NEWS & VIEWS

NEWS & VIEWS - AUGUST 2023

New MSA Websites!



MSA United International Consortium

https://www.msaunited.org/

Defeat MSA Awareness Shoe

https://www.msashoe.org/

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

NEW WAY TO DONATE!

Defeat MSA Alliance

@defeatmsa

venmo

We Mourn the Passing of Michael Smith



It is with great sadness we announce the passing of our dear friend**:**

Michael Smith (1954 - 2023)

Mike passed peacefully on June 3, 2023 at home with his family.

Mike was an integral part of Defeat MSA Alliance and MSA United International Consortium from being on the Alliance's board of directors as our patient advocate, as an advisor, charity vice president and brain hub network administrator. He was our number one supporter - always together with us, fighting MSA!

Mike was diagnosed with Multiple System Atrophy in 2014, with the symptoms onset since 2008. He lived an incredible 15 years with this disease and defied all the odds.

Knowing that MSA would probably take him, he made the selfless decision to donate his brain to further research and thereby help others. We are grateful for his efforts to be of service to others and for the many gifts that Mike gave so willingly.

Rest in peace Mike, and fly high, until we see you again!

Photo: Mike helps us #KickMSA by posing with the MSA Awareness Shoe. A link to a research Legacy Fund established in tribute to Mike Smith will be posted on our website soon.

Introducing Ross McLennan to the Australia Board of Directors



Ross McLennan, PhD

RESEARCH DIRECTOR, DIRECTOR, BOARD OF DIRECTORS; MSA UNITED CONSORTIUM GLOBAL RESEARCH COMMITTEE, MSA UNITED CONSORTIUM LEADERS COUNCIL

Executive Director, Research Services
Macquarie University, Sydney, New South Wales

MSA CLINICAL TRIAL UPDATES

We are pleased to report that several companies are now working on exciting new clinical trials for MSA. Defeat MSA Alliance and its affiliated charities in MSA United Consortium are working tirelessly to advocate for more trials and increased MSA research worldwide. **We are committed to persuading medical, government and industry sectors that help for the MSA community is urgently needed.**

See below, for some exciting news from **Theravance** and **AskBio**!

For a complete list of drug trials, visit Defeat MSA Alliance's Pipeline page here.

If you are a current patient or caregiver, register with our drug and MSA research information registry: https://defeatmsa.org/research-registry/



Theravance Biopharma

Defeat MSA Alliance is pleased to announce the launch of THERAVANCE's CYPRESS STUDY for Neurogenic Orthostatic Hypotension (nOH)!

Theravance Biopharma is currently recruiting for the Phase 3 CYPRESS clinical trial researching ampreloxetine, an investigational once-daily tablet in development for the treatment of symptomatic neurogenic orthostatic hypotension (nOH) in patients with multiple system atrophy (MSA). The CYPRESS study has a 20-week treatment period, with all participants receiving ampreloxetine during the study's open-label period, followed by a treatment with either placebo or the investigational drug during a double-blinded period and optional 2-year long-term extension. **Theravance** previously assessed ampreloxetine in a study that had a similar design to the CYPRESS study. In that study there was improvement in the symptoms of nOH in a pre-specified population of MSA participants.

The CYPRESS study aims to confirm whether the investigational drug is effective and safe in treating nOH symptoms in MSA patients and to learn about any unwanted side effects. Theravance's goal is to significantly improve MSA patients' and their caregivers' quality of life.

The CYPRESS trial was designed with participant convenience in mind. Of the 9 study visits in the treatment period, only the initial screening visit needs to be in-clinic; all remaining visits having the option of being conducted in your home after discussion with your study doctor.

Study sites are currently open and active across the U.S. Click here to stay up-to-date with CYPRESS site activations. To explore additional participation options that address your specific situation, contact **Theravance** at cypress@theravance.com or telephone: +1-650-808-3737.

There are risks and benefits to participating in any clinical study, and participating should be discussed with your doctor. Learn more about the CYPRESS trial at https://www.cypress-study.com.

Theravance Biopharma is an official sponsor (Platinum Level) of the Fourth Annual Defeat MSA Alliance & MSA United All-Community Virtual MSA Conference (Sept 22-24, 2023).

AskBio

A Bayer Cell & Gene Therapy Platform Company

Now Recruiting

AskBio MSA Phase 1/2 Clinical Program



Learn more about our actively recruiting study at Multiple System Atrophy (MSA) Clinical Trial - AskBio, or connect with us directly at askfirst@askbio.com.

At AskBio, bringing the potential for life-changing advanced gene therapeutics to patients with diseases that have a high unmet medical need fuels our research and development pipeline.



AskBio's approach to potentially treating multiple system atrophy (MSA) uses a glial cell-line neurotrophic factor (GDNF) gene therapy that takes advantage of the brain's natural production of the GDNF protein, which is required for the development and maintenance of dopamine brain cells. These brain cells are typically lost in MSA patients. Our goal with AB-1005 (also known as AAV2-GDNF-MSA) is to potentially promote the survival and function of dopamine producing brain cells, which may lead to significant motor function recovery for MSA patients.

MSA-101 is a randomized, Phase 1/2 clinical trial evaluating the safety and potential effects of AB-1005 in people with multiple system atrophy-parkinsonian type (MSA-p).

- AB-1005 is a one-time gene therapy delivered surgically into the brain to provide a continuous expression of the GDNF protein.
- Eligible participants have a 2 out of 3 chance of receiving active treatment versus placebo.
- Participants randomized to placebo will undergo minimal surgery and may be offered the gene therapy product after the main part of the study.

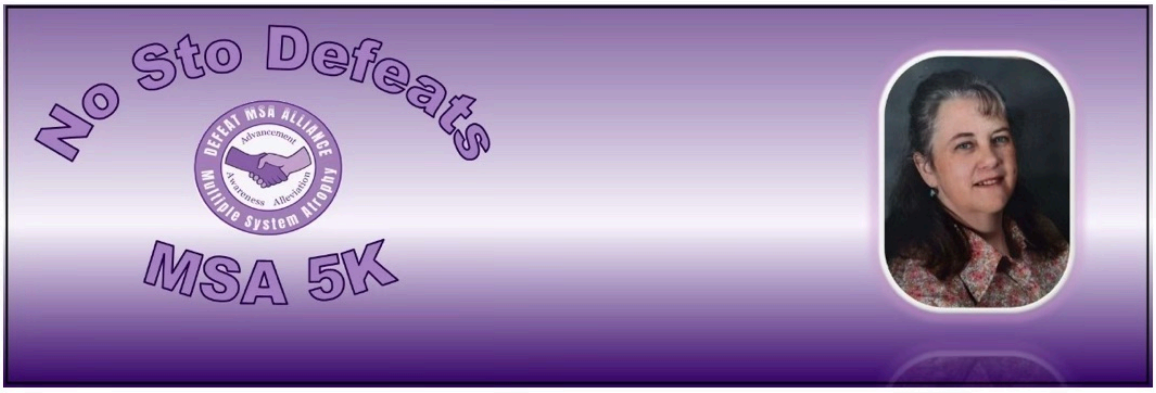
AB-1005 is an investigational therapy and has not been approved by the U.S. Food & Drug Administration (FDA) or any other health authority.

AskBio is an official sponsor of the 4th Annual Defeat MSA Alliance All-Community Virtual MSA Conference (22-24 of September, 2023) Free and Multilingual! Register now at **defeatmsa.cventevents.com**

***AskBio is able to only include US residents at this time.**

If you are interested in participating in research trials, please visit our research information registry:

https://defeatmsa.org/research-registry/



No Sto Defeats MSA 5K and Fitness Walk

Saturday, September 16, 2023

LOCATION: Wheeler High School, North Stonington, CT US 06359

TYPE: Run Only, Walk Only, Run or Run/Walk

CLICK HERE TO LEARN ABOUT #NO STO DEFEATS MSA !

REGISTER FREE NOW!

DEFEATMSA.CVENTEVENTS.COM

September 22-24, 2023

MISSION MSA: HOPE FOR A CURE

MULTIPLE SYSTEM ATROPHY UNITED

4th Annual Free All-Community MSA Virtual Conference

Breakout Sessions • World-Renown Speakers
Q & A: Talk to Experts • New Research Updates
MSA Documentaries • Wellness Talks

Selected Speakers:



Hon. Tarun Dua, MD
World Health Organization



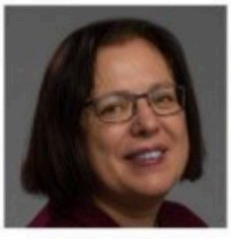
Edwin George, MD, PhD
Movement Disorders, Drug Evaluation (FDA)



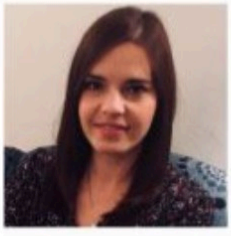
Elizabeth Coon, MD
Mayo, MN



Wouter Peelaerts, PhD
KU Leuven, Belgium



Katie Kompoliti, MD
Rush, Chicago



Iva Stankovic, MD, PhD
Belgrade, Serbia

CLICK - REGISTER FOR CONFERENCE NOW!

FREE REGISTRATION

***All US attendees can receive a conference packet with a booklet and other awareness gifts!**

***US residents only, while supplies last, 1 per household & unable to ship packages after September 8, 2023.**

Defeat MSA Alliance & MSA United Consortium are operated entirely by the hard work of our dedicated volunteers and this conference is completely funded by public donations.

If you want to help us improve this annual conference next year, please do reach out: volunteer@defeatmsa.org

SHOP MSA AWARENESS APPAREL!

One way to help us defeat MSA is to purchase official **DEFEAT MSA MERCH!** Proceeds go towards our research and awarenss efforts.

Help spread awareness by posting your merch haul to social media with **#defeatmsa #kickmsa**



Cuffed Beanie



Unisex T-Shirt

MUGS, HATS, AND MORE AT OUR OFFICIAL STORE

- Create a Facebook Fundraiser: www.facebook.com/fund/DefeatMSA
- Create a Virtual Fundraiser (dedications to a loved one are possible too): https://defeatmsa.org/fundraising/#crowd-fundraising
- Donate Directly to Our Secure Website (dedications to a loved one are possible too): www.defeatmsa.org/donate-to-us/
- Via Check, Send to: **Defeat MSA Alliance, 29924 Jefferson, Saint Clair Shores, Michigan, 48082, USA**

All the charities affiliated with **MSA United International Consortium** are staffed entirely by volunteers - every single donation goes directly into our great cause.

We are the WORLD'S ONLY MAJOR CHARITY still operated entirely by volunteers. That means, we do not use public donations to pay high salaries of executives and staff!

Lastly, **MSA United International Consortium** is the world's only research consortium of MSA organizations.

Help Us Defeat MSA Now and Forever!

MSA United International Consortium

Donate - USA

Donate - Canada

Donate - Australia

Donate - New Zealand

Donate - Denmark

Donate - Spain

Donate - Italy

DEFEAT MSA ALLIANCE & MSA UNITED CONSORTIUM

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info@defeatmsa.org

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