

Defeat MSA Alliance & MSA Research Consortium Quarterly Newsletter

Many Hearts, One Hope

ABOUT US **DONATE**



GEARING UP FOR MSA AWARENESS MONTH & RARE DISEASE DAY!

"Every Voice Counts, Every Fight Matters—End MSA!"

"Rare is Many. Rare is Strong. Rare is Proud!"

RARE DISEASE DAY®

February 28 is Rare Disease Day

MSA is a **devastating rare disease** with no cure. This **Rare Disease Day**, support research — **every donation fuels hope and the fight against MSA.**



March is MSA Awareness Month

Donations fuel critical **MSA research, patient support, and advocacy efforts**.

This March, make an impact— **start a fundraiser or donate direct - every dollar brings more hope to all those with Multiple System Atrophy.**

GIVE HELP, GIVE HOPE

Your donation will make a difference, if you want more information please get in touch with us.

DONATE NOW!

UPCOMING FUNDRAISERS



🎸Rocking for a Cause: Jack Russell's Tribute Event Supports Defeat MSA Alliance 🎸

On **Tuesday, March 25, at 7 PM PDT**, the iconic Whisky A Go Go in West Hollywood will host a special tribute celebrating the life and music of **Jack Russell**, the legendary frontman of **Great White**. While tickets are sold out, you can still support his legacy, making a difference by donating to the **Jack Russell - Defeat MSA Alliance Fund**. All proceeds will help the fight against **Multiple System Atrophy (MSA)**, this relentless neurodegenerative disease.

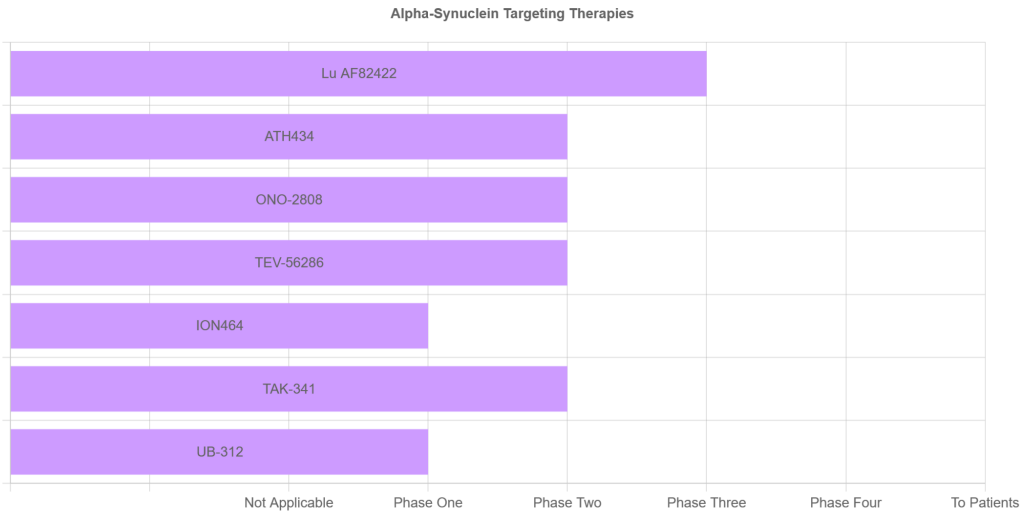
Join us in honoring Jack's memory and helping those affected by MSA! 💜

JACK RUSSELL - DEFEAT MSA ALLIANCE FUND

TRIALS & RESEARCH UPDATES

THE RESEARCH RADAR



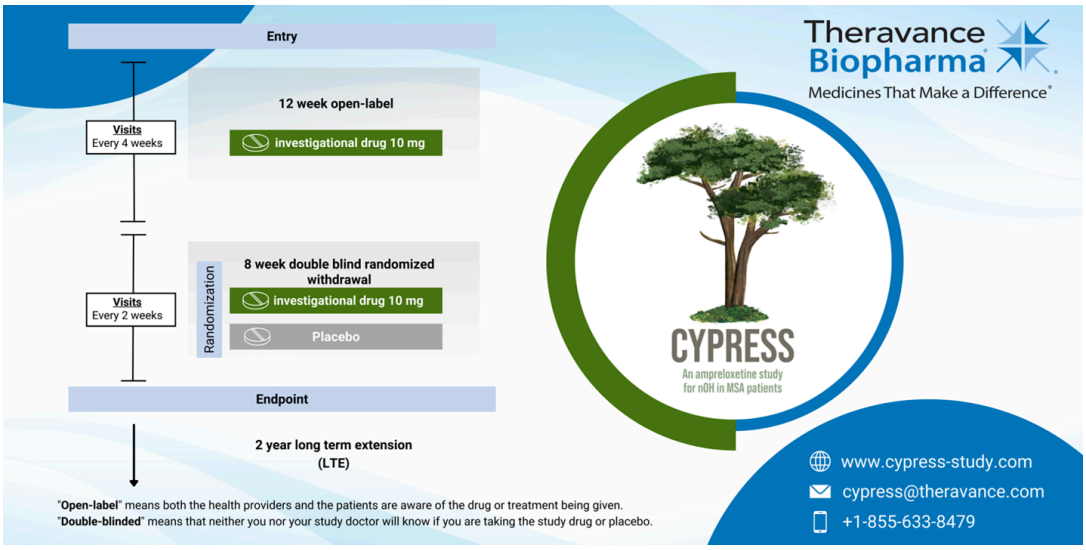


UPDATED DRUG PIPELINES

Want to learn about new drugs and therapies in development?

Visit our pipelines page!

VISIT THE PIPELINE



DEFEAT MSA ALLIANCE OFFICIAL PARTNER TRIAL UPDATE

Theravance Biopharma continues to enroll eligible participants to take part in the Phase 3 CYPRESS study.

Symptomatic nOH is common in MSA, with symptoms such as dizziness, light-headedness, and feeling faint affecting an estimated 4 out of 5 MSA patients. These symptoms can reduce independence, freedom, and the quality of life. The Phase 3 CYPRESS study aims to research the investigational drug **Ampreloxetine**, a once-daily therapy in development for treating symptomatic nOH in people with MSA.

The CYPRESS study is a global clinical trial consisting of 9 visits over a 20-week study treatment period. All participants will receive the investigational drug for 12 weeks during an open-label period, followed by randomization to either placebo or the investigational drug in a blinded fashion during the randomized withdrawal period for an additional 8 weeks. A composite assessment of the symptoms of **neurogenic orthostatic hypotension** including dizziness, vision impairment, weakness, fatigue, trouble concentrating, and head and neck discomfort will form the basis of the primary evaluation and results for this study. All participants that complete the initial 20 weeks of the trial will also be invited to continue participating in a long-term extension and receive the

investigational drug in an open-label fashion for up to an additional 2 years.

If you, or someone you know, experiences symptoms of nOH, have an MSA diagnosis, and are over 30 years old, that person may be eligible to participate in the CYPRESS study. For more information regarding trial participation, including the locations of study centers, please e-mail Theravance at cypress@theravance.com, give them a phone call at 1-855-633-8479, or visit the study website at www.cypress-study.com. **Ampreloxetine** is not currently approved by any health agency for use in treating symptoms of nOH in patients with MSA.

CLICK TO LEARN MORE ABOUT THE CYPRESS STUDY







CLICK STUDY GRAPHIC OF INTEREST TO LEARN MORE



DEFEAT MSA USA - TOP SPONSOR OF THE WORLD SYNUCLEIN MEETING

Defeat MSA Alliance Announces Top Sponsor of the Synuclein Meeting, the most important meeting on the basic science and translational research related to the alpha-synuclein protein, the accumulation of which is thought to cause Multiple System Atrophy, Parkinson's and Lewy Body Dementia.

VISIT THE SYNUCLEIN MEETING WEBSITE

Welcome - New Research Consortium Partners!

- **National MSA Research (Australia)**
- **MSA Partnership (Ireland)**
- **Atrofia Multisistémica (Spain)**
- **Atrofia Multisistémica (Mexico)**

LEARN MORE

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



ANNOUNCING NEW

LEGACY FUNDS



Michael L. Smith

Michael Leigh Smith, 69, a resident of Lubbock, Texas, passed away on Saturday, June 3, 2023, at his home. Mike was a longtime patient advocate and former vice-president of Defeat MSA Alliance. He was also instrumental in the formation of MSA United, the now ten charity wide research consortium connected with Defeat MSA Alliance.

Read more above Mike after the jump.

MIKE SMITH LEGACY FUND



Kimberly (Hartley) Turner

The Kimberly A. Turner Legacy Fund is dedicated to fostering promising research and patient support programs.

Kimberly Turner, 59, passed away Tuesday, May 7, 2024 at home surrounded by her loving family.

Learn more and donate to the fund after the jump.

KIMBERLY TURNER LEGACY FUND

Meet A Board Director



Meet Board Director:

LISA BILEK

During graduate school, Lisa's father was diagnosed with Multiple System Atrophy. Since that time, Lisa has committed herself to doing whatever she can to give back and help find a cure for MSA.

Lisa received her doctorate in Pharmacology & Experimental Neuroscience from the University of Nebraska Medical Center (UNMC). Her research focused on the immunology of neurodegenerative diseases.

For the past decade, she has worked in medical affairs within the pharmaceutical industry. She is also a co-creator and mentor for

her company's first ever postdoc fellowship program for PhD's in medical affairs.

Outside of her career, Lisa enjoys engaging with her community: she has served as member and president of the UNMC Graduate Studies Alumni Engagement Council, has been a speaker for BioNebraska Women in STEM seminar series, and has co-founded a non-profit, LOLA, that seeks to create professional development and mentoring opportunities for women in the Omaha metro area. She is married to her husband, Tony, and they have two children, Benny (6) and Nora (3). Lisa joined Defeat MSA's Board of Directors in 2024.



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 for our urgent MSA cause with doctors, pharma and other industry sectors.

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 these keys dates in mind:

- **Abstract Submission Deadline: 2 April**
- **Early Bird Registration Deadline: 23 July**

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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