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ADVANCING MSA RESEARCH IN 2026

March Newsletter

Defeat MSA Alliance (USA)
& MSA United Research Consortium

Many Hearts, One Hope

MOVE FOR MSA

We are pleased to welcome **Move for MSA (501(c)(3))** as a new partner organization within the MSA United Research Consortium.

What is Move for MSA?
Move for MSA is a global movement that encourages people to walk, run, cycle, or move in their own way to support research and families affected by Multiple System Atrophy. Every step helps fund research, support patients, and bring much-needed hope to those living with MSA.

The movement continues to grow, with expanding partnerships in **Canada, Australia, and beyond**, strengthening our shared commitment to accelerating research and supporting the global MSA community.

Move for MSA apparel coming soon.

Move for MSA





February 28 marked **Rare Disease Day**, a global effort to raise awareness for conditions like Multiple System Atrophy, leading into **MSA Awareness Month throughout March**.

Over the past several weeks, our community has shared facts, personal stories, and educational resources to help make this disease more visible and better understood.

We also released updated **social media awareness frames** to make it easy to show support and start conversations all year long. There are now **four MSA awareness frames available**, including the new "I have MSA and I'm rare" **WARRIOR** frame.

Visibility leads to understanding.
Understanding leads to action.

Use the Awareness Frames

NEW TOOL: DEFEAT MSA TRIAL TRACKER

Participating in research is one of the most direct ways to move the field forward.

Our new **Trial Tracker** helps patients and families find active clinical studies and research opportunities worldwide, including trials currently recruiting.

This tool works alongside the MSA Pipelines to provide the most up-to-date view of ongoing research.

MSA Trial Tracker

RESEARCH UPDATES & NEWS

Earlier this year, we announced eight 2026 grant awardees. Now, we're sharing more about the scientists behind the work and the research driving progress forward.

Among this year's funded investigators is **Professor George Tofaris**.



George Tofaris is Professor of Neurology and Translational Neuroscience at the **University of Oxford** and a Consultant Neurologist at the John Radcliffe Hospital, where he leads specialist clinics in movement disorders and neurogenetic conditions.

His research focuses on understanding the molecular mechanisms that drive neurodegeneration, with the goal of identifying biomarkers and developing future therapies.

Professor Tofaris will lead a study focused on the underlying disease process of Multiple System Atrophy by examining how different brain cells interact and contribute to degeneration. Using advanced stem-cell–based models derived from patient samples, his team will investigate how these cellular interactions may trigger or accelerate disease.

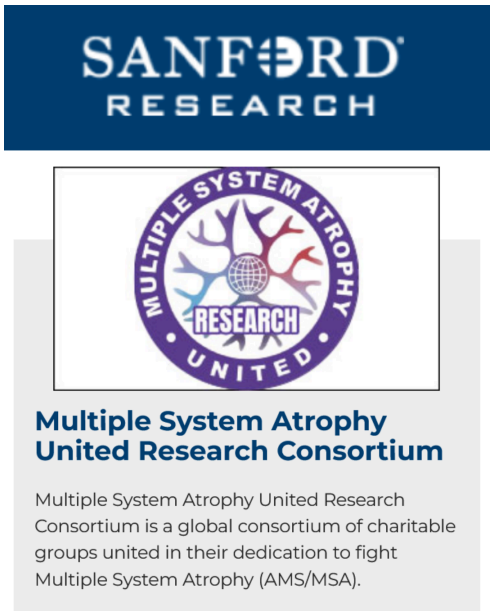
Understanding the biological pathways that lead to MSA is essential for developing targeted treatments. This research represents an important step toward clarifying disease mechanisms and supporting the development of future therapeutic strategies.



MSA United continues to expand its global reach through new partnerships, research collaboration, and international patient engagement.

Recent developments include:

• MSA United joined **CoRDS**,(Coordination of Rare Diseases at Sanford), a global rare disease registry network that connects patients, researchers, and advocacy groups to support data sharing and accelerate research.



CoRDS is a centralized international registry designed to collect patient data across thousands of rare diseases to help advance understanding, clinical trials, and treatment development.

• Relaunch of the **MSA New Zealand Trust website** to strengthen international access to information and support

• Addition of **Move for MSA** as a partner organization within the consortium (see section above)

Together, these efforts strengthen global collaboration and help ensure that research, patient data, and advocacy continue to grow worldwide.



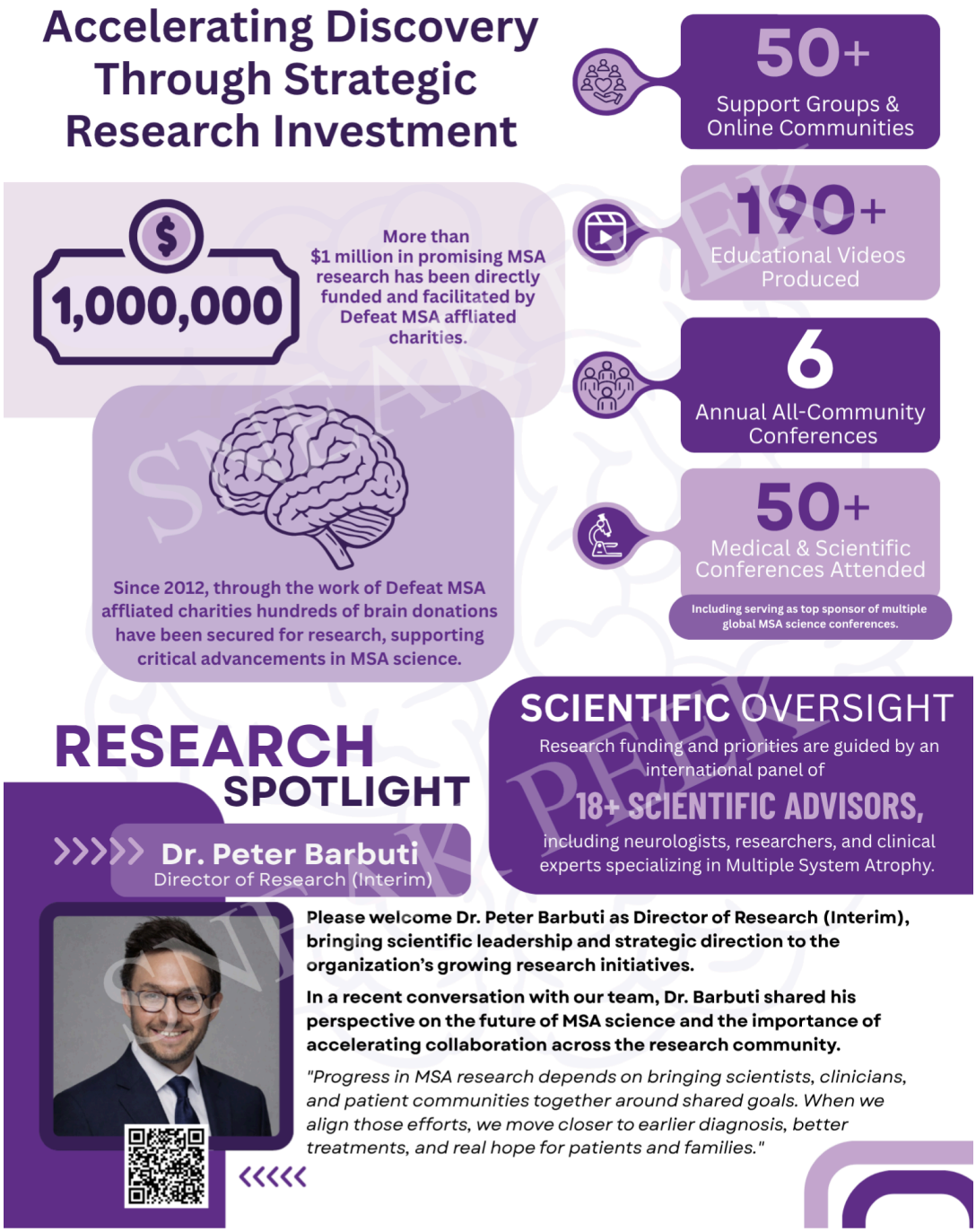
Our **MSA Research Pipelines** continue to track therapeutic development, clinical trials, and emerging science across the world.

We have also completed Annual 2026 Research Prospectus, outlining current priorities, funded projects, and future research strategy.

This document will be shared separately in a dedicated email. Here is a sneak peak (below)

Together, these resources help ensure transparency, coordination, and strategic progress.

View the Pipelines





Phase 3 MASCOT Study

Lundbeck recently announced that the final patient has been randomized ahead of schedule in the Phase 3 MASCOT trial studying amlenetug as a potential treatment for MSA.

This trial represents an important step forward in the search for therapies that may slow disease progression.

While the treatment is still under investigation and not yet approved, reaching this stage reflects growing momentum in MSA research.

"With no currently available treatments to slow the clinical progression of MSA, the urgency for innovation is exceptionally high."
— **Johan Luthman,** *Head of Research & Development, Lundbeck*

We will continue sharing updates as results become available.

Read Full Update





Beyond research, we remain committed to practical support for individuals and families navigating MSA.

Available resources include:

• Loaner Closet
• Support Groups
• The MSA Hub 2.0 online community

Join the MSA Hub 2.0



Looking Ahead:

There are several important events ahead that bring our community together and help drive awareness, engagement, and progress throughout the year, including:

- **The 7th Annual Virtual Conference (September)**

Defeat MSA Alliance and MSA United Research Consortium will also continue advocating the MSA community at key neurology conferences, including:

- **American Academy of Neurology (AAN) (April 18–22, Chicago) – Exhibitor**
- **Society of Neuroscience (SfN) (Nov 14-18, Washington D.C.)**

We'll be sharing additional details and ways to participate as plans are finalized.





Spring is the perfect time for a fresh start — and an opportunity to turn an unused vehicle into meaningful support for MSA research and patient programs.

You can donate a car, truck, motorcycle, boat, or RV, and the proceeds go directly toward advancing research, education, and support.

Learn More

Sustained research progress requires long-term planning.

Through FreeWill, supporters can create a no-cost will and include Defeat MSA Alliance (USA) as a beneficiary — helping ensure research sustainability for years to come.

FreeWill

Support the mission in a way that works best for you.

You can make an impact through GoFundMe campaigns, Facebook fundraisers, birthday fundraisers, planned giving, stock or vehicle donations, memorial gifts, personal fundraising, or by volunteering your time.

Every contribution helps move research forward and supports families affected by Multiple System Atrophy.

Explore ways to give

GIVE HELP, GIVE HOPE

Defeat MSA Alliance (USA) in partnership with its affiliates in **MSA United** stand alone as the only MSA

charities still operated by volunteers, people personally impacted by MSA. No donor dollars go toward the management salaries of people unconnected with MSA - every contribution advances research, education, support and advocacy.

DONATE NOW

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