheson Trust. The SMT is very grateful for the £55,000 received.

Sarah Matheson Trust for
Multiple System Atrophy

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

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

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

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

www.msaweb.co.uk

The Trust is financed entirely by voluntary donations.

Registered Charity Number 1062308

Membership Numbers
as of Nov 2007

Current MSA members	848
Other patient members	42
Relatives & carers	398
Professionals	1332
Others	151

Gift Aid — an unqualified success

For the interest of readers I have the gift aid figures received by the Trust as follows: for 12 months to July 2007 the sum produced by individual donors who have patiently filled in the relevant forms for return to the Trust, these being processed by the wonderful Liz Balmford so that the task of reclaiming the tax by me is no longer arduous, amounted to £8,384. On top of that a further £3,242 of gift aid was received from those donors using the Just Giving.com system.

These are extraordinary figures and underline the generosity of so many people without whom the Trust would not exist. Even so and I certainly do not wish to appear to criticise, we could improve on these figures. The total received by way of donations in recent years has averaged in excess of £100,000, including those from Charitable Trusts where gift aid is not reclaimable. It is not possible to be precise; however I would hazard a guess by suggesting that between us we could double the gift aid figure without too much extra work. The forms are available in the office and don't forget that if you are a top rate (40%) tax payer you can claim back 12% yourselves (28% having come to the trust via your tax return).

All of the above may seem as if we are less than grateful for the wonderful generosity of our donors. Far from it. We are shortly to pass the 10th anniversary of the formation of the Sarah Matheson Trust and this is entirely due to your support and those who have sadly gone before. The Trustees join me in thanking all concerned; it has been a privilege to be closely associated with the Trust throughout its first decade.

Val Fleming, Treasurer

Abbreviated Financial Statement

for the year to 31st March 2007

	£000's
Income	
Donations	110
Investments	13
Fundraising	49
Total	172
Expenditure	
Research Grants & patient welfare	27
Staff salaries	44
Other various	4
Total	75
Net income	97
Total funds at 1st April 2006	270
Balance at 1st April 2007	367

Awareness Day dates for your diary

Cornwall & Devon Support Meeting – January 2008

Aberdeen Awarness Day – March 20008

Belfast Awarness Day – May 2008

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

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