



# MSA Trust Impact Report 2018 - 2019

"I remember well the words of the neurologist the day of the diagnosis, saying we may find some useful information from MSA Trust. Little did we realise how important their help would become!"  
*a person with MSA*





Welcome to the MSA Trust impact report for 2018-19.  
We are delighted to share some of the highlights of our year:

New Support Groups were started in Lancashire, Tayside, Merseyside, South and West London.

MSA News was sent to over **4700** members 3 times per year.

Our **4th Nurse** trained **131** health and care professionals in her new area.



We employed an Advocacy Officer who took on over **150 cases** for people in exceptional hardship.

**150**

people with MSA answered our call for people to register on the

**100,000 Genomes Study.**



Our Advocacy Officer handled more than **900** queries about a range of issues including benefits, NHS Continuing Healthcare and grants for equipment.



**Our HealthUnlocked forum,** where people support and help one another, continued to grow and flourish.



Our Children's Activity Book was published in February 2019. In just two months it was sent to over

**50**

families to support children aged 4 - 11 who have been affected by a loved one's diagnosis of MSA.



We helped people find answers to their questions about MSA – our website usage saw a **47%** increase in users, while there was a **12%** increase in phone and email enquiries.

# Information and Services

- We support **1446 people** with MSA and **2399** carers, family and friends
- In just one year, **726** new members registered with us. **40%** were people with MSA.
- We ran **135 support groups** throughout the UK and Ireland
- Our MSA Nurse Specialists attended **81 specialist clinics** in the UK and Ireland.
- We purchased **4 new lightwriters** to people most in need of a communication aid on free loan
- Our MSA Nurse Specialists delivered **41 training sessions** to health and care professionals, ensuring they are better able to support someone with MSA

We are now reaching an estimated

# 80%

of newly diagnosed people each year.

Given the prevalence rate of MSA within the UK and Ireland and the proportion of people not yet diagnosed.



## Campaigning for people with MSA

We are now involved in policy and campaigning work, especially in those areas we know are crucial to families affected by MSA.

We provided information to benefits assessors working with the Department of Work and Pensions, on the condition and how it affects a person's daily living.

We had continuous involvement with NHS England to improve the health and care services for people with progressive neurological conditions like MSA.





# Advocacy

**Our recently appointed Advocacy Officer works on behalf of people with MSA, ensuring their voices are heard and that they get the Benefits and Grants they are entitled to.**

Looking carefully at the needs of a person with MSA she:

- helps families prepare for assessment
- advises on Benefit claims such as Personal Independence Payment
- ensures families are aware of NHS Continuing Healthcare, advising on appeals if refused.

She also helps prepare people for the future, giving advice on:

- Lasting Powers of Attorney
- Advance Care Plans
- Housing adaptations
- Living alone checks

**In total 20 Grants were awarded to support families whose lives have been devastated by an MSA diagnosis.**



# Volunteers

**We wouldn't be able to provide most of our services we offer without the time, effort and determination given by our dedicated volunteers.**

Over 100 of them this year supported us in a range of roles:

- **29** facilitated our Support Groups around the country
- **3** supported us at the office with administrative tasks, events and projects
- **6** raised awareness of MSA at presentations and meetings
- **12** sat on the Trust's User Review Panel updating our MSA Guides and factsheets
- Many volunteers supported us in ad-hoc ways such as distributing information at local hospitals
- Volunteers also helped us to raise vital funds through street collections and cheering on event participants.
- **11** Trustees met 4 times during the year to support the development of excellent Governance in the charity

# Research

- In the latest Research Grant round, we funded 3 innovative scientific research projects totalling £375,000.
- Association of British Neurologists (ABN) Research Fellow, Viorica Chelban keeps our members up to date on MSA research and manages the 'Prospect-M database, the first ever databank of information gathered from MSA patients.
- We have made a 5-year commitment totalling £250,000 to the 'Prospect-M Database ensuring that it remains an invaluable resource for MSA researchers to continue their studies focussed on earlier diagnosis of MSA.
- We welcomed our new chair of the Scientific Advisory Panel (SAP) and trustee, Dr Christopher Kobylecki. Many thanks to our retiring SAP chair, Professor David Burn.



# Fundraising and Community

We are so grateful to our events and community supporters - Our very own **Fundraising Stars!** They have raised an incredible amount to support people affected by MSA.



**London Marathon Raised £22,000**

**Great North Run Raised £10,000**



**Mass participation events around the country Raised £22,000**



**Ride London Raised £10,000**



**Milk, Sugar And Tea Parties Raised £10,500**



Sarah's Wood, at the heart of Sherwood Forest continues to be a special place for the MSA community. The Oak trees provide a symbol of hope and resilience for all those affected by MSA. 70 saplings have been planted over 4 planting days in the past 2 years. Last year a summer social was held to celebrate the new sign, donated by Sarah's sister.

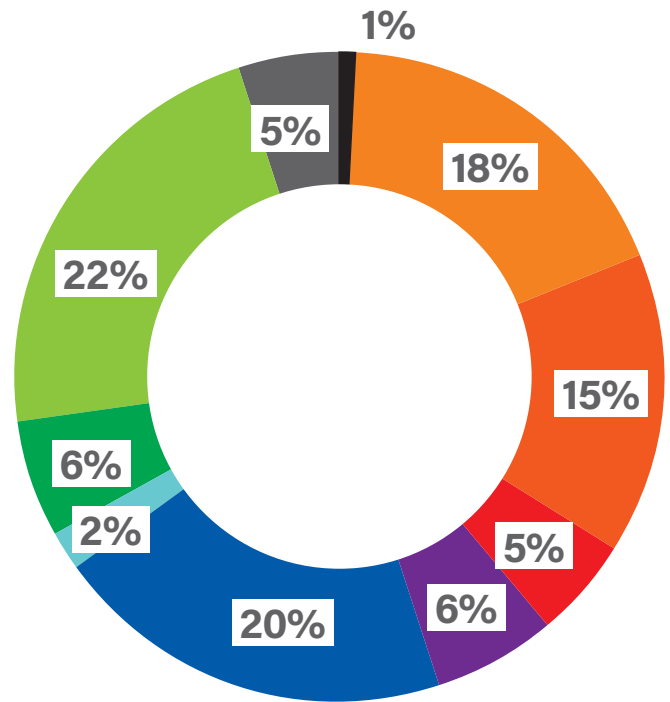


# Finance

2018-2019 Summary of Year End

## MSA Trust Income

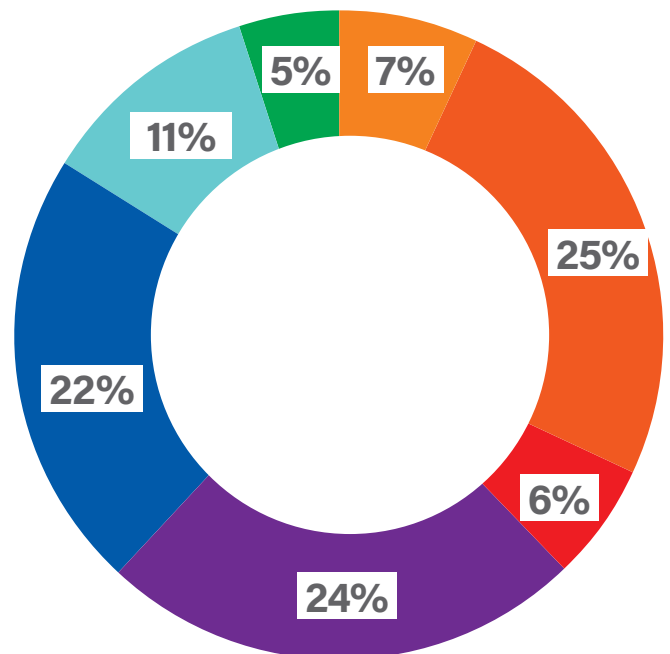
- Appeals
- Trusts & Foundations
- Community Fundraising
- Corporate Giving
- Gift Aid
- Memoriam
- Merchandise
- Standing Order
- Events
- Unsolicited Donations



Total Operational Income =  
**£710,675**

## MSA Trust Expenditure

- Governance
- Frontline Support Services
- Welfare and Advocacy work
- Information and Support Services
- Fundraising and Event costs
- Office Costs
- Travel Costs



Total Operational Expenditure =  
**£590,271**

These figures are taken from the operational management accounts and have not yet been fully audited. The figures do not include any bank interest, investment income or legacy income. Research expenditure is summarised in the research section and due to the nature of the expenditure being over more than one year it is not detailed here. Please check on our website, [www.msatrust.org.uk](http://www.msatrust.org.uk) in early October for full audited annual accounts, which contains information on all income and expenditure of the MSA trust.