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Defeat MSA Alliance & MSA Research Consortium Quarterly Newsletter

Many Hearts, One Hope

ABOUT **DONATE**


SAVE THE DATE!
SEPTEMBER 13-14 2025
MULTIPLE SYSTEM ATROPHY
RESEARCH
UNITED
6th Multilingual Free
All-Community
MSA Virtual Conference
"MANIFESTING HOPE
FOR PEOPLE WITH MSA"



***** All registered HUB members in the USA can receive a FREE mailed MSA welcome package (contains educational & research Info. and promotional gifts, while supplies last).**

Call For Research Proposals

MSA United Research Consortium (501c3 - US) is pleased to announce the first round of our 2025 seed grant program to foster the development of new research on Multiple System Atrophy (MSA), with particular emphasis on the collaborative projects. MSA United Research is a network of 10 charities, the leaders of which are Defeat MSA Alliance USA and Defeat MSA/ Vaincre AMS Canada. Funding for seed grants will prioritize research that:

1) Contributes to our mission of cultivating research into biomarkers and translational science

2) Fosters research targeting slowing MSA and helping living patients.

3) Explores repurposing drugs for use in MSA

4) Provides data that may be beneficial to other related disorders

5) Demonstrates innovative and novel methods and ideas

To read the complete RFP, view it here.

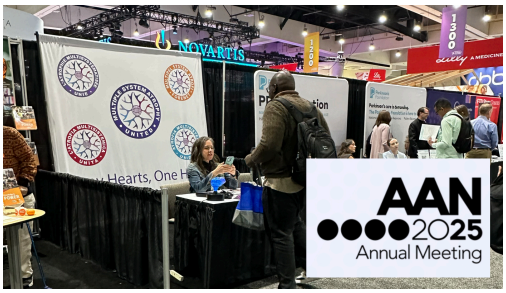
GIVE HELP, GIVE HOPE

Your donation will make a difference, if you want more information please get in touch with us. Help us boost our worldwide research impact. Let's Defeat MSA Now!

DONATE NOW!

Charity Meeting Recaps





Leading MSA Research Focus

The fourth goal in Defeat MSA's mission involves cultivating promising research into possible treatments and therapies to slow disease progression. To this end, Defeat MSA has sought to encourage new research in MSA.

This year, Defeat MSA was able to support the **Synuclein Meeting**. The biannual conference is the world's preeminent scientific MSA research event. In attendance was Philip Fortier (Chair/President) and Dr. Bydie Thomas Moore (Science Writer and Research Advisor). Stay tuned for a comprehensive readout and research updates from the conference!

Advocacy at the AAN!

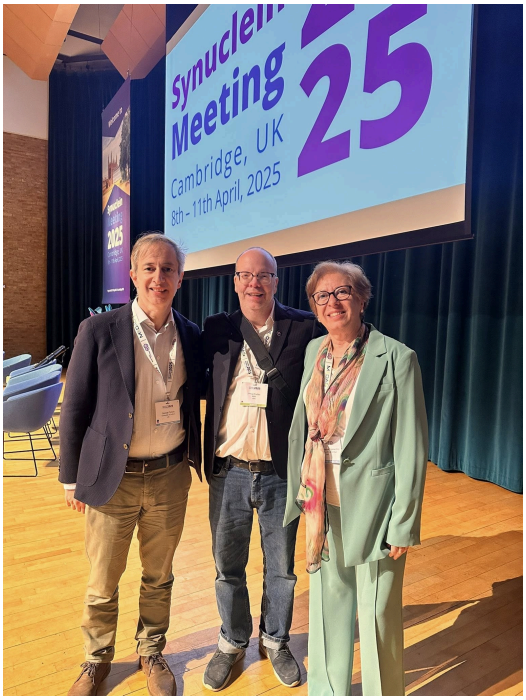
Three board directors from Defeat MSA, Jennifer Frost (Vice-Chair), Philip Fortier (Chair) and Andrea O'Neal (Medical Advisor) represented the MSA cause at the American Academy of Neurology Annual Meeting 2025.

Defeat MSA Alliance was the **ONLY advocacy organization for MSA** at the conference. The annual meeting is the largest neurology conference in the world, drawing thousands of healthcare providers each year.


Synuclein
Meeting
Cambridge, UK
8th – 11th April, 2025
20
25


MSA UNITED
" Many Hearts, One Hope "
www.msaunited.org




Meeting
Cambridge, UK
8th - 11th April, 2025
25





March Event Recap

The Jack Russell Tribute Memorial

Los Angeles, CA - March 2025

On March 26, a charity concert in honor of **Jack Russell**, former lead singer of the "Great White" band was held at the iconic venue, "Whisky A Go-Go" in West Hollywood, California. The event celebrated Russell's life and music, with proceeds going to Defeat MSA Alliance earmarked for promising MSA research. Known for hits such as “Rock Me” and "Save Your Love," Jack Russell passed from MSA in August of 2024. MSA Ambassador and Miss Las Vegas, **Arianna Siefert**, her husband **Justin Siefert** and **Phil Fortier**, Chair/President of the charity, all volunteers, represented Defeat MSA Alliance at the event. Arianna lost her father and Phil lost his brother to Multiple System Atrophy.







Individual Photos (Left-Right): MSA Awareness Ambassador and Miss Las Vegas, **Arianna Siefer** and Defeat MSA Chair, **Phil Fortier**; Arianna Siefert #KicksMSA with the MSA Awareness Shoe; Rock n Roll vicalist, **Lorraine Lews** (@femmefatalerocks) and Arianna Siefert cradle the MSA Awareness Shoe.



L-R: **Arianna Siefert** (Miss Las Vegas and MSA Awareness Ambassador), husband **Josh Siefert**, & Defeat MSA Chair **Phil Fortier;** Phil Fortier & **Nancy Sayle** (Publicist and Friend of Jack

Russell), Comedian **Hal Sparks** (center photo), Musician **Don Dokken;** Arianna Siefert displays the MSA Awareness Shoe.

Our heartfelt thanks to Jack Russell's family and friends for a fantastic night raising funds and MSA awareness! If you wish to honor a great man and an amazing artist, please consider a donation to Jack's Legacy:

Donate To The 'Jack Russell Legacy Fund'

THE RESEARCH RADAR



RESEARCH STUDIES
- NOW RECRUITING -



Symptomatic neurogenic orthostatic hypotension (nOH) is common in patients with multiple system atrophy (MSA), with symptoms such as dizziness, light-headedness, and feeling faint affecting an estimated 4 out of 5 MSA patients.

Theravance Biopharma is actively enrolling eligible participants to take part in the Phase 3 CYPRESS study. The purpose of this study is to look at whether an investigational drug works and how safe it is when taken over several months to treat symptomatic nOH in people with MSA. The primary assessments will determine whether the investigational drug can improve the symptoms of nOH.

Key eligibility criteria for the CYPRESS trial:

- at least 30 years of age
- symptoms related to nOH
- a diagnosis of MSA

Additional criteria will need to be met to qualify, and a study doctor will explain those.

To learn more about the CYPRESS trial, please visit www.cypress-study.com







UPDATED DRUG PIPELINES

Want to learn about new drugs and therapies in development?

Visit our pipelines page!

VISIT THE PIPELINE

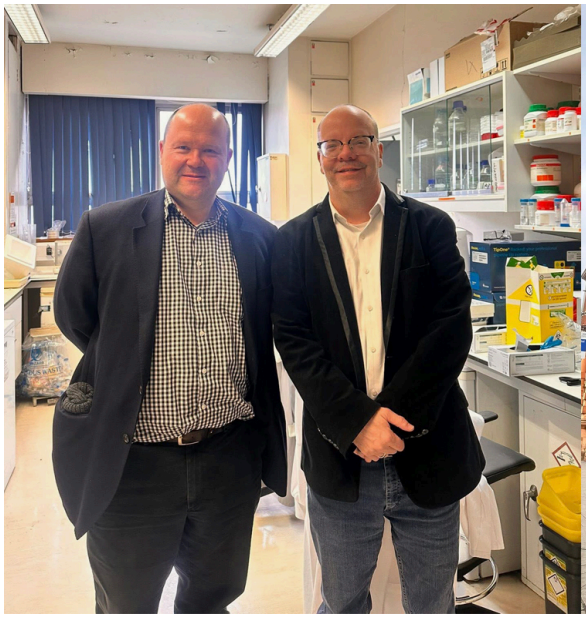
Looking for Volunteers!

Do You Have What It Takes?
Be the Change You Want to See!

Seeking: Advisors, Committee/Board Members & Professionals of All Types (Fundraising, Marketing, Web Development, Writing, Social Media Management, Event Management, Patient Support, Translation, Social Work, Advocacy Work)



Contact: volunteer@defeatmsa.org
www.defeatmsa.org





Research Advisor, University College

Board Chair **Phil Fortier** visited with **Professor Henry Houlden**

London, UK
Professor Houlden

(Univ College London/Queen's Square). **Professor Houlden** serves on the Defeat MSA and MSA United Research Consortium Advisory Committee and is one of the world's foremost MSA experts. The professor discussed ways to encourage more patients to participate in research and funding of new research for 2025 and 2026.

Meet Board Director Jennifer Torres

K



JENNIFER TORRES

A skilled graphic artist, Jennifer Torres joined the board in 2023. Jennifer is a busy mom to 4 beautiful children and has been married to her husband, Isiah, for 6 years. Jennifer lost her father, Michael Smith to MSA. Mike served on the board of Defeat MSA and held the position of VP as well. After

losing her father In June of 2023, Jennifer vowed to continue her father's work by joining Defeat MSA Alliance. We are grateful to Jennifer for her much needed graphic design help and dedication to our urgent cause!

Remember Defeat MSA and MSA United Consortium are both operated entirely by volunteers. Defeat MSA is the ***ONLY major MSA charity*** in the world still operated by volunteers. We do not pay high salaries to high-powered executives or cumbersome staff. Every donation dollar goes directly to our MSA cause!

Upcoming Meetings



We are thrilled to invite all neurology professionals in the global MSA community to the **XXVII World Congress of Neurology (WCN 2025)**, taking place in the vibrant city of **Seoul, South Korea, from October 12–15, 2025.** Co-hosted by the **Korean Neurological Association**, this global event will bring together neurologists, researchers, and healthcare professionals to explore the latest advancements in the field.

MSA United Research Consortium, including its lead organization, Defeat MSA Alliance USA will be exhibiting all week at the Congress! advocating on behalf of our MSA warriors around the world.

WCN 2025 promises a dynamic program featuring **groundbreaking research**, **insightful keynote speakers**, **and engaging scientific sessions** covering a wide range of topics, from neurogenetics to dementia research and stroke management. Attendees can also take part in **interactive teaching courses**, **thought-provoking poster presentations**, and the exciting **Tournament of the Minds**.

If you are a medical, scientific or industry professional, please keep the Early Bird Registration Deadline of 23 July in mind.

Beyond the academic program, WCN 2025 also offers Congress attendees valuable networking opportunities and a chance to experience Seoul's unique blend of tradition and technology—a city known for its leadership in medical innovation.

If you are a neurology professional, please consider attending this important conference and if you attend, please do stop by our exhibit booth to connect with other clinicians, researchers and industry professionals interested in MSA.

Doctors, Researchers & Advocates - Register Here

GIVE HELP, GIVE HOPE

DONATE NOW!

Defeat MSA Alliance (USA)
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