# NEWS & VIEWS

## NEWS & VIEWS: NOVEMBER 2023

## MSA Research Trial Updates




**THERAVANCE BIOPHARMA** continues to increase enrollment efforts for their CYPRESS study. Neurogenic Orthostatic Hypotension (NOH) is extremely common in Multiple System Atrophy, affecting approximately 70-90% of MSA patients.

The CYPRESS trial is a Phase 3 trial and has been designed to help minimize some of the challenges encountered during clinical trial participation. For example, with your study doctor's guidance, participation visits after the screening visit may be conducted in either a clinic/hospital setting or at participants' home to alleviate the burden of travel. In addition, the administration of the investigational drug is convenient and is given orally as a single, once-a-day tablet.

If you have MSA, consider joining their study to help manage symptoms of neurogenic orthostatic hypotension. They are currently enrolling at study centers across the US and opening centers worldwide. For more information regarding trial participation, including the locations of study centers, e-mail Theravance:

cypress@theravance.com, or call 1-650-808-3737, or visit the study website at www.cypress-study.com



**ASK BIO** is NOW RECRUITING for their AAV2-GDNF-MSA study.

Click here for the study website for more information




**IONIS HORIZON STUDY -**

This is a first-in-human, randomized, blinded, placebo-controlled, multiple-ascending-dose (MAD) study (Part 1) to evaluate the safety, tolerability, PK, and PD of ION464 in adult participants diagnosed with MSA with a long-term extension (LTE) (Part 2). The study will include up to approximately 40 participants. Part 1 of the study consists of a Screening Period of up to 6 weeks, a Treatment Period of 12 weeks, and a Follow-up Period of 24 weeks. The study duration for each participant in Part 2 will be approximately 96 weeks, which consists of a 72-week Treatment Period and a 24-week Follow-up Period.

*Contact Ionis Pharmaceuticals, Inc. for more info -*

**Phone Number** : (844) 748-5844

**Email** : IonisHORIZONStudy@clinicaltrialmedia.com




# 4th Annual Free All-Community MSA Virtual Conference

## Videos from the conference are now available on our YouTube channel!

**CLICK HERE TO VISIT YOUTUBE TO WATCH THE 2023 MSA CONFERENCE**

**MLB Seattle Mariners' Roberto Clemente Award Nomination "Huge**

# Honor" for Marco Gonzales




**Marco** and **Monica Gonzales** have led efforts to raise awareness and funds to support research for Multiple System Atrophy (MSA). This rare, degenerative neurological disorder impacted their family in 2016 and inspired their initiative to help other MSA families and assist organizations dedicated to finding a cure.

Marco and Monica partnered with a local Seattle area bagel shop to create their signature **"Mr. & Mrs. Bulldog"** breakfast sandwiches to benefit Defeat MSA Alliance**.**

**Defeat MSA Alliance** is a national charity that aspires to balance support for patients, education of medical professionals, raise public awareness and nurture promising research and advocacy for the MSA community. **Defeat MSA Alliance** is devoted to improving the quality of life and building hope for people affected by MSA through support, education, research and advocacy.

# Jennifer Torres Joins Board of Directors






We are excited to announce that **Jennifer Torres** has joined the Board of Directors as of July 2023.

**Jennifer** is the daughter of **Mike Smith** who sadly passed from MSA on June 3, 2023.

Mike was an integral part of Defeat MSA Alliance and MSA United International Consortium from being on the Alliance's board of directors as the patient advocate, as an advisor, charity vice president and brain hub app network administrator.

He was Defeat MSA Alliance's number one supporter - always fighting MSA!

Now his daughter has chosen to continue his fight by joining the US Board as well as helping the global consortium, MSA United International.

Learn more about **Mike** and donate to his Research Legacy Fund here.

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




## GIVING TUESDAY IS NOVEMBER 28

#GivingTuesday is a global generosity movement, unleashing the power of people and organizations to transform their communities and the world. While #GivingTuesday happens every Tuesday, this year's annual celebration of generosity will happen on **November 28, 2023.**

**4 Ways to Help Defeat MSA:**

**1) Create a Facebook Fundraiser:**
https://www.facebook.com/fund/DefeatMSA/

**2) Create a Virtual Fundraiser (dedications to a loved one are possible too):**
https://www.justgiving.com/defeatmsaalliance

**3) Donate Directly to Our Secure Website (dedications to a loved one are possible too):**
https://www.defeatmsa.org/donate-to-us/

**4) Via Check, Send to:**
Defeat MSA Alliance, 29924 Jefferson Avenue, Saint Clair Shores, Michigan, 48082, USA

**NO AMOUNT IS TOO SMALL – BECAUSE EVERY CENT GIVES HOPE!**

**TOGETHER, WE CAN & WILL DEFEAT MSA NOW!**

Copenhagen, Dublin, Seattle, & Montreal (CAN)

# CHECK OUT SOME RECENT APPEARANCES OF OUR MSA SHOE




## Copenhagen

Our amazing globetrotting MSA shoe visited Copenhagen's iconic *Little Mermaid* statue in September 2023.

Based on the 1837 fairy tale of the same name by Danish author Hans Christian

Andersen, the statue has been a major tourist attraction in Copenhagen since 1913.



## Dublin Movement Disorder Doctors Kick MSA

The MSA Awareness Shoe stopped off to visit Professors Richard Walsh and Conor Fearon at the Dublin Neurological Institute in Dublin, Ireland. The Institute treats MSA patients and others with similar disorders. It also conducts research related to MSA.










## The Seattle Mariners & the World Congress of Neurology Host the MSA Shoe

**Marco** and **Monica Gonzales** of the **Seattle Mariners** welcomed the MSA Awareness Shoe in September. Mariners Pitcher **Marco Gonzales** was nominated for the **MLB Roberto Clemente Award** for Community Activism.

**Dr. Tarun Dua**, Chief of Brain Health for the **World Health Organization (WHO)**, was pleased to help bring awareness about MSA in Montreal, Canada at the World Conference of Neurology in October of 2023. **Dr. Dua** recently presented on the WHO plan for defeating neurological diseases during the Defeat MSA Alliance's 4th Annual Virtual All-Community MSA Conference. Watch her presentation here.

## 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 hashtags: **#defeatmsa** & **#kickmsa**



**Cuffed Beanie**




**Unisex T-Shirt**

**MUGS, HATS, AND MORE AT OUR OFFICIAL STORE**

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!**

Donate - USA

Donate - Canada

Donate - Australia

Donate - New Zealand

Donate - Denmark

Donate - Spain

Donate - Italy


**DEFEAT MSA ALLIANCE & MSA UNITED CONSORTIUM**

**29924 Jefferson Ave,**

**St. Clair Shores, Michigan, 48082 USA**

855 542-5672 (855 Kick-MSA)
info@defeatmsa.org



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**www.defeatmsa.org**

**MSA United International Consortium:**
**www.msaunited.org**


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