msa *news*

MSA Trust Members Magazine | issue 55 | June 2019

Research to unlock the *mysteries of MSA*

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Welcome to issue 55

A warm welcome to your Summer edition of MSA News. In addition to articles on NHS Continuing Healthcare and Benefits on pages 10 and 18, Liz Garrood, a Specialist Neurological Coordinator, has written a helpful article about saliva management. We also have another research update for you on page 12, along with some of our regular features.

Many of you will start receiving your MSA Needs Survey questionnaires very soon, either by post or email, depending on your contact preferences. This is the most wide ranging piece of research ever undertaken by us focussing on the needs and experiences of people living with MSA. You can find out more information about the survey and why we're doing it on page 5.

We're also excited about our next Health and Care Professionals Study Day which this year will be held in Birmingham on the 10th October. The last two events have been hugely successful with all attendees saying they felt much more able to support people with MSA after participating. Tickets are now available on our website so if you are a professional supporting someone with MSA, we'd love to see you there. Best wishes, Emma and Andy. msa *news*

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Hearts of Oak - Heart of a Community

In June 2017, our 20th anniversary, we opened and began planting Sarah's Wood, a copse of oak trees in Sherwood Forest, to commemorate the Trust's founder Sarah Matheson. This will serve as a symbol of hope and resilience for all those living with MSA and inspire the memories of those lost to it.

The Wood is located in Thoresby Estate, Nottinghamshire, in the heart of Sherwood Forest. Planted with hardy Sherwood Oaks, this will become a permanent testament to the MSA Community. There are various ways that we hope people will get involved with Sarah's Wood, we have outlined these below.

Path to a Cure

Starting this year, we have begun building a path to the centre of this haven, our 'Path to a Cure'. This will be laid with bricks engraved with your or a loved one's name; symbolising the steps we are taking to fight and eventually beat MSA.

The path will extend through Sarah's Wood as more and more of our community become involved, marking the location as a monument to people affected by MSA and our shared efforts to live in a world free from the condition.

If you would like to find out more about contributing an engraved brick to the Path please email us at the address below or call the office to speak to our Fundraising team.

Summer Social

On the 27th July we will hold our first ever Summer Social where we will be hosting a garden party for people to get together, have fun and support the Trust.

There will be an afternoon tea followed by a guided Treasure Trail through the woods and gardens for children (of all ages). In addition, there will be croquet and a tour around the Grand House. We will round off the afternoon with the unveiling of our brand new Path to a Cure including the first engraved bricks to be laid at the Wood.

We look forward to welcoming you to this beautiful space. Tickets are on sale now so please complete the slip on the back page and return to us with payment.

Plant a Tree

We also hold regular tree planting sessions at Sarah's Wood for those people who wish to plant their own tree as a lasting symbol of being part of the MSA community.

Our next planting dates are 23rd November 2019 and 24th January 2020. You can either attend a session yourself or have us plant a tree on your behalf.

On attending you will meet with the Thoresby Forester and will be able to plant a sapling within Sarah's Wood. If you would like to come to one of the tree planting days or have a tree planted on your behalf please email us at the address below.

If you need more information about any aspect of Sarah's Wood, please contact the office on 0333 323 4591 or email **fundraising@msatrust.org.uk**

msa *news*

WHAT IS CLINICAL RESEARCH?

The Process of Research -

Why it matters

We know that research is important to people affected by MSA. This is why the Trust allocates a significant proportion of our resources into this area (see page 12 for an update on one of our current projects). Our MSA Nurse Specialist, Emma Saunders, explains what is meant by "clinical research" and demonstrates how important research is.

The aim of undertaking clinical research is to gather evidence that can be applied for improved understanding of health and healthcare and the development of safe and effective treatments.

Most clinical research in the NHS will take the form of a research study or a clinical trial. A research study aims to better understand health and health conditions and may gather information from a person about their history, medical condition, treatments and outcomes. A research study collates information but does not introduce new or experimental treatment. A clinical trial, however, compares the effects of two treatments, usually either a new drug (but possibly new technologies or methods), or the use of an existing drug in a medical condition that it has not previously been used for.

There are commonly four phases of clinical trials:

- ***Phase I -*** *is the first clinical phase and usually involves small groups of healthy volunteers or patients, to assess the safety of the drug*
- ***Phase 2 -*** *involves slight larger numbers of people, usually patients, and assesses the safety, effect, optimal dose and side-effects of the drug*
- ***Phase 3 -*** *involves testing the drug in large numbers of the patient population, to compare the drug to current or placebo treatment, assess effectiveness, safety and longer-term effects.*
- ***Phase 4 -*** *usually once the drug has been shown to work and licenced for use, a phase 4 study can examine how well the drug works when used more widely, long term risks and benefits and possible rare side-effects.*

Participating in research is always entirely voluntary and a person can withdraw from a research study at any time and without their clinical care being affected. There is more information about clinical research and questions to consider on the NHS website **www.nhs.uk/conditions/clinical-trial**. All clinical research undertaken in the NHS must be approved by a Scientific Committee and by a Research Ethics Committee to ensure the research is scientifically valid and ethical. All expected risks and benefits of any research should be fully explained before a decision to take part.

We are not aware of any clinical trials currently recruiting people with MSA in the UK. Recruitment is currently open for the 'PROSPECT-M' research study. The aim of this to track changes in the condition over time with the aim of improving methods for early diagnosis and tracking disease progression.

If you are interested in taking part in research ask your specialist about what research is being done in your area. You can find out more about research, search for studies that are currently recruiting and find research results via the UK Clinical Trials Gateway website at **www.bepartofresearch.nihr.ac.uk** and **www.clinicaltrials.gov**. msa *news*

If you would like to find out more about taking part in the PROSPECT-M study please visit **www.msatrust.org.uk/current-research** or contact **v.chelban@ucl.ac.uk**.

NEWS ROUNDUP

Trust Research Call

In 2017, we put out a call to the neurological research community for applications specifically for projects to aid earlier identification of MSA. We had an amazing response and funded three very good projects, which are all ongoing and which we will continue to report on in MSA News as they progress. This year we will once again be making funding available for bids. The criteria will be advertised on our website in the Autumn but we would encourage any researchers with specific MSA linked projects to contact us for exploratory discussions. msa *news*

Hospice Course

Several of our members recently attended a course at the Wellbeing Centre in Weston Hospice for people living with neurological conditions. The four week course aimed to inform people about the hospice support available for them.

It started with a session introducing hospice services and then looked at other useful local services. The course also included sessions on wellbeing and advanced care planning as well as relaxation and an introduction to complimentary therapies. The final week included practical information on financial support and Power of Attorney.

Some hospices may also run, or might be interested in running, similar initiatives. Why not find out what is available at your local hospice? Find your nearest hospice on the Hospice UK website - **www.hospiceuk.org/about-hospice-care/find-a-hospice**. msa *news*

Celebrating our Nurses

We recently highlighted on social media the work of all four of our MSA Nurse Specialists for International Nurses day. We received some wonderful feedback from you about their work, thank you. This year two of them, Samantha Pavey and Katie Rigg, celebrate the milestone of ten years working at the MSA Trust. We're so proud of all of their work and commitment to supporting all people affected by MSA and we are glad to know that so many of our members join us in saying a huge thank you for all their passion, hard work and expertise. msa *news*

SMAMANTHA PAVEY

KATIE RIGG

Help us to help you

We are days away from launching the first ever survey looking at the needs of people living with MSA. We are working with an organisation called Quality Health with whom we have developed a questionnaire that will look at the main needs that you feel are important in living with MSA. This will address not just medical needs but other more general issues such as finances, planning and relationships.

We have spent the last few months testing out the questionnaire so that it makes sense and is sensitive to the particular issues people may experience.

We know we ask a lot of our community but we really need as many of our members as possible to complete this survey to give us the strongest evidence possible. We will use this information to improve our services, raise awareness of the needs of our community and to ensure we can argue, with robust evidence, that more support is needed in specific areas to make life easier for people affected by MSA.

We will begin to send out the surveys around the beginning of July, by email or post depending on your contact preferences. The survey is aimed at finding out the needs of people affected by MSA and can be completed by carers as long as the responses are from the person living with the condition. It will take about 40 minutes to an hour to complete, but can be done in stages. We will be feeding back results in future editions of MSA News. msa *news*

Saliva *Control*

A common issue for many, Liz Garood, Specialist Neurological Co-ordinator in Bedfordshire explains the range of options that can be used to manage saliva effectively.

Many people I support complain that one of the biggest problems they face is drooling, and/or thick saliva, that they find difficult to clear. It can have a significant negative social impact, causing embarrassment and distress at the inability to keep saliva in the mouth.

General health may also be affected with risks regarding dehydration, possible development of infections in and around the mouth and occasionally, chest infections, which can sometimes turn to pneumonia if saliva accidentally enters the lungs (this is called aspiration). Therefore, it is extremely important for professionals to listen when people describe trying to manage their saliva, so that an appropriate treatment plan can be worked out.

Saliva production is normal and essential to assist digestion, preserve moisture in the mouth and maintain good dental health. Saliva is also antibacterial. We produce about one and half litres every day and it is estimated that a person will create enough saliva to fill two average size swimming pools during their lifetime. As we naturally swallow about once every minute, it is not normally a problem. However, if the nerves that control our saliva production, swallow and/or, ability to close our mouths are not working properly, then saliva will tend to pool and spill out over our lips.

> *People with MSA may experience either too much saliva or thick secretions and a dry mouth and sometimes both, which is particularly problematic.*

At present there is little scientific proof detailing how to manage these symptoms but there is a wealth of experience amongst professionals and recognition that access to a multidisciplinary team, can be beneficial. This team will work closely with you and your family to develop a management plan that tries to achieve an improvement, without creating a raft of extra complications from unwanted side effects of medications.

Speech Therapists can help to assess swallow and work out where the root of the problem may be such as poor lip closure, inability to move the tongue, or just forgetting to swallow. They can advise about specific exercises and how to develop swallow reminders, as well as regularly reviewing patients to monitor changes and recommending referral to other specialists for treatment such as Botox therapy if appropriate.

Dietitians will look at whether the inability to swallow has caused weight loss or dehydration and whether dietary factors may be contributing to symptoms (spiced foods, milk-based products, caffeine, alcohol, etc). They can advise about diet alterations and natural products to help, such as pineapple juice for thick secretions and grape juice for thin, runny saliva.

Occupational Therapists can ensure that optimum posture is achieved by providing appropriate items of equipment to help such as, neck collars, head back wheelchairs, seating cushions etc.

Physiotherapists can assist with exercises that improve posture and relieve tension across the shoulders and neck that may be contributing to the 'flexed posture' (head down). They may also be able to help by providing or teaching oral suction that patients or families can then manage themselves to clear saliva when it is particularly challenging.

The Clinical Nurse Specialist will explore any contributory factors that may be affecting the situation such as, other underlying conditions, oral infection (thrush), poor fitting dentures or gum disease, posture, lifestyle influences, such as smoking or drinking and whether they may be causing increased symptoms. They will also look at whether diet has been affected and what the potential health risks may be. They will liaise with the GP, Neurologist and other members of the multidisciplinary team to ensure that conservative measures, for example treatment of other conditions or local infection is undertaken. They should advise about good oral hygiene (including visits to the dentist) and ensure that positioning, exercise, diet, steam inhalation (salt water nebulisation) and suction have all been tried first, before considering prescription of medications that can affect the flow of saliva. They will also consider whether current medication being taken may be contributing to the problem and whether any new drugs will interact with these, causing more problems.

Only when these initial treatments have been tried and failed will alternatives, such as Botox therapy, be considered. Botulinum toxin (Botox) is a neurotoxin that is given by injection, directly into the salivary glands and works by stopping the function of the cells that secrete saliva. Therefore the main side effects are dry mouth and thickened secretions, with effects (good and bad) lasting up to six months.

Sometime symptoms can be very severe and the above measures remain ineffective. People may then be considered for radiotherapy or surgery of the salivary glands, but this is extremely rare and considered a 'last resort'.

It is important people know that no one treatment is likely to be successful and often a combination of approaches is required. Symptoms can also improve and then become worse again, so regular review and treatment variation is extremely important.

Saliva management can be difficult not only for people affected by MSA, but also for us professionals. By all of us working together we are able to make the best of sometimes challenging situations. msa *news*

In Memory

John Day
Rowland Hill
Robert Proctor
Marion Darby
Lynn Ginn
Irene Thomson
Richard Perry
Christine Lloyd
Joyce Higton
Michael Oliver
Penny Walmsley
Gill Bowden-Green
John Humphrey
David Heatley
Rajen Balgobin
Christine Humpleby
Philip Tookey
Janet Somerville
Andrew Hart
Christine Ridsdill-Smith
Colin Allan
James White
Brendan Sheridan
Phillip Fahey
Leslie Walker-Wall
Paul Longworth
Norma Jean Williams
Caryl Male
Pamela Leslie
Patrick Murphy
Paula Stainer
Patricia Peasey
June Black
Susan Little
Pauline Spann
Philip Morris
Robin Matthews
Ginny Davies
Hilary Fitton
Colin Holmes
Martha Whitehead
Wayne Criddle
Leonie Jameson
Joy Sparrow
Evelyn Luke
Richard Faircliff
Bob Harle
Glynn Griffiths
Colin Baker
Kathleen Foster
Robert Hursey
Anne Maher
Philip Day
Francis McGeown
Martha Kernaghan Campbell

LEGACY GIVING

We are a charity entirely funded by donations. Through wonderful generosity and tireless fundraising our supporters enable us to continue and develop our work, increasing the number of people we support.

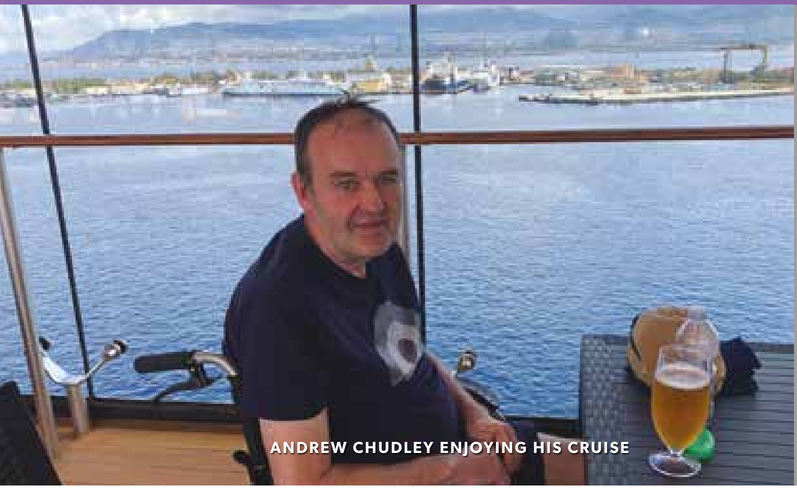
Whilst we rely on donations and general fundraising a growing part of the Trusts income over the last few years has been through legacy giving. Mentioning and leaving a gift to the Trust in a Will can make a real difference to our work and also has the benefit of being inheritance tax free.

We have a Legacy Pack for guidance if you could consider a gift in your Will, but we would also recommend consulting a solicitor.

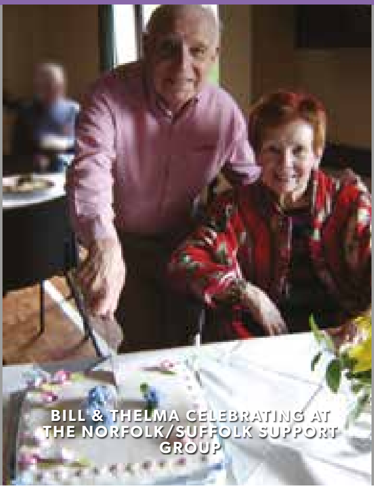
Through recent legacies we have been able to increase our research funding and develop the first ever MSA Needs Survey so you can be sure that any legacy, big or small, will really help and be used effectively.

If you would like to find out more or to get our Legacy Pack please call 0333 323 4591 or email **fundraising@msatrust.org.uk**.

Member Stories



ANDREW CHUDLEY ENJOYING HIS CRUISE



BILL & THELMA CELEBRATING AT THE NORFOLK/SUFFOLK SUPPORT GROUP

Sea's the Moment

"The gladdest moment in human life is a departure into unknown lands." – Sir Richard Burton

The summer months are just around the corner and we know a lot you will be looking forward to a break away. Two of our members, Andy, who has MSA and his wife, Andrea have just returned from a fantastic cruise. They travelled to Genoa, Naples, Sicily, Malta, Barcelona and Marseille, taking in all the sights along the way. They said they found the information on our website and in the 'Travelling and MSA' factsheet excellent when planning their trip.

> *"We made sure to plan ahead, which guaranteed our journey was straightforward and simple. The cruise ship was equipped with everything we needed and staff went out of their way to help make our holiday memorable. Who would have thought we'd have the opportunity to see all these wonderful countries following a diagnosis of MSA? With careful planning and the right attitude, anything is possible."*

It is all too easy to put off going away because of worries about managing daily needs in different and unfamiliar surroundings. However, careful planning and being prepared will help to ensure an enjoyable holiday experience. You can download the factsheet from our website **www.msatrust.org.uk** or call us on 0333 323 4591 and we'll be happy to post you out a copy. msa *news*

Celebrating Over 60 Years

Thelma and I first met when we were 16 and 17. Against family advice we married three years later in 1959, at the ages of 19 and 20. Contrary to family predictions, we have had a wonderful 60 years together. She has always been the most beautiful woman I have ever seen.

We have enjoyed friendship and mutual interests, travelled the world and had two children, six grandchildren and been wonderfully happy. Thelma was a senior dealer for NatWest in the City and I had 35 years in the dock industry and 13 years in aggregates.

Our passions have been home building, travel and walking. We have walked and visited extensively abroad and have been to nearly every part of the UK. However now, in addition to MSA, Thelma also has Alzheimer's which means she has no memories of our life together. It is a sadness of our situation, that we are no longer able to pursue these previous activities.

The Support Groups we attend for MSA and Alzheimer's are very helpful, providing support, friendship and advice. I would thoroughly recommend anyone with such problems to contact their local group. We are fortunate in Suffolk/Norfolk to have a very good MSA group, run excellently by Julie Hillary and her wonderful group of volunteers. We were very touched by their generous celebration of our 60th Wedding Anniversary, which included a wonderful cake baked by Julie's friend, Mary.

By Bill Luxford. msa *news*

When needs become *complex*...

In England and Wales NHS Continuing Health Care (CHC) funding is available to people who are assessed as having a 'primary health care need' and who are not in hospital.

NHS CHC funding is just one source of care. Information and advice on other options and how to access care, is available from your local Social Services or from us at the MSA Trust.

People who have complex, intense or unpredictable health care needs may be eligible for a package of care that is arranged and funded by the NHS. A diagnosis of MSA does not, in itself, give eligibility and it can be challenging to obtain NHS CHC funding.

Getting NHS CHC funding depends upon the outcome of a detailed assessment of needs and is usually a two stage process. An initial 'check list' screening is carried out and, if it is felt that a person should have a full assessment, this is completed using a document known as the 'Decision Support Tool'. This looks at needs across 12 domains (for example, mobility, nutrition and cognition) and at the nature, intensity, complexity and unpredictability of a person's health care needs.

If a person has a rapidly deteriorating condition and may be approaching the end of their life a much simpler 'fast track application' can be made by a doctor or nurse.

If you think you may be eligible for NHS CHC funding ask a health or social care professional (for example, your District Nurse, Social Worker or GP) to arrange an assessment.

NHS CHC funding is designed to meet the costs of an individual's care package at home or to cover all of their fees in a care home. There is no charge for the care and no means test applies. NHS CHC funding should cover all of an individual's care costs and 'top up' funding should not be requested from the individual or their family.

In England your local CCG (Clinical Commissioning Group) is responsible for NHS CHC funding whereas in Wales it is the responsibility of the Health Boards.

In Northern Ireland advice on CHC type funding is available from your local Health and Social Care Trust - **www.nidirect.gov.uk/contacts/health-and-social-care-trusts**.

NHS CHC funding does not exist in Scotland but personal care, along with nursing care, is now available free of charge to adults of all ages who require it. See **www2.gov.scot/Topics/Health/Support-Social-Care/Support/Adult-Social-Care/Free-Personal-Nursing-Care** for more information.

Different services exist in the Republic of Ireland and you can find out more information here - **www.citizensinformation.ie/en/health/health_system**.

If an application is unsuccessful an appeal process can be used.

You can contact our Advocacy Officer, Jane Stein at **jane.stein@msatrust.org.uk** for more information on NHS Continuing Health Care.

– JOANNE (RIGHT) WITH HER DAUGHTER RACHEL AND DOG BUDDY

Joanne's Story

Joanne Wright, who is living with MSA, and her 27 year old daughter Rachel had not heard of NHS CHC funding until the District Nurse suggested it and completed a checklist assessment with them. Joanne had just started to have carers coming in although Rachel was providing much of her care support. The District Nurse explained the system to them and gained Joanne's consent to access medical and social care records and to talk to other professionals about her needs.

After the check list a full assessment was quickly arranged which took place over two days because the assessor could see that Joanne was becoming very tired. Joanne and Rachel say they both felt fully included in the process. Rachel explains "We didn't think Mum would get it but they looked at her as an individual and understood her needs. We were so well supported through the process – they really couldn't do enough to help."

> **"They asked my Mum what three things she would like and she chose swimming and getting out more. She also said 'for Rachel to do less'." They also fund hydrotherapy sessions which I take Mum to."**

Joanne, from North Somerset, now has carers seven days a week from 8am until 6pm with extra carers helping at specific times in the day when two people are needed. Rachel has returned to a job outside the home three days a week but is paid 16 hours a week by the CHC funding for supporting her mum – mostly with leisure activities. Having someone at home with Joanne throughout the day has also enabled them to acquire a rescue dog called 'Buddy', a delightful addition to their family home.

Joanne was offered options about how her care was provided – through employing carers of her own choice using a personal health budget or through an agency.

For Joanne and Rachel one of the most important benefits has been having the ongoing support of a fantastic care co-ordinator at the Clinical Commissioning Group. She wasn't involved in the assessment but is quick to respond if Rachel calls her. For example, she sorted out an increased care package for Joanne when Rachel felt it was needed. The co-ordinator has also stressed to them that if Joanne is ever taken into hospital they must liaise with her to ensure a timely discharge home. The care package was reviewed after three months with the emphasis being on checking it was meeting Joanne's needs.

Both Joanne and Rachel advise others "Don't be put off by the process. Obtaining the support is worth it." As Rachel says "Now Mum has someone with her all day she is able to do so much more and I worry so much less." msa *news*

UPDATE FROM OUR RESEARCH FELLOW

The need for biomarkers in MSA


VIORICA CHELBAN

Biomarkers are measurable indicators that provide insight into the different biological processes that take place within our bodies. They may indicate either normal or diseased processes in the body. Widely used in research and clinical practice, they help to provide an accurate diagnosis. However, their use goes beyond being just a diagnostic tool. Fluid biomarkers have gained attention in the past decade because they provide an opportunity to track disease progression and monitor efficacy of drugs and other treatments. A fluid biomarker is one that can be obtained through the extraction of biological fluids such as blood (plasma and serum, for example) and cerebrospinal fluid (CSF).

We have significant challenges to overcome in order to find modifying treatments for MSA. These include the length of time it can take before getting a diagnosis and our limited understanding of what causes MSA, coupled with the lack of a reliable measure to track the disease progression. "I would love to have a blood test that is validated in a large MSA group of patients, has good correlation with disease severity and progression, and is easy for patients to provide. A fluid biomarker, an imaging protocol or a combination of the two would be ideal." says Professor Henry Houlden who is leading the MSA clinic and research at the UCL Institute of Neurology, London.

One such opportunity may come from a protein called neurofilament light chain (NfL). NfL provides structural support to nerve cells. It is released into the blood or the fluid around the brain and spinal cord (CSF) when the nerve cells or their connections are damaged. Therefore the level of NfL in the blood or the cerebrospinal fluid is a measure of nerve cell breakdown and as such, it provides a dynamic marker for the severity of the cells' destruction process during the course of diseases. NfL is not a specific marker for MSA or a particular disease but it has been shown to correlate well with disease severity and progression in other neurodegenerative conditions such as Alzheimer's disease and Parkinson's disease (PD). A higher level of this protein released into the blood or CSF is usually associated with a more severe disease and a normalisation of the NfL level represents a halt in damage to nerve cells.

A marker that correlates with the severity of the disease at the nerve cell level is of great interest for MSA. So far, the response to treatment in most MSA drug trials has relied on changes in patients' symptoms and scores based on the severity of symptoms. Having a blood test that helps us understand if the drug has reduced or halted the nerve cell damage during a drug trial would be a game-changer in MSA research, particularly if that biomarker correlates well with the changes in patients' symptoms. Some hints that NfL could be helpful in providing this information for MSA come from small studies of atypical parkinsonism showing that there is an increased level of NfL in CSF and serum in patients with MSA compared to patients with PD and healthy controls. However the MSA number of patients included in these studies was very small, varying between 10 and 48 individuals.

For the last three years I have been collecting blood samples and CSF from patients and healthy controls to build a biobank that would allow us to measure markers of MSA. So far we have an impressive set of blood samples from 90 patients. In the next few months you can find me in the lab where I will be measuring NfL from participants. I will compare results

with the severity of symptoms in each patient in order to draw a profile of this marker in MSA.

A fundamental challenge in MSA research is the numbers game. Dr Lucia Schottlaender has spent the last six years researching the genetic architecture of MSA:

> *"My experience doing MSA research was rewarding but also very challenging. Patients and their families were always very kind, generous and willing to participate. However, a key limitation was obtaining large sample sets of patients to give us enough statistical power. Although significant progress has been achieved in the past years, we still need to join efforts though collaborative projects including but not limited to scientists, clinicians, charities, research councils and patients all over the world."*

Dr Schottlaender is undoubtedly right and the need to join forces for research is increasingly acknowledged throughout the MSA research community. We have recently established collaboration with the MSA research centre in Barcelona, Spain. Last month I received plasma and CSF from 55 Spanish patients with MSA to measure their NfL profile too, aiming to increase the statistical power of our experiment. Other MSA research centres from Europe are joining our project and we will soon transfer samples from MSA patients in Russia and France to our lab. Similarly, we are always monitoring research that happens elsewhere and we are contributing with data and samples to join global efforts towards finding a biomarker that can track the disease or its severity, and the efficacy of possible drugs treatments in the future.

Ultimately, my aim is to acquire a set of biomarkers derived from blood and CSF as well as brain scans from each person with MSA. We will then be able to correlate the changes in the blood with the changes seen on scans and the severity of symptoms so that when drug companies invite us to participate in drug trials we will be able to objectively monitor the effect of the potential treatment. Not relying solely on symptom-based scores and having these measurable fluid and imaging biomarkers will drive earlier interventions even when symptoms are mild or questionable - the best time for a disease-modifying intervention. msa *news*

I am grateful to all the patients and their families for their participation in the research. The UK MSA biobank of samples, scans and clinical data supported by the MSA Trust is a crucial resource that drives further biomarker initiatives. I am also the coordinator for the PROSPECT-M research study (more on this on page 4) so if you would like more information about this please contact me at **v.chelban@ucl.ac.uk**.

A MARATHON EFFORT

*Our supporters were out in force this April to cheer on our **London Marathon** team. All ten runners crossed the finish line and so far they have raised close to £27,000 towards our work.*

*A huge thank you to **Shaun Leach, John Sullivan, Andrew Symes, Mike Sillitoe, David Maclennan, Alice Morris, Rebecca Tubridy, Naomi Todd, Angharad Williams and Tina Clark** for their phenomenal work this year.*

*If you'd like to take part in 2020 applications are now open. Please contact our Fundraising team at **fundraising@msatrust.org.uk**.*

***Michael Spence, Clare Luery and Jasmine Swanborough** ran the **Manchester Marathon** for the trust and raised £725, £510 and £375 respectively. They even met up on the start line!*

***Katie Watson** ran the **Barcelona Marathon** in memory of her father, Michael Herbert, raising £700. Katie's mother, Stella and the Sherwood Rotary Club have been helping us make Sarah's Wood a special place for the MSA Community. We are so grateful to the Herbert family for their continuous support.*

***Harry Manley** completed the **Brighton Marathon** in just under four hours and raised an incredible £1,025 to support his aunt who has MSA, Eileen Shaw.*

*For those of you thinking about running we are excited to be partnering with a third-party agency to bring you local and international Marathons including those in Amsterdam, Paris, Barcelona, Manchester and Edinburgh. We also have MSA Trust places in the world's most popular Half Marathon, the Great North Run. If you, or anyone you know, are interested in these world-famous runs, please get in touch with our Events team – **fundraising@msatrust.org.uk**.*

MID-AIR FUNDRAISING CHALLENGES

__Hollie Lough-Scott__ did a sponsored skydive to give something back to the Trust for all the support received for her Nana, Patricia Dickens, who sadly passed away recently. She raised close to £1,000.

__Chloe Child__ did a 15,000 ft tandem skydive to cap off her season of fundraising and raised more than £1,300 for the Trust. Well done divers and we hope you enjoyed the view from up there!

IN THE COMMUNITY

__Julie Hillary__, friends and family held a bucket collection during MSA Awareness Month at Diss Train Station. In just one afternoon they collected £124.56!

__Beverley Wrigley, Zoe Long and Nichola Kinane__ organised the Masquerade Charity Ball in memory of Beverley's brother, Eric Armitage. The event was coordinated by Engaging Safety and had some amazing raffle prizes donated by local businesses such as Mercedes Bury, RRG Toyota Rochdale and Eric's family business, Armitage Productions. Eric's parents accepted the cheque for £2,500 on behalf of the Trust at Engaging Safety's office. We are so grateful to Beverley and the entire Armitage family and look forward to their next event at Rochdale AFC Crown Arena.

__Gillian and Paul Wheeler__ requested that the 2018 class of Ministry of Defence Police Recruits fundraise for the Trust. Paul had served 32 years in the Criminal Investigation Department, until sadly he had to retire due to his MSA diagnosis. Gill is still with the force. The recruits did an incredible job and raised over £1,000.

Last year, Club President __Heather Bailey__ nominated us as __Soroptimist International Croydon and District Club's__ Charity of the Year. Long standing member of Club, Penny Veness lost her husband, Bob to MSA and the Club wished to have all their social events in aid of the Trust. Events ranged from a stall at the Warlingham Fair, to a Quiz and Curry night and even a Line dancing evening. A fantastic cheque presentation saw Penny and Heather handing over the £7,200 amount raised by the Club.

EMMA RUSHTON PRESENTS HER REGULAR ROUNDUP OF YOUR TOP SUPPORT GROUP TIPS

Supporting & Helping Each Other

We now have more Support Groups in our network than ever before, which means more opportunities for our members to support each other and get expert information from our MSA Nurse Specialists. Our Nurses, and often our Advocacy Officer and other staff, try to attend as many of these Support Groups as possible each year. Throughout the first half of this year there's been a huge amount of useful information shared so here's a roundup of our top tips and hints...

At the Glasgow Support Group a member spoke about a device called 'SpillNot' which helps when carrying drinks. It has a strap which makes it easy to hold or hang on to something (for example a walker) and is designed so that it does not spill any liquid. The member reported that it can be swung around at an angle and the cup stays on the SpillNot without spillage. Our MSA Nurse Specialist thought this could also be helpful for people with MSA that have a tremor or need to keep their hands free when walking. More information about these and how to buy one can be found here - **www.spillnot.myshopify.com**.

A member who attended the last Sligo Support Group in Northern Ireland spoke about using a system called BUDDI. This is a fall alarm which also has a tiny transmitter inside which means it works when you're out of the house as well as at home. They have found it to be very reliable and easy to use. Find out more by visiting the BUDDI website here - **www.buddi.co.uk/faq/general**.

The Solihull Support Group, which is run by the Marie Curie Hospice but our MSA Nurse Specialist, Emma often attends, discussed bladder and bowel issues which can be problematic for most people with MSA. A carer spoke about her husband, who has MSA, getting two to three urinary tract infections a month. He ended up getting a catheter fitted which has a silver coating. Silver naturally prevents bacteria from bonding to the surface of a catheter, so reducing the chance of developing urinary tract infections. The gentleman has since had no urine infections in over two months. To get more information about this please contact your MSA Nurse Specialist, all their details can be found on our website **www.msatrust.org.uk** or by calling 0333 323 4591.

Linking to bladder concerns, our Tyne and Wear Support Group had a visit from a Continence Nurse who offered advice to people that find they have to get up a lot in the night to use the toilet. They suggested having a lie down with feet raised above hip level on a pillow for 30 minutes around two to three hours before going to bed. This raises blood pressure which improves the efficiency of blood flow to the kidneys. The kidneys then draw excess fluid out of the blood and into the bladder making it more likely urine is cleared before going to bed.

Blood pressure issues are common with MSA and two Support Groups shared ideas on how to best cope with this. At the recent Kent meeting a member said they found eating six smaller meals a day, rather than three larger meals, the best way to regulate blood pressure. The Belfast Support Group shared that a tilt-in-space commode or shower chair was useful in the shower to ensure that falls don't happen if a drop-in blood pressure occurs. msa *news*

If you have any questions about anything included in this article please contact your MSA Nurse Specialist at **support@msatrust.org.uk**.

Support Groups are a great way to meet other people affected by MSA, listen to presentations from healthcare professionals who can support you and meet our MSA Nurse Specialists. Please contact the Trust's office on 0333 323 4591 or email support@msatrust.org.uk for more details. These groups are subject to change, so please check the Trust's website or ring the office for up-to-date information.

GROUP	VENUE	DATE & TIME
Surrey	Shalford Village Hall, Kings Road, Guildford, GU4 8JU	Tue, 18 Jun - 2pm
Edinburgh	Goodtrees Neighbourhood Centre, 5 Moredunvale Place, Edinburgh EH17 7LB	Wed, 19 Jun - 1.30pm
South Yorkshire	St Peter and St Paul Church Hall, Todwick, Sheffield S26 1HN	Wed, 19 Jun - 1.30pm
Glasgow	Beechwood Community Centre, Shortroods Road, Paisley PA3 2NT	Thur, 20 Jun - 1:30pm
County Durham	Day Room, Front Street, Chester le Street, County Durham DH3 3AT	Mon, 24 Jun - 1.30pm
Greater Manchester	Disabled Living Centre, Burrows House, 10 Priestley Road, Wardley Industrial Estate M28 2LY	Thur, 27 Jun - 1.30pm
Bristol	The West of England MS Therapy Centre, Bradbury House clinic, Wheatfield Drive, Bristol BS32 9DB	Thur, 27 Jun - 1pm
Hertfordshire	Hospice of St Francis, Spring Garden Lane, Off Shootersway, Berkhamsted, HP4 3GW	Thur, 27 Jun - 2pm
West London	St.Paul's Centre, Queen Caroline Street, London W6 9PJ	Fri, 28 Jun - 2pm
North London	Southgate Hockey Centre, Snakes Lane, London EN4 0PS	Mon, 03 Jul - 2pm
Cumbria	Burton Memorial Hall, Main Street, Burton in Kendal, Carnforth LA6 1NA	Fri, 05 Jul - 1.30pm
Tyne & Wear	St. John's Church Community Hall, West Lane, Killingworth, Tyne and Wear NE12 6BL	Tue, 09 Jul - 11am
East Yorkshire	Etton Village Hall, 37 Main Street, Etton, Beverley HU17 7PG	Wed, 10 Jul - 1.30pm
West Yorkshire	Small Hall, Kirkgate Centre, 39a Kirkgate, Shipley, West Yorkshire BD18 3JH	Fri, 12 Jul - 1.30pm
Cardiff	City Hospice, Whitchurch Hospital Grounds, Whitchurch, Cardiff, CF14 7BF	Wed, 17 Jul - 11am
Cornwall	Carnon Downs Village Hall, Tregye Road, Carnon Downs, Truro TR3 6GH	Thur, 18 Jul - 1.30pm
Dorset	The Grove Hotel, 2 Grove Road, East Cliff, Bournemouth, BH1 3AU	Mon, 22 Jul - 11am
Devon	Baptist Church, High Street, Cullompton EX15 1AA	Wed, 31 Jul - 2pm
West Midlands	Bournville Gardens, 49 Bristol Road South, Birmingham, West Midlands B31 2FR	Mon, 05 Aug - 2pm
West Sussex	Worthing Quaker Meeting House, 34 Mill Road, Worthing, BN11 5DR	Tue, 06 Aug - 2pm
Lancashire	Community Room, Tesco Extra, Clifton Retail Park, Clifton Road, Blackpool FY4 4UJ	Fri, 09 Aug - 1.30pm
Tayside	Coupar Angus Town Hall, Union Street, Coupar Angus, PH13 9AE	Thur, 15 Aug – 1.30pm
County Sligo	Therapy Room, St John's Community Hospital, 8 Ballytivnan Road, Sligo	Wed, 21 Aug - 1.30pm
County Kerry	Great Southern Hotel, East Avenue, Killarney, County Kerry	Mon, 26 Aug - 1.30pm
Belfast	Marie Curie Hospice, 1A Kensington Road, Belfast BT5 6NF	Tue, 27 Aug - 2.30pm
Three Counties	Boys Brigade Community Centre, Canterbury Leys, Newtown, Tewkesbury GL20 8BP	Tue, 27 Aug - 3.30pm
Dublin	Education Centre, St. Francis Hospice, Blanchardstown, Dublin	Wed, 28 Aug - 1.30pm
Shropshire	The Lantern, Meadow Farm Drive, Shrewsbury SY1 4NG	Mon, 02 Sept - 1.30pm
Surrey	Shalford Village Hall, Kings Road, Guildford, GU4 8JU	Tue, 03 Sept - 2pm
Leicestershire	Village Hall, Main Street, Swannington, Coalville LE67 8QL	Tue, 10 Sept - 11am
Staffordshire	Katharine House Hospice, Weston Road, Stafford, ST16 3SB	Wed, 11 Sept - 10am
Greater Manchester	St. Andrews Church, Hope Centre, 27 Tattersall Avenue, Bolton BL1 5TE	Wed, 18 Sept - 1.30pm
Cambridge	Cherry Hinton Village Leisure Centre, Colville Rd, Cambridge CB1 9EJ	Thur, 19 Sept - 2pm
Southport	St James's Church Hall, 26 Lulworth Road, Birkdale, Southport PR2 2BQ	Thur, 19 Sept - 2pm
Bristol	The West of England MS Therapy Centre, Bradbury House clinic, Wheatfield Drive, Bristol BS32 9DB	Thur, 19 Sept - 1pm

UPDATE FROM OUR ADVOCACY OFFICER

For Your benefit

Important information if you are under state pension age

The age at which people can access their state pension has been, and still is, changing. With the changes to state pension age comes accompanying changes to the age limits for Personal Independence Payment (PIP) and Attendance Allowance (AA).

Previously people under 65 who needed assistance with personal care and/or who had mobility difficulties applied for PIP, and people over 65 who needed help with personal care applied for AA.

PIP claims can now be made up until you reach your state pension age. This may be advantageous because PIP has a mobility component to it but AA does not. Anyone approaching their state pension age is advised to ensure they are in receipt of PIP if they are entitled to it, and that they are receiving the correct rate of the mobility component.

People already receiving PIP when they reach state pension age can remain on this benefit (not transferring to AA) and the care component of it can be increased if necessary. Even if you already receive PIP, the mobility component cannot be applied for after you reach state pension age, nor can it be increased after this date, but you can remain on your existing level of the mobility component. If in receipt of the enhanced rate, you can continue to use the Motability scheme, which offers cars on lease, powered wheelchairs and mobility scooters. msa *news*

If you require further information or telephone support to complete forms please contact our Advocacy Officer, Jane Stein on 01404 44241.

Extension of free personal care to under 65's in Scotland

As many of our members will be aware care support services vary significantly in different parts of the United Kingdom and the Republic of Ireland. In Scotland free personal care support has been available to people over 65 for some time. Since 1st April 2019 this has been extended to include adults of all ages regardless of their financial circumstances.

To access free personal care support at home or in a care home it is necessary to have an assessment of your needs from your local social work department. Personal care covers assistance with tasks such as washing and dressing but does not include assistance with shopping, cleaning or laundry. Charges may still be made for these services.

If you are a care home resident and your local authority agrees that you require assistance with personal care it will contribute £177 a week directly to the care provider.

People living at home will be provided with the personal care services they need or they can be allocated a budget to purchase the care for themselves.

For further information please see:

www2.gov.scot/Topics/Health/Support-Social-Care/Support/Adult-Social-Care/Free-Personal-Nursing-Care and https://careinfoscotland.scot or call 0800 011 3200. msa *news*

Partners in Fundraising

This year we have again been working in partnership with some amazing companies who have gone the extra mile to help those we serve.

Klondyke Group are a chain of 22 Garden Centres in Scotland, Northern England and Wales. Their support started in 2016, as their Founder, Bob Gault passed away from MSA. Last year the Edinburgh branch, Mortonhall Garden Centre, created a Christmas display of a miniature village. Customers who donated to view the display raised an astounding £2,000. Along with the sale proceeds from carrier bags Klondyke's total raised was more than £8,000.

We were delighted that **Papa John's Pizza** incorporated the Trust in their Pennies Scheme. This allowed customers to donate their change to the Trust when ordering pizzas online. Sarah Bridges works at Papa Johns and nominated the Trust for support as Sarah's sister, Jane, has MSA. Papa John's, their dedicated employees and the Scheme has raised more than £11,500!

Perfect Skin Solutions is a Portsmouth based skin care specialist clinic. The founder, Dr Dev Patel lost his father Ramesh to MSA in 2016. The clinic kindly donated part of the sale proceeds from tickets for a product launch event in September last year.

We are always looking for new ways of working with businesses and organisations. So if you, or anyone you know, has any links please get in touch with Tanya at **tanya.mitra@msatrust.org.uk**. msa *news*

Inspiration for the Global MSA Walkathon

In May last year, the Joyce James Memorial Walk was completed by Joyce's husband Frank, daughters Shirell and Andrea and their family and friends (pictured). It was 50 miles along the South West Coastal path, completed over six days. The walk was chosen as Joyce was a wonderful gardener and loved visiting botanical gardens. The team managed to raise well over £5,000.

If you are inspired by this fantastic achievement, then you may be interested in the Global MSA Walkathon. In collaboration with the USA based MSA Coalition, the aim is that people affected by MSA all over the world will together walk over 52,000 miles, the distance between all the major MSA organisations globally.

You can join by registering online and getting friends and family to sponsor your goal. Then start tracking all the miles you walk, jog or run between now and World MSA day, 3rd October. As it is a collaborative, virtual event anyone can help contribute to the total miles walked, no matter where they are. For more information and to sign up visit **www.msatrust.org.uk/msawalkathon** or contact us at **fundraising@msatrust.org**. msa *news*

Raise a cup *for MSA*

3rd October 2019 is **World MSA Day** and we are asking you to hold a **M**ilk, **S**ugar **A**nd **T**ea party to mark it.

£10
+ £2.50 P&P

Whether it's a tea party in your community, a garden party with family and friends or a cake sale at work or school, we'd love if you could help us raise vital awareness and funds to support the work of our MSA Nurse Specialists. Our Nurses form the front line of our support for members, so holding a Tea Party would be a great way to celebrate their commitment and expertise.

We're also introducing our new Tea Party mugs so that you can have your **M**ilk **S**ugar **A**nd **T**ea parties branded in MSA Trust colours! Order them using the slip below, online on our shop at **www.msatrust.org.uk/shop** or call the office on 0333 323 4591.

*If you'd like to hold a **M**ilk, **S**ugar **A**nd **T**ea party on World MSA Day (or any other date for that matter) then send back the slip below or email **fundraising@msatrust.org.uk** to order your pack today!*

Name:..

Address:...

Telephone:.. Email:..

○ I would like to hold a **M**ilk, **S**ugar **A**nd **T**ea party and order my pack

When will you hold your Tea Party? 3rd Oct / Other ....

How many people are you expecting? ....

I would like to order **M**ilk, **S**ugar **A**nd **T**ea party mugs for **£10** each plus **£2.50 P&P**. Quantity ....

Total payment enclosed £...

Sarah's Wood Summer Social

○ I would like to order **Sarah's Wood Summer Social** tickets and have enclosed a cheque for **£20** per ticket (under 14's go free)

Number of tickets:....................... Total payment enclosed £..

Please let us know how you want us to keep in touch for fundraising news and events. Fill out your contact preferences below:

○ Telephone ○ Post ○ Email.. ○ I prefer no contact

Please make all cheques payable to 'MSA Trust' & return slip to MSA Trust, 51 St. Olav's Court, Lower Road, London SE16 2XB

The Trust can take donations online at **www.msatrust.org.uk/donate** and over the phone on 0333 323 4591.