



S MarT News

The newsletter of the Sarah Matheson Trust

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Mark Williamson at the Great North Run. Find out who else has been raising money for SMT in the fundraising section.

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Next issue:

Understanding Palliative Care

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 Nurses

Welcome to the New Year to all our members particularly those new to the Trust. Our numbers continue to steadily increase which keeps us happily busy providing information and continuing to provide a range of support services.

Thanks to a generous donation but modest donor (who does not wish to be named) we have been able to purchase a further six light writers. This will make a serious reduction to the waiting times for members who need the help of a communication aid to make themselves heard.

At the end of last year we had a flurry of awareness days from Edinburgh to Bristol. These are a great way to connect with members who we only speak to on the phone or the professionals involved in your care, and they are the best remedy for the overwhelming sense of isolation that the diagnosis of MSA brings. We hope to cover most regions again this year so keep checking for dates on the back page.

We are delighted that the requests for welfare gifts continue to arrive. Although the gifts are small (anything up to £100) they have been used to buy small pieces of equipment like swallow reminders, or put towards a voice amplifier. One gift helped provide respite care and another helped towards a holiday. The gift scheme is all about making a difference no matter how small to our members and we hope that you will keep this in mind should the need arise.

The addition to our team of our administrator Niki has in the few short months made a dramatic difference to our services. As our numbers have grown we have struggled at times to provide as much support as we hoped, now that much of the administrative load has been lifted by Niki we will be able to meet the needs and even develop some services in the near future. Watch this space for details.

The tragedy that unfolded as the world watched the Boxing Day tsunami was met with such huge compassion and generosity that commentators and the public found quite incredible. We witnessed the initial panic and fear followed by the desperation and bewilderment. As days passed the realisation of the situation bought grief and sadness. Some people did start to pick themselves up and with the help offered picked others up around them. While the circumstances are very different the individual effect of the disaster mirrors that experienced by many people diagnosed with conditions like Multiple System Atrophy (MSA) and Pure Autonomic Failure (PAF). Our thoughts are will everyone who has experienced any of these emotions, whatever the cause.

The incredible response to the tsunami also has significance with the response of individuals and families affected by MSA and PAF. Even during the hardest times people have the capacity to give, the warmth of the support meetings, the active contact scheme, the family members that fundraise for the Trust are all testament to that. The focus in this edition is the work of brain research centres which are dependant on the determination and courage of people to donate their brain after their death. Karen Shaw, the nurse at the Queen Square Brain Bank feels "donation, which may help others in the future, can offer patients and relatives the opportunity to salvage some meaning from an otherwise confusing situation". This seems like yet another parallel with recent events.

Catherine & Alison

Our feature this edition focuses on two important aspects of research that involve donation. The first is about the work of brain research centres; a sensitive subject because the nature of brain donation can only be made after death. The second involves the very modern and complex study of human genes and involves that less demanding donation of a blood sample.

Brain Centre Research

One important area of neurological research involves the process of brain donation. This is a sensitive subject to discuss as brain donation can only occur after death and for many health professionals this discussion seems to work against their efforts in manage symptoms and improve the daily lives of their patients.

However we know that many of our members are interested in all types of research, including brain donation and want to understand more about it.

What is a brain research centre?

A brain research centre (sometimes called a brain bank) is a scientific facility involved in the diagnosis, treatment and research of neurological disorders by examining donated brain tissue after someone's death.

Who works in a brain centre?

Brain banks are highly specialised laboratories and highly skilled medical and research staff undertake the actual tissue examination. Usually a neurologist or neuropathologist (a doctor who specialises in the structure and function of the brain) will lead the unit.

However the process can only happen with support staff capable of open discussion about donation with patients and respectfully coordinating donations with families during a time of grief. It is these support staff who you are likely to speak to if you contact a brain centre.

What actually happens in a brain research centre?

When brain tissue arrives at the brain bank it is either preserved in fixative or frozen quickly. It can then be examined

under a microscope for abnormalities. Further specialised studies that can look at individual cells or DNA can also be performed. The examination process, called histopathology, can take time, sometimes several months but can reveal destructive changes that occur because of disease such as multiple system atrophy (MSA), Parkinson's disease (PD) and progressive supranuclear palsy (PSP).

The examination process will provide a diagnosis.

As well as looking at brains that have neurological disease brain centres also examine brain tissue that has no neurological disease. These brains are

“Some family members have registered together so the centre will eventually have a ‘normal’ brain and an ‘MSA’ brain”

very important as abnormalities can only be detected if we doctors know and understand about a ‘normal’ brain.

What else can tissue be used for?

After a diagnosis has been made, tissue may be used in research studies to improve our understanding of the cell changes and damage. Studying the brain tissue this way can help us to understand the causes of neurological disease and may help the development of diagnostic tests and new drugs or treatments.

The tissue may also be used for medical or scientific training. Donors can decide whether they would like their tissue to be used in any of these ways.

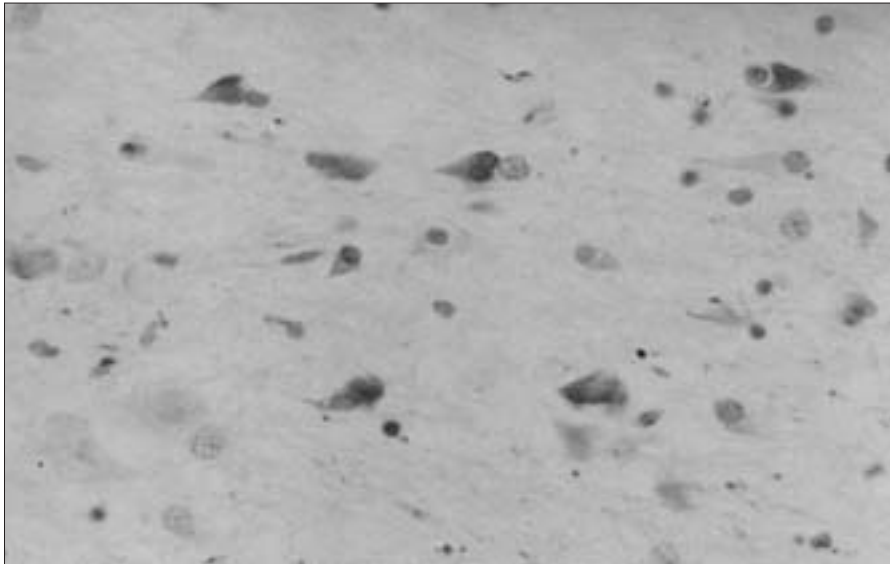
While MSA is not hereditary (passed on in families) tissue may also be used in the future to identify any genetic clues or markers for neurological diseases.

Why do people donate?

While people with MSA will have many neurological investigations to rule out other causes for their symptoms there is currently no test to confirm the diagnosis. The only opportunity for a definite diagnosis to confirm MSA is by microscopic examination of brain tissue after death. So brain donation is a means of getting a definitive diagnosis.

Donation can also contribute to neurological knowledge, providing understanding of the causes of neurological conditions and contributing to treatment. Some Sarah Matheson Trust family members have registered together with their family member with MSA so that the brain centre will eventually have a ‘normal’ brain and an ‘MSA’ brain.

Karen Shaw has been the nurse at Queen Square Brain Bank for the last four years, and has talked to patients, relatives and the public about the benefits of brain donation for around eight years. She believes the benefits of brain donation are well recognised. For families of deceased patients, benefits of brain donation include the comfort of certainty of diagnosis, contributing to the advancement of medical knowledge, and helping others in the



Comet-shaped glial inclusion bodies seen under the microscope

future. For clinicians these include the confirmation and clarification of clinical diagnosis, allowing clinical practice to be gradually improved.

How important are brain research centres in finding out about MSA?

Brain donation has enabled the discovery of glial inclusion bodies which are peculiar to MSA. These inclusion bodies contain tangles of a protein called alpha synuclein which can be seen under a microscope as comet shaped structures. The relationship between cell damage and inclusion bodies is not fully understood at present but it is an exciting area of current research. Different protein tangles are associated with other neurological diseases such as Parkinson's disease, which means they are important features of degenerative neurological disorders.

Brain centre examination has been incorporated (voluntarily) into some research trials such as Natural History and Neuro-protection in Parkinsonism (NNIPPS) to help identify and evaluate any benefit from the treatment to the brain itself.

Another important function of brain centres is to improve the accuracy of diagnosis. The information obtained from the examination is shared with the patient's consultant. The consultant can

then use this knowledge for the benefit of their future patients.

All research undertaken on brain tissue must meet ethical and legal requirements the whole donation process is has regulatory polices.

How does the brain get to the research centre?

Once the staff of the brain bank are notified of a donor's death they will organise the brain retrieval process. This can be done over the telephone.

The next of kin are asked to give permission for brain donation and if they consent the funeral directors take the body to the nearest hospital where the removal of the brain (and if agreed the spinal cord) occurs. The donor's body is returned to the family's funeral director and the funeral arrangements can then proceed. As brain donation does not disfigure the face arrangements for an open casket can still be made if desired.

The brain bank staff arrange with the hospital mortuary staff for the brain tissue to be transferred to the brain bank where it is stored securely and confidentially.

Susan Stoneham has worked for the Queen Square Brain Bank at Queen Square for 15 years and provides an out-of-hours service for the brain donor scheme, a role shared with Linda Kilford, Senior Research Technician.

Susan and Linda liaise with hospital mortuaries, pathologists and funeral directors to ensure the quick and efficient removal of the brain and its safe delivery to the brain bank with least distress to the bereaved family. Susan like other brain centre staff feels that 'brain donation is a gift the brain and without this important gift research cannot go ahead'.

Does it take long?

As soon as the brain centre staff are made aware of a death they can start the retrieval process so that it will not delay the funeral. The ideal is to complete the process within 48 hours of death.

How to I become a brain donor?

Before you make the decision to be a brain donor you should get as much information as you need to help you and you should discuss it with your family and your next of kin so that they are clear about your wishes.

Most brain banks ask you to register your intention to donate with them and will provide the necessary forms. They will ask you update this information at intervals. They may send you additional information and a donor card.

What if I change my mind?

You are free to change your mind at any time about being a donor. Let your family know so that they are aware of your wishes and let the centre know and they can take you off their register.

Making the decision to donate or not to donate will never affect any aspect of the care you receive from health professionals.

What if I never registered?

Even if a person did not registered at a centre it is still possible to arrange donation provided the next of kin feel that this is what their relative wanted and give permission.

If this is the case the family should contact a brain centre as soon as they can following a death.

Continued overleaf

Are there many brain banks in Britain?

There are around a dozen centres throughout the UK with different criteria for accepting donations.

How can I find out more?

For a list of regional brain centres contact Niki at the SMT office or visit www.alzheimers.org.uk/After_diagnosis/Helping_with_research/info_brain_donation.htm

Some centres have open days or give presentations where you can find out more.

Both Karen and Susan at the Queen Square Brain Bank are happy to talk to anyone who is interested on 020 7837 8370 or email s.stoneham@ion.ucl.ac.uk or k.shaw@ion.ucl.ac.uk

Our thanks to Susan Stoneham, Karen Shaw and Dr Kingsbury of the Queen Square Brain Bank for help in writing this article.

If you have any questions about brain donation please write or telephone us and we will publish them together with responses from brain bank staff in next edition of SMarT News

Key points

- Talk to family about this subject; make sure they know your wishes.
- Contact your nearest brain research centre for more information.
- At your next appointment, talk to your specialist doctor or nurse.
- Remember that donation should not delay funeral arrangements.
- For some people donation may offer some comfort, knowing the cause of death.
- Not everyone will want to consider donation, this personal choice will not affect the care you receive.

DNA Banking

The other research question that members ask us concerns genetic testing. This worries some people who worry that because genetic testing has been mentioned it means that MSA can be inherited within families. MSA is not hereditary; it does not appear to be passed on through family generations. Human genetic science involves the examination of human genes which carry information about our characteristics and body processes.

What are genes?

Genes are tiny strings of chemicals which contain the coded information that enables our body to grow, develop and function. Genes are made of a substance called DeoxyriboNucleic Acid (DNA) which is packed into every body cell as a chromosome.

We all have about 35,000 inherited genes half from our father and half from our mother. It is the DNA inside our genes that controls heredity. However most of the DNA in our chromosomes actually lies outside our genes. Quite what all this surplus DNA – sometimes known as ‘junk DNA’ – does is not yet known, though it could be ‘dead genes’ – old inactive DNA, including DNA inserted during virus infections, that has been automatically copied and passed down from generation to generation.

Examining this junk DNA together with the DNA in the chromosomes of people with MSA might help us to understand how MSA comes about and if there are treatments to slow its progression or prevent it occurring. At the moment collecting these samples involves a blood sample which is stored securely and confidentially (just as the brain donations are) for examination and research.

We are grateful to Professor Karen Morrison of the Institute of Biomedical Research, for responding to our questions about DNA banking which

her team at the University of Birmingham undertake as part of the NNIPPS study.

What is the NNIPPS (Natural History and Neuroprotection in Parkinson's Plus Syndromes) study?

This study commenced a few years ago, funded by the European Union, and under the overall leadership and co-ordination of Professor Nigel Leigh, Institute of Psychiatry, London. The study involved patients with PSP and MSA recruited from the UK, France and Germany and had a number of aims. The first was to recruit patients with either PSP or MSA to a clinical trial to determine if the drug riluzole improves survival. Riluzole is a compound with many actions, one of which is to reduce the activity of the brain's main excitatory neurotransmitter, glutamate. Riluzole has been shown to be of some benefit in prolonging life in the neuro-

“We all have about 35,000 inherited genes; half from our father and half from our mother”

degenerative disorder of motor neurone disease (MND) in the mid 1990s, and researchers wanted to know if this benefit extends to people diagnosed with PSP or MSA. Another aim of the NNIPPS study was to consider the clinical features which lead to a diagnosis of either MSA or PSP being made, to follow people with these diagnoses over time and monitor how these features change over time (hence the terms ‘natural history’ in the title of the study). A further aspect of the study was to perform magnetic resonance

brain imaging (MRI) in people on recruitment to the study and again later in the course of the disease, to determine if there are imaging features that allow us to more accurately classify people as having MSA or PSP, and also consider how these MRI features might change over time. Another part of the study involved consenting individuals in the study to donate their brains to the study post mortem, to allow careful pathological examination of the brain tissue.

At present such pathological examination is the only way of definitely being able to diagnose PSP and MSA. It is hoped that when diagnosis can be confirmed by such pathological examination in cases enrolled in the trial, linking back to the brain MRI and clinical histories will allow more accurate clinical diagnostic criteria for these disorders to be developed.

Where does the NNIPPS study DNA bank fit in?

When setting up the NNIPPS study it was clear that the study would involve a large number of clinically (and subsequently pathologically) well characterised patients with either PSP or MSA. The study co-ordinators thus added to the main trial a DNA bank, aiming to collect DNA from all of the participants in the trial. The huge benefit of this DNA bank derives from the fact that the cases in the bank have all been carefully assessed by clinicians experienced in diagnosing PSP and MSA, the cases have been followed over time, so there is a lot of clinical data available linked to the DNA samples and crucially, many of the cases will have pathologically confirmed diagnoses. Separate co-ordinating centres for the DNA bank were set up in each of the three participating countries. The UK centre for the bank is in the Molecular Neurology Group, University of Birmingham, co-ordinated by Professor Karen Morrison.

Why was Birmingham selected as the UK NNIPPS DNA bank centre?

The Molecular Neurology Group within the Institute of Biomedical Research in the University of Birmingham Medical School has established a number of local and national DNA collections covering various neurodegenerative diseases. The laboratory, headed by Professor Morrison, had funding for an experienced technician to perform the DNA extractions, has expertise in handling large numbers of samples for DNA extraction and storage and also has the infrastructure to allow secure long-term DNA storage.

How were patients recruited to the bank?

All patients enrolled in the NNIPPS trial were invited to take part in the NNIPPS DNA bank. Donors to the bank had to be enrolled in the NNIPPS trial, to ensure that the clinical data, MRI results and eventually post mortem findings, could all be linked to the DNA sample. Individuals with MSA or PSP not enrolled in the NNIPPS study were not eligible to be included.

Were any control DNA samples collected?

In the UK and France, ethical permission was granted to allow the NNIPPS investigators to collect DNA samples from carers, most often spouses, of people enrolled in the trial. These control DNA samples are extremely valuable when undertaking certain types of studies of genes that may be important in causing susceptibility to either PSP or MSA, as the spouse samples are likely to be fairly well matched with the patient samples for age and some environmental exposures.

DNA samples in the bank are 'anonymised'. What does this mean?

Samples stored in the DNA bank are labelled with the NNIPPS trial code for

"The Sarah Matheson Trust gave money to help fund the collection of DNA samples from UK MSA patients enrolled in the NNIPPS study"

each donor, and a similar code is used for control samples. All research work on the samples in the bank is performed using these trial codes. The samples are not labelled with a donor's name. There is however a central computer database which links these code numbers back to information that would allow tracing to an individual's name. It is necessary to maintain the possibility of linking back to a donor's name in case of the very rare occasions when a donor might wish their sample to be removed from the bank. If this situation were to arise we need to have a way of tracing the code number of a sample from the donor's name.

At what stage is the NNIPPS trial now?

At present the NNIPPS study is in the open label phase, meaning that all the participants with clinically diagnosed PSP and MSA who were randomly allocated to receive either the drug riluzole or placebo, are now taking the active drug, pending the analysis of the clinical trial data. It is hoped that the results of the clinical trial, to determine if riluzole improves survival in MSA and/or PSP, will be available early in 2005. I'm sure that future editions of *SMarT News* will carry full reports of the findings of the NNIPPS trial.

At what stage is the NNIPPS DNA bank at present?

We have now finished recruitment to

Continued overleaf

the NNIPPS DNA bank, as all patients enrolled in the NNIPPS trial have been recruited. This means that we are not collecting further samples for the bank with the exception that some repeat samples for cell lines are being collected where the initial sample arrived too late in the laboratory, as detailed above. In total the three countries have collected over 500 DNA samples, which represents the largest collection world-wide of DNA samples available from well-characterised MSA and PSP patients.

For how long will the NNIPPS DNA bank samples be stored?

We have not stated a time limit for storage of the NNIPPS DNA samples.

We anticipate that the resource will be used by many research groups over many years – until a cure for MSA and PSP has been found.

Is any research work being performed now on the DNA bank samples?

Within the last few weeks work has begun on some basic genetic studies on the bank samples. This includes analysis of the Tau gene in both the MSA and PSP samples, and also screening of the FRAXA and FRAXE genes in the MSA samples.

How will the DNA bank resource be used in the future?

The co-ordinators of the DNA bank and

the NNIPPS Trial Steering Committee have recently met and agreed a process for researchers who wish to study the DNA resource to follow. Applications to use the resource should be made initially to Professor Leigh who will then link with the trial Genetics Committee to provide samples.

What is the role of the Sarah Matheson Trust in the NNIPPS DNA Bank?

The Sarah Matheson Trust gave money to help fund the collection of DNA samples from UK MSA patients enrolled in the NNIPPS study. This donation covered the cost of the reagents involved in collecting and extracting the UK DNA samples.

Research news

Quality of Life Questionnaire

Thank you to all our members who have contributed to the development of this research tool. It is being presented to international neurologists in March 2005. Dr Anette Schrag will be writing in the next *SMarT News* about the response to the questionnaire.

Are accessible toilets accessible? The Inclusive Design of Away From Home (Public) Toilets in City Centres

“I come out of some loos feeling I have done 10 minutes on an army assault course; who designs these loos?” (Quote from ITAAL)

Researchers at University College London (UCL) are currently investigating the layout and design of ‘away from home’ (public) toilets in London, Manchester and Sheffield city centres. The project is ‘real time’ research that is tracking the impact of the Disability Discrimination Act, in regards to toilet provision for people with disabilities.

The remit of the DDA includes the design and construction of all aspects of

the public toilet. The entrance and exit, fixtures, fittings and furnishing are all covered by the act, so that just about every feature, from the cubicle to the soap dispenser, will need re-thinking.

As an Inclusive Design research project we have been talking directly to many support and community groups, specifically about the problems they find with the design and management of public toilets. In focus group settings many users have detailed their individual experiences of finding and using toilet facilities in pubs, cafes, restaurants and those operated by local authorities.

The outcome of this study will be to provide architects, planners and toilet providers with details of what is really needed to make public toilets safe and comfortable to use.

We are offering a payment of £15 for 90 minutes participation in a focus group to be held either at University College London or at a local location convenient for the group.

If you are interested in taking part in a focus group, either as an individual or as a support group, and would like more

information, please contact Jo-Anne Bichard on 020 7679 8224 or e-mail j.bichard@ucl.ac.uk

OT study report

The value of different kinds of therapy in progressive neurological disorders has always been difficult to establish. Although most patients experience individual benefit there have been very few clinical trials to evaluate this. One of the first trials to examine the effectiveness of occupational therapy involved people with multiple system atrophy, many of whom were members of the SMT. Shilpa Jain, MSc (OT) SROT, and colleagues undertook a small study which concluded occupational therapy interventions were beneficial for people with mild to moderate disability associated with MSA. This inspiring piece of work will hopefully encourage the further study of the benefits of therapies in managing MSA.

Reference: *Shilpa Jain et al. Occupational Therapy in Multiple System Atrophy: A Pilot Randomized Controlled Trial. Movement Disorders, Vol. 19, No.11 2004.*

Message from America

After attending a European Autonomic Meeting we were fortunate that Don Summers, President of the American SDS/MSA Support Group, and his wife Sylvia were able to visit the SMT office.

Don is looking forward to “the advancements that can be brought about by, in a sense, combining the strength of both groups to promote more research and to jointly continue to educate all of the people involved with Multiple System Atrophy whether these people are patients, caregivers, family members or physicians. Together we will be able to work for more timely diagnosis, more patient oriented



(l to r) Peter Murray, Alison Abery, Sylvia Summers, Don Summers and Catherine Best

research and an increase in the interest in finding better palliative medication for those who are suffering with MSA.

I believe that our beginning to share the effort will bring much progress!”

After an interesting discussion it

was clear that the problems facing people with MSA are similar on either side of the Atlantic. The information and support available from health and social care is organised differently in each country but is equally sparse. Both the UK & American groups seek to bridge this gap in a variety of ways. Although the way we work differs, the goals of each organisation are identical: to educate and support people with the condition.

“Although we both knew of each other’s organisation before the visit it was good to engage personally. We hope this will be the start of a more personal connection with the SDS/MSA Support Group,” said Don.

Disability Discrimination Act

The final provision of Part III of the Disability Discrimination Act (DDA) that relates to access to goods and services came into effect on 1st October 2004. The final stage of the duties of this Act means service providers may have to consider making permanent physical adjustments to their premises (e.g. ramps, widened doorways, lifts) to ensure that access is not unreasonably difficult for people with disabilities.

The Disability Rights Commission (DRC) has an Open 4 All campaign and invites feedback from people experiencing difficulties. They can also provide you with postcards and campaign packs to help you make your local businesses and organisations aware of their responsibilities and the difficulties you are experiencing.

Contact the DRC at FREEPOST NWW5473A, Manchester, M4 3AQ, campaigns@drc-gb.org or www.open4all.org

Know Your Rights

The new Carers UK website at www.carersuk.org has information on current campaigns for carers and details of how to access their publications including their new Carers Rights Guide, events around the country and support services. Their telephone advice line remains on 0808 808 7777.

Carers news

Carers Health

Research by Carers UK found that 65% of carers with significant health problems did not get an increase in support services when they approached social services despite government directives to social services departments to ensure that inadequate service provision does not put carers’ own health at risk.

Carers UK are also lobbying for GPs to identify carers and offer them fuller support in recognition of this additional role and the responsibilities they carry. Carers often worry about what will happen to the person they care for in the event of their own illness or an accident. It is important that the need for support is clearly identified to help support agencies relieve these worries and plan for any eventualities.

The general guidance for carers is to inform your GP of your caring role and responsibilities, have regular health checks for yourself and seek early treatment if you become unwell, and to ensure you have a Carers Assessment from your local social services department that is updated as your role changes overtime.

For more information contact the SMT nurses or Carers UK, 20-25 Glasshouse Yard, London EC1A 4JT. 0808 808 7777.

Fun Walk – Sunday 12th September 2004

Attended by a dedicated group of walkers and picnickers the day was a success. The weather held good although a little windy at times – our “base camp” tried valiantly to leap into orbit and finally succeeded! The Champagne Draw for the walkers was won by Alison Terry; the Treasure Hunt was won by Jennifer & Elizabeth Hutt.



(from top, clockwise) Treasure Hunt winners Jennifer and Elizabeth Hutt; Alison Terry collecting her Champagne; Doreen Dowling and fellow stall holders



The FunWalk raised around £1,000 plus money raised by Doreen Dowling and her friends who were selling handmade greeting cards to boost our funds.

Fundraising events across the UK & beyond

● **Sponsored Swim**

Jonean Denholm raised around £1000 doing a sponsored swim in memory of her father John Croly (pictured here after completing her marathon efforts with Jaden Calderwood, John’s first great grandson).



● **Girls Nite**

The staff at Vinyard Lodge in Hurstierpoint, Sussex held a Girls Nite to raise funds for the SMT and the local hospice. Catherine Barton-Smith (proprietor) and her sister Sarah were keen to raise funds for both organisations as we support their mother, Angela. An amazing £1000 was raised overall.

● **Liverpool Half Marathon**

Thanks to the support and fundraising efforts of family, friends and work colleagues SMT received a cheque for £900 from the family of the late Dorothy Butler. Mark Butler and his sister Julie Probert, along with Julie’s husband Barrie and their 13-year old son Jack all completed the half marathon, Jack completed in an impressive 2 hours 8 minutes. Congratulations!

● **London £10km Run**

Neil Hawker raised £80 from this event, his wife Sarah is daughter to Janet & Bryan Fear.

● **Sponsored Bike Ride**

Billy Brown, Craig Sterrett, Simon Hinks and John Hunter from Cummins Engineering in Daventry raised money cycling from their plant in Darlington to the plant in Daventry in memory of their former colleague Lee Grant, an SMT member.



(l-r) Chloe Brentnall, Simon Hinks, Craig Sterrett, Stephen Brentnall, Billy Brown and John Hunter

Courtesy of The Daventry Express

● **Blackpool Marathon**

Mark Butler raised £213 running for us in memory of his mother, Dorothy.

● **Border Trek 04**

Vincent O’Reilly and Eamon Flanagan completed the trek from Enniskillen to Sligo and raised £441.49 for SMT

between them and an equal amount for Co-operation Ireland.

● **Dublin Marathon**

Eoin Keating, whose mother Maura is an SMT member, completed the Dublin Marathon for SMT and the Irish Parkinson’s Association. SMT received £466 for his efforts. He highly recommends running as a great way to raise funds to support people with MSA!



Eoin and Maura Keating

● **Social Night**

Residents in the Salisbury View sheltered housing development in Mayfield raised £300 for SMT at one of their regular gatherings, members Carol & Tommy Rodgerson are residents.

● **Parachute Jump**

Rebecca Bate bravely leapt into the skies in June and raised £222 for Sarah Matheson Trust..

● **Golden Wedding Party**

Evelyn & Kenny Atherton asked for donations to SMT in lieu of gifts on their anniversary. Their generous family and friends donated £765.

● 60th Birthday Celebration

Leslie Barr's brother Douglas asked for donations in lieu of gifts on the occasion of his 60th birthday. Friends and family rallied to the cause and filled our coffers with £605!

● Coffee Mornings

Les & Joyce Ward in Norfolk whose daughter Linda Stone is a member of SMT raised £213 with a coffee morning.

Janet Fear and friends raised a further £200 at an event in Devon and Jill Bourke friends from Kent raised £30 in a raffle at a coffee morning.

● Great North Run

This year saw an increase in runners in this Northern event for the Trust. Allan Comette raised £100, Lucie Colbourne raised £240 in memory of Lee Grant and another of Lee's



*Paul Falconer
and Anna
Carrington*

friends, Mark Williamson, raised £171.50. Paul Falconer & Anna Carrington raised £1,022.50. Paul's father Robin is a member of SMT. A



Mark Williamson

● Dress Down Day

Pupils of Trinity High School, Chingford raised £1,372 by donating £1 each not to wear uniform for the day.

● Seasonal Concert

Once again the voices of the Croft Singers in Norfolk were raised in melody to swell our coffers by a further £100.

● School Fundraising

The pupils at Aldenham School, Elstree, nominated SMT to receive £1000 from their fundraising efforts. The funds were donated in memory of Derek Balson, whose son Joe is a pupil at the school.

London Marathon 2005 This year we have nine runners (that we know of, please let us know if you are running for us and are not mentioned here). Our Golden Bond places have been awarded to: Allan Comette, Nick Webster, Susan Bourke, Joseph Rham, Clare Dixon, Hayley Lemas and Stuart Loxhall. Mark Steel and Pam Parsons both were successful in obtaining places through the ballot. Anyone who has time to offer their support on the day, this year's event will take place on Sunday April 17th. We wish them all luck, good weather and blister-less feet!

Collections at Wembley Arena & Sainsbury's Pimlico.

Allan Comette has remained a stalwart of the Wembley collections that are offered to SMT for a variety of concerts & events. This year to date we have raised nearly £3000 at Wembley. Linda Campbell organised an all-day collection at her local Sainsbury's where she and a posse of collectors raised £555.

Forthcoming sponsored events

● **Bath Half Marathon, 20th March 2005** Julie Johnson is running again for us this year

● **Walking the Wight, May 2005**

We potentially have a family group walking for us this year

● **Everest Trek, October 2005**

The SMT link with Nepal is growing! Sarah Matheson trekked there before MSA held her back and some of our Trustees have been walking, or still walk, in the region and have wonderful tales of their experiences.

Clive Grove is currently rallying a group of keen walkers to trek over the high passes to the Everest region of



Would anyone with easy access to London who is willing to give a couple of hours once in a while (usually 6pm-8.30pm) to raise funds for the SMT in collections at Wembley Arena (or other venues) please send your contact details (address, phone numbers, email) to the SMT office. We will keep you updated with any fixed collection dates and will contact you for any ad hoc ones we are offered. You will always be part of a team (even if a team of two!) and not be collecting alone unless you choose to. We have raised nearly £3000 in collections this year.

Nepal. They will be trekking for 4-8 hours a day on the 25 day trip and are expecting to find the altitude a challenge.

Clive had always planned to do this adventure with his long time friend Paul Griggs, to whom this trek is now dedicated. The participants, currently taking 9 places on a party size of 10-12 people, have all met the costs of about £1,600 each and will be donating any funds raised to SMT. There are still places available (or there were when we printed this!) and Clive is happy to act as an intermediary for any other fit people out there who fancy joining the party. It could well be a once in a lifetime experience – or you too may get hooked!

More details on www.peregrineadventures.co.uk and Clive can be contacted on 01202 826449 or emailed at clive@cgrove.fslife.co.uk

We will publish any reports and photos from events in the future editions of SMarT News. Please do let us know of any fundraising events taking place so that we can let people know and offer our support.

Countdown to pain relief

Colin Yates has had a lot of success with self-hypnosis. Initially he just thought he'd use it for pain control but he's gone on to use it extensively and wonders if it might be of use to others.

Self-hypnosis is definitely a skill worth acquiring. I say a skill, but the great thing about it is that anyone can do it. I've found that if you convince yourself that you can do it then you can. You surprise yourself how easy it is to do. Convincing yourself, that self-belief is probably the hardest thing to get your head round but that's the hardest part. And it's not that hard, really.

I learnt how to do it at our local council's residential school but I didn't take enough notice the first time and so had to repeat it. I learnt these two simple techniques for pain control and they work brilliantly.

The two techniques were to imagine the pain showing on a dial measuring 0-10 (I get at least five distinctly different pains so I found it (find it) useful to imagine a different dial for each one) & then to imagine turning down the dial, not all the way down to zero, (I use 0.2-0.5) your brain needs to be able to receive messages about anything wrong

with your body and pain is just another message really.

It is quite extraordinary how well it works. To test it, Bev, my wife, asked me turn one of the dials up. I'm glad I only turned it up to "five", it was agony but it went away immediately I imagined turning the dial down again.

I don't usually need to use the other technique but I'm a huge coward with pain and I often cover myself anyway.

You imagine your pain as a shape and give it a colour then imagine the background has a different colour (I use orange for the shape and blue for the background) and then imagine changing the colour of the shape to the same colour as the background.

Being cautious I'd have to say that at first most people would have to be guided by someone experienced in the use of hypnotherapy.

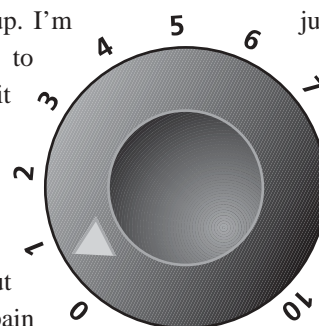
I also visualised my MSA as a

small, weak, stupid thing that I told to go away or to progress very slowly, much more slowly than it has already and if I still don't get any joy, then I'll just go with the flow and not worry about it.

That all must sound very strange but I'm certain I'm not deluding myself that there is some kind of miracle cure. I can't get disappointed because I can only gain if this comes off and if it doesn't I haven't lost anything by giving it a try.

However I do think that the mind is potentially a very powerful tool and I don't think I've got anything to lose by giving it a try.

That sounds like it could be prepared to make concessions to mysticism and quackery. I'd like to say that I may not have explained it very well but it is a genuine effort to be open minded and allow for any possibility.



Letters

Thanks to a Kiwi Friend

It has been six years since Linda's Multiple System Atrophy condition was diagnosed. We have done some adjusting, as have many of our friends. They have been understanding and tried to do those extra things that are the mark of friendship.

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

Liz is one of those friends. She immigrated to England years back and we worked together in the same town. Life moved on but we kept in contact and tried to meet up at least annually. Of course, initially we could meet virtually anywhere. With the onset of the MSA our meeting venues needed some consideration. Liz put much effort into finding accessible places. Even so there were hiccups: one café had a very convenient level door from the street - the only one in the neighbourhood - but the wheelchair could not get through the toilet door. Then there was the hotel - magnificent - it had the grandest loo we have seen but the only entrance to the

hotel we could find was up a flight of steps!

Well this year Liz was 60 and she wanted a party meal for her friends and family. She wanted to ensure Linda was able to attend and to feel comfortable. This time she hit the jackpot, Abbevilles in Clapham, London. It is a restaurant which is on the ground floor and all on one level with a gentle ramp to the (second) entrance. Staff had arranged convenient parking for us. Liz booked the whole restaurant for a Sunday afternoon and there were about 40 of us, including children.

What a wonderful occasion. We were looked after by attentive friendly

Appreciating Tim Young

This is a particularly relevant time to write about Dr Tim Young, who has devoted the last 3 years to advancing clinical research into multiple system atrophy and allied autonomic disorders. As you are well aware, advances in the treatment and cure of any disease is crucially dependent on top quality clinical research. This was recognised by the Sarah Matheson Trustees, who agreed on the importance of funding a Clinical Research Fellow. This would not have been possible without the immense support and finance raised by patients, carers, their families and friends. Tim was appointed in August 2001, having completed various clinical posts. He was cognisant of the fact that to excel in clinical research one must be knowledgeable of disorder that one is hoping to advance treatment into. I was particularly pleased, as his Clinical and Research Supervisor, that he utilised the multiple facilities in our two departments, at St Mary's and the National Hospital, Queen Square along with those at Imperial College London and the Institute of Neurology, University College London. He initially joined me in various clinics, thus

enabling him to acquire experience and benefit from the depth and breadth of the many autonomic disorders that are referred to us from all over the country, many parts of Europe and even North America. Tim also acquired the key research skills needed and then applied his knowledge in two major directions, the diagnosis of MSA at an early stage, and the treatment of orthostatic hypotension, an aspect of autonomic disease that can be devastatingly disabling.

Tim has completed a number of clinical research studies which will be incorporated in his Doctor of Philosophy thesis, to be submitted early in 2005 for consideration of a degree by the University of London, through Imperial College London. A number of his publications on this work will emerge over the next months in highly-regarded medical journals and I hope to be reporting on these at intervals. Of immediate relevance are observations on the beneficial effects of water which has caught the attention of a number of publishers, newspapers and the BBC. Of particular importance, is the credit provided to the Sarah Matheson Trust

for supporting this research, which will aid further dissemination of the valuable work of the Trust and the importance of spreading knowledge about these disorders so they can be detected early and treated efficiently.

I have been particularly delighted with how Tim has progressed over the years. He has now left us to continue with his clinical training, and in a few years should be eligible for Consultant Neurologist appointments. I am sure that you will join me in wishing Tim much success in his future career and, I hope, we will be welcoming him back to the fold in due course. He has set a superb example for others to follow and to continue his excellent work in advancing the diagnosis and treatment of MSA and allied conditions.

Professor Mathias

Reference:

TM Young, CJ Mathias The effects of water ingestion on orthostatic hypotension in two groups of chronic autonomic failure: multiple system atrophy and pure autonomic failure. Journal of Neurology Neurosurgery and Psychiatry, 2004. 75:1737-1741

waiters. Most important of all was that the food was delicious. Linda would say as important was that the toilets were completely accessible.

The afternoon came to an end and we were thinking what a special do this had been. The chef and staff were receiving applause for their appreciated efforts. It was then we learnt what was so different about this restaurant. It is part of a project, First Steps Trust, which sets out to provide quality services delivered by people who have been disadvantaged in some way.

We hope to return to this accessible restaurant, which provides excellent food and a good service at a reasonable price.

For those who are interested here are the details: Abbeville, 88 Clapham Park Road, London SW4 7B Telephone 020 7498 2185. And we have found a web site www.fst.org.uk, which gives details of this and their other projects.

Why does it take a New Zealander to introduce us to such delights in our own back yard, and not for the first time? Thanks Liz.

**Kieran and Linda Stone,
Hertfordshire**

What about external catheters?

Thank you for your review of continence. I am somewhat surprised that you do not mention external

catheters (i.e. Conveen), which I have used successfully for some years and are definitely less irritating than the indwelling sort. Before this I used 'Tena for Men' pouches which are quite good in the early stages.

Peter Mente, Hampshire

Note from the Editors: Ooops! Sorry about that. When we spoke to Continence Nurses they were wary of generally advising external catheters if people did not empty their bladders fully as this could encourage infections.

Letters



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

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Catherine Best (Nurse)
Nikita Ranade (Administrator)

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From the treasurer

I write as one of the founding trustees, which number five out of a total now of eleven. The five were either related to (or very close friends of) Sarah Matheson.

With her inspiring help during the final two years of her life we were determined to create a support group for her fellow sufferers of MSA which would, in her name, stand the test of time. At that stage we had no idea of the shape which the Trust would take, nor of its possible size.

Today, I think it is fair to say, the original five are even bemused by how far the Trust has come, and grown, in the seven years since its foundation. Needless to say we are fortunate indeed to have working with us Catherine and Alison, our two specialist nurses, and latterly the further six trustees, all markedly younger and thus adding extra dynamic to our joint efforts.

Recently we have also been joined by Niki Ranade as part-time administrator who as most readers will know now works alongside Alison at St Mary's.

The problem is this: the average age of the original five is nearly 70 and the later arrivals are all in full-time employment. It follows that the Trustees cannot themselves undertake any further tasks for the Trust and this could render difficult any expansion of our activities from here on; a possibility with little attraction as you may imagine.

The point of this piece is to enquire whether any of our readers would be keen to consider a voluntary secretarial role for the Trust working from home. This would entail picking up many of the loose ends which future expansion will doubtless generate.

If this possibility appeals at all, please in the first instance get in touch with Alison or Niki at St Mary's.

Val Fleming

Dates for your diary

- **Derby Awareness Day** Friday 18th March, Hospital for the Elderly, Derbyshire Royal Infirmary, London Road, Derby
- **London Marathon Supporters** Sunday April 17th, Come support our runners, watch the marathon at a pub near the finish and congratulate them when they stagger in for a drink.

All our members will automatically be notified of any Awareness Days held in their area; an invitation will be forthcoming once the date and details are fixed. For details of meetings outside your region please contact the SMT office.

In Memory

Donations received with gratitude in memory of:

- | | | |
|---------------------------|-----------------------|-------------------|
| ● Trish Adams | ● Mr PR Franks | ● Brenda Rolton |
| ● William & Josie Barrett | ● Pamela Gibson | ● Roy Russell |
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