NEWS & VIEWS

NEWS & VIEWS: APRIL 2024

CONGRATS TO OUR CANADIAN FRIENDS!







Kudos to Canada for leading MSA Awareness Month!

Sister charity **Defeat MSA Canada/Vaincre I'AMS Canada** held their 2nd "Move for MSA" at Niagara Falls, Ontario on Friday, March 29, 2024. They also had the **Ottawa Sign TURN PURPLE** for MSA Awareness Month as well as have the **CN Tower** in Toronto, Ontario to #LIGHTUPPURPLE!

What a wonderful month of MSA awareness in CANADA!!!

THANK YOU CANADA!

#MOVE4MSA #MOVEFORTHOSEWHOCANT #MSASUX #DEFEATMSA #KICKMSA

ADVOCACY AND EDUCATION





Volunteer **Phil Fortier** attended the 5th Pan-American Parkinson's Disease and Movement Disorders Congress, February 9-11 in Cartagena, Colombia!

Phil is pictured with Movement Disorders Neurologist and MSA expert, **Dr. Enrique Urrea-Mendoza**, originally from Colombia

but now working in Tallahassee, Florida.

Thank you Phil for all that you do, fighting for those who cannot, advocating for our warriors among doctors everywhere and raising MSA awareness!

DEFEAT MSA BUILDS WORLD's 1st MSA AWARENESS PARADE FLOAT!







The FIRST EVER MSA AWARENESS PARADE FLOAT was constructed in Detroit, Michigan!

Wouldn't you like to see a float in your town!?? Defeat MSA is committed to raising awareness BIGTIME! If you are donating to the MSA cause, join us, help us put our heart and soul ("sole"?) into raising awareness!

Let's #KickMSA in your town!

The float made it's *grand debut* at Detroit's ***Marche du Nain Rouge*** ("March of the Red Devil" - the theme centers on driving evil and negativity from the city).

After 15 days of hard work, and many many long hours, with help from multiple volunteers, it was finished. We thank our talented artists and engineers to bring this remarkable idea to reality.

- **Ian MacLachlan, Sr. ("Ian the Elder")**
- **Phil Zanotti**
- **Josh Felice**
- **Lindsay McCosh**
- **Ian MacLachlan, Jr. ("Ian the Younger")**
- **Peter Bernal**

Also thanks to **Dr. Edwin George** (formerly, Director of Movement Disorders at WSU and currently, at the FDA) and **Phil Fortier** for driving the float!

Look out for the float to come to your area - more information to come on this great opportunity! If you are interested to help, please email us: defeatmsa@gmail.com

And keep watching our Facebook and Instagram!

TOGETHER, WE CAN & WILL DEFEAT MSA FOREVER!



WHY DONATE TO DEFEAT MSA ALLIANCE?

Here are just a few facts about Defeat MSA Alliance which some donors find important:

- **Currently, Defeat MSA is the ONLY major American charity still operated entirely by volunteers.**

  -- Defeat MSA is platinum rated for financial transparency by Candid/Guidestar - the highest rating possible!

  -- Defeat MSA has received 4 out of 4 stars by Charity Navigator & is also evaluated as a top rated “Great

NonProfit" by Great Nonprofits!

-- Defeat MSA is led by volunteers with a very personal connection to the disease. Why is this fact important? - Because we have witnessed this disease up close and personal and this experience drives our passion to Defeat MSA!

-- Defeat MSA hosts the largest, most diverse and completely free annual MSA conference in the world (most of these lectures are available online 160+ expert video lectures and films, check out our YouTube channel, https://youtube.com/@DefeatMSAAlliance).

-- Defeat MSA is the ONLY American MSA charity which hosts an equipment and assistive device loaner closet.

-- Defeat MSA has constructed the world's first MSA awareness parade float! Defeat MSA has also produced the first animation, the first documentary, the first children's US coloring book, the first patient support app, and sponsored the first ongoing podcast series about MSA!

-- Defeat MSA is the ONLY American MSA charity which participates in a global research funding consortium: www.MSAunited.org

Finally, Defeat MSA is not about new packaging, we do not spend huge sums on marketing and management salaries - we are what we always have been - trusted and true - and as always, committed to the final and utter defeat of MSA forever!

Help Us Defeat MSA Now!
www.defeatmsa.org/donate-to-us/

SHOUTOUT TO THE MSA CRUSADERS FOR RAISING MSA AWARENESS!



LISTEN ON SPOTIFY, YOUTUBE, PODBEAN, & iHeartRadio!

Join MSA Warriors, **David Knox** and **Daisy Paige**, while they create awareness one journey at a time!

- Interviews
- Life Stories
- Advocacy
- Fundraising

CLICK HERE TO LISTEN ON YOUTUBE

MSA Research Trial Updates

IONIS

Find a Study

Multiple System Atrophy | Part 1: ION464

Study to Evaluate the Safety, Tolerability, and Pharmacokinetics of ION464 Administered to Adults With Multiple System Atrophy (HORIZON)

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.

IONIS:

NEW MSA DRUG TRIAL INFORMATION - STUDY LOCATIONS: UK, PORTUGAL, FRANCE, AUSTRIA AND GERMANY - If you are

interested, do reach out to DEFEAT MSA ALLIANCE, we will help connect you: info@defeatmsa.org

https://ionistrials.com/?s=msa



THERAVANCE BIOPHARMA - NEW MSA DRUG TRIAL - FOR ORTHOSTATIC HYPOTENSION

Start the year on the right foot, Theravance Biopharma continues to enroll participants in the Phase 3 CYPRESS study.

Consider joining the study as they take another critical step toward the goal of managing symptoms of nOH for people

with MSA.

If you have been diagnosed with MSA and have blood pressure problems, contact them! They may be able to help.

For more information, including the locations of study centers, please email them at: 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

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**



KICK MSA T-Shirt



Distressed Dad Hat

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 - 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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