Inspiring stories of action and hope. View in browser



Defeat MSA Alliance (USA)
& MSA United Research Consortium

Many Hearts, One Hope

Defeat MSA Alliance & MSA United are U.S. based organizations geared toward global impact - and the only major MSA charities still run entirely by volunteers.



Defeat MSA Represents the MSA Community at #1VoiceSummit 2026



Defeat MSA is excited to share that **Phil Fortier**, founder and president of both **Defeat MSA/Vaincre AMS Canada** and **Defeat MSA Alliance (USA)**, was invited to represent the MSA community at **Lundbeck International #1VoiceSummit** 2026 in Copenhagen, Denmark.

The Summit, now in its 12th year, is an annual gathering of leading global advocacy organizations and Lundbeck senior leadership. The event is designed to foster collaboration and strengthen partnerships in support of the patient community. This year, Defeat MSA was honored to be one of only 14 neurology-focused advocacy organizations invited to participate.

Defeat MSA's aim was to help ensure that the needs and experiences of people affected by Multiple System Atrophy are represented in discussions with decision-makers.



Phil Fortier was also among the few participants attending the conference in a volunteer capacity. Unlike other participating organizations, Defeat MSA is entirely volunteer-led, does not compensate charity leaders, and each of its board members has had a personal experience with MSA.



We are pleased to introduce **Hope MSA**, a new initiative committed to giving a stronger voice and greater visibility to those affected by Multiple System Atrophy and related Atypical Parkinsonian disorders.

Built from the foundation of the MSA Awareness Shoe campaign, **Hope MSA** represents the next step forward.

Through storytelling (sharing journeys), advocacy, education, and community engagement, **Hope MSA** provides a forum for individuals and families to share their lived experiences, personal journeys, and unique perspectives. By highlighting the real lives behind the diagnosis—their stories, challenges, hopes, and resilience—we aim to foster greater understanding, strengthen connections, and ensure that the voices of those living with MSA are heard and valued. If you want to share your story, please do reach out to either **Hope MSA** or **Defeat MSA**. We would be grateful to spotlight you and yours, because it is the sharing of lived experiences in our MSA community that could really help change the landscape of MSA.

Explore Hope MSA





In April, Defeat MSA was thrilled to participate in Parkinson's Awareness Month at the conference hosted by the Michigan Parkinson Foundation.

It was an important opportunity to meet with patients, caregivers, families, and advocates while continuing to raise awareness about MSA and share resources.

We were also honored to spend time with our newest board member, **Vicki Moeller** (**Move for MSA**), and strengthen community relationships through meaningful interactions in Michigan.

Thank you to everyone who stopped by and shared part of their PD or MSA journey with us.





In April, **Defeat MSA** and **MSA United** attended the Annual Meeting of the **American Academy of Neurology (AAN)**, the largest gathering of neurologists in the world. We extend our thanks to Board directors, **Rodney Rastall, Jennifer Torres, Philip Fortier**, **Lisa Bilek** and volunteer, **Isiah Torres**.

Being visibly present at the AAN gives us the opportunity to elevate awareness, educate doctors, strengthen clinical and research relationships, advocate before pharma and industry and ensure the patient voice remains a priority.

Every event like the AAN helps spotlight MSA patients, the unmet need and, their urgent cause. Defeat MSA has exhibited yearly at the AAN for more than 10 years.



This month, we finalized our latest Research Prospectus, highlighting funded initiatives, scientific priorities, and our global work being done to move MSA research forward.

This resource helps advocates, donors, researchers, and supporters better understand where progress is happening and where support is needed most.

View Research Prospectus



Earlier this year, we released a **blog feature with Dr. Peter Barbuti, Director of Research**, where he shared his perspective on the current landscape of MSA research and where the field is headed next.

Now, we're sharing the full conversation in video format.

In this interview, **Dr. Barbuti** discusses:

- Current priorities in MSA research
- The importance of collaboration across the global MSA community
- Emerging opportunities in treatment development
- Reasons for hope in the future

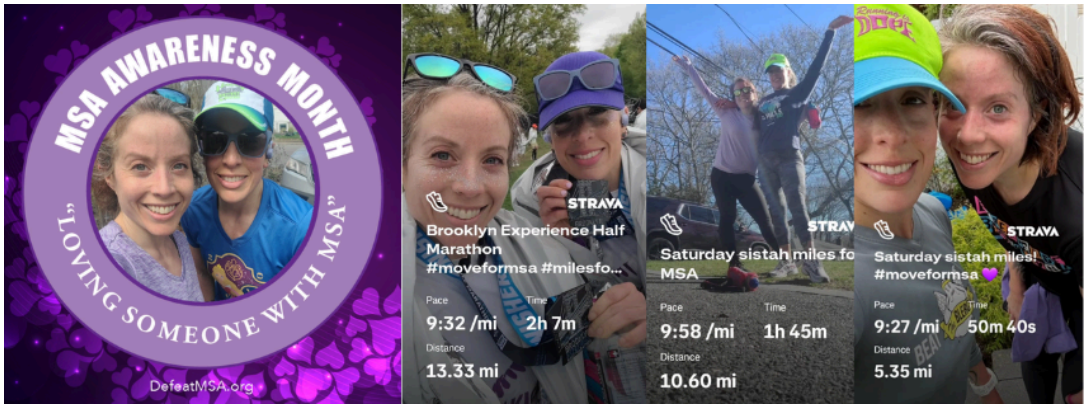
Watch Video



Move For MSA Continues to Grow

Whether you walk, run, ride, or move in your own way, every step helps raise awareness and support for the MSA community.

This month, we're spotlighting two sisters, Kristine & Laura who ran **The Brooklyn Experience Half Marathon** on Sunday, April 26 in support of Defeat MSA. After their father was recently diagnosed with MSA, they began learning more about the disease and looking for a way to support him and others living with MSA.



Move For MSA

As runners, they turned their miles into a way to raise awareness and funds for research.

Their story is a powerful reminder that "Moving for MSA" can begin with one meaningful event, inspired by something deeply personal: one family, one diagnosis, a reason to keep moving, and a desire to help make a change. From there, it can continue to develop and be a catalyst for an even bigger change in our community.

Move For MSA first began in 2016 with the launch of a major US city billboard campaign. Since then, **Defeat MSA/Vaincre AMS Canada** has adopted the campaign with multiple successful events involving movement for MSA. Move For MSA has now developed into a concrete way for supporters to raise awareness, foster new research funding and, honor a loved one with MSA. We are also exploring a larger national runner program to expand this movement even further and create more opportunities for people across the country to get involved.

Want to get involved?
Learn more about **Move For MSA** and how you can participate, fundraise, or support an upcoming event.

SUPPORT, RESOURCES & COMMUNITY



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

Available resources include:

- Defeat MSA Loaner Closet
- Support Groups
- MSA Hub Community

Join MSA Hub 2.0



Looking Ahead:

There are several important events ahead that promise to bring our community together and drive awareness, engagement, and real progress on MSA including:



The 7th Annual All-Community Global Virtual Conference

- **Sept 19: Clinical & Caregiving Topics**
- **Sept 20: Scientific & Research Topics**

In addition, Defeat MSA Alliance and MSA United Research Consortium will be advocating on behalf of MSA patients & caregivers at these conferences for the rest of the year, including:

- **Society of Neuroscience (SfN)**
  (Nov 14-18, Washington D.C.)
- **International Congress of Parkinson's Disease and Movement Disorders**
  (Oct 4-8, Seoul, Korea)

We'll be sharing additional information on these and others soon.



Upcoming Conference:

12th Congress of the European Academy of Neurology

The 12th Congress of the European Academy of Neurology will take place June 27–30, 2026, in Geneva, Switzerland, with virtual access also available.

This international congress brings together professionals involved in MSA and related disorders, including neurologists, scientists, educators, healthcare professionals, and industry leaders, to share the latest developments in brain and neurological health. The program includes scientific and educational sessions, research presentations, poster sessions, workshops, and opportunities for further professional collaboration.

For those with a professional background, please consider attending this important event.

Learn more and register



Webinar Replay Now Available:
"Understanding MSA Research and Clinical Trials"

The replay is now available for our educational webinar, **Understanding MSA Research and Clinical Trials**, presented in partnership with **Teva Pharmaceuticals**.

This free webinar helps the MSA community better understand current research, clinical trials, and the future of treatment development.

The program features Teva clinicians and research leaders, with opening remarks from **Dr. Peter Barbuti, Director of Research for Defeat MSA & MSA United**

Topics included:

- How emerging therapies may target MSA pathology
- Understanding the drug development process
- A closer look at the TOPAS-MSA clinical study
- The role of biomarkers in shaping future research

Watch the replay to learn more about the latest progress in MSA research and clinical trial development.

Watch the Replay



Our Trial Tracker is live!

Designed to help patients, families, and caregivers find active and recruiting MSA trials.

Access to research matters, and staying informed is one of the most powerful tools to help Defeat MSA.

Trial Tracker

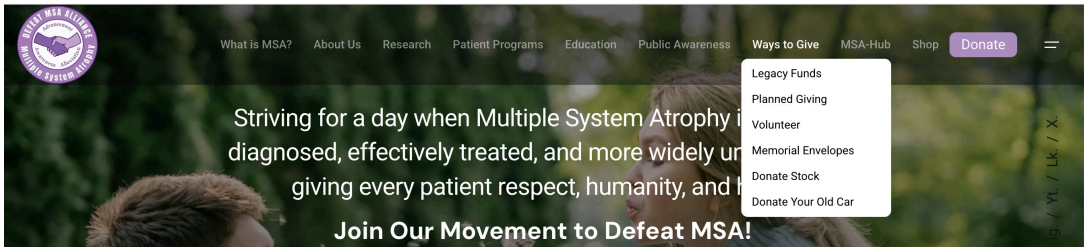


FREEWILL

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 birthday fundraisers, Legacy funds, 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.

Visit Homepage > 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

TOLL FREE

1 855 542-5672

(855 KICK-MSA)

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