NEWS & VIEWS

NEWS & VIEWS: JUNE 2023

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

MSA Awareness in New Zealand



MSA warrior Phil Dickinson was recently profiled in New Zealand's largest news website, *Stuff!* The article covers Phil's journey toward diagnosis and the impact of the disease on his wife, Chloe, and their son.

Because there is little awareness about MSA in NZ, Chloe decided to swim 1km every day in May to raise much-needed research funds and increase MSA awareness!

If you are interested in supporting Phil and Chloe in this effort, please visit their Givealittle page. You can also look back on her marathon on the SWIM4MSA Facebook page.

A documentary was done about Chloe's amazing effort (and we can certainly say, heroic too!). Watch a brief clip below.









MSA Awareness in Australia



Sarah Fry, her family and friends at ORA Toorak Fitness Studio near Melbourne, Australia, devoted a solid 24 hours on the bike & ski erg to raise over 25k (AUD) for MSA Research! Check out her GoFundme page and help her by donating even more!

Learn about this amazing accomplishment and why Sarah is so passionate about defeating MSA! (Video)

MSA Awareness in Boston



Defeat MSA Alliance (USA) Board members Jennifer Huzar-Frost and Philip Fortier advocated for MSA patients and the MSA community at the 2023 American Academy of Neurology (AAN) Annual Meeting in Boston! **Thank you Jennifer & Philip!**




MSA UNITED
" Many Hearts, One Hope "



Above check out some of the amazing swag from the Defeat MSA Alliance booth. With a membership of over 40,000 neurologists, the **American Academy of Neurology (AAN)** annual meeting is considered to be the largest neurologists professional meeting in the world.

It is absolutely crucial to get the word out there about MSA among the core doctors that are likely to see it first! Defeat MSA Alliance and all the volunteers affiliated with the charities in the MSA United Consortium are doing just that - spreading awareness among health providers - far and wide!

Help Us Be the Change We Want to See!

Be A Changemaker!



"Cere" Bellum, the AAN's mascot, uses her big brain to raise awareness with the MSA Awareness Shoe! Read about the famous globetrotting shoe here

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 must convince medical, government and industry sectors that help for the MSA community is urgently needed.**

This month, we have exciting news from **Theravance and Alterity**!

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 is now recruiting for their CYPRESS Phase 3 clinical study. Today marks another critical step forward for MSA patients toward the goal of nOH symptom relief! Contact them at cypress@theravance.com or call +1.650.808.3737 for more information.

We've received this special communication from the Theravance team:

"If you are suffering from blood pressure issues associated with MSA and are interested in a research trial for this promising new treatment, please do reach out."

Plus, **more good news!** Ampreloxetine was just granted orphan drug designation by the US FDA for the treatment of symptomatic orthostatic hypotension in patients with MSA.

"Ampreloxetine is a once-daily norepinephrine reuptake inhibitor discovered at Theravance Biopharma. Previous clinical studies have demonstrated that ampreloxetine increased norepinephrine levels, prevented a drop in blood pressure, and prevented symptom worsening in patients with MSA. Approximately 80% of the 50,000 MSA patients in the U.S. suffer from nOH.1.2."

For more information, see their press release here.



Alterity

Alterity's Phase Two Clinical Trials tests the value of ATH434 as a new drug for people with Multiple System Atrophy.

Alterity is a biotechnology company dedicated to developing disease-modifying treatments for neurodegenerative diseases.

They're pleased to announce the first participant has been dosed in the United Kingdom in the Company's Phase 2 clinical trial!

"MSA is a rare and highly debilitating Parkinsonian disorder, and our Phase 2 clinical program is designed to evaluate the effects of ATH434 in individuals with early-stage disease with no current therapeutic treatment options," said David Stamler, M.D., Chief Executive Officer, Alterity. "With sites open in five countries, the clinical trial is steadily enrolling globally, and the enrollment of our first patient in the United Kingdom expands our reach in Europe."

To learn more, see their press release here.

SAVE THE DATE!

September 22-24, 2023

SAVE THE DATE!

MISSION MSA: HOPE FOR A CURE

4th Annual Free All-Community MSA Virtual Conference

Breakout Sessions • World-Renown Speakers
New Research Updates • MSA Documentaries

Selected Speakers:



Elizabeth Coon, MD
Mayo, MN



Wouter Peelaerts, PhD
KU Leuven, Belgium



Katie Kompoliti, MD
Rush, Chicago



Iva Stankovic, MD, PhD
Belgrade, Serbia

AskBio

Theravance Biopharma

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**



Unisex Tee



Unisex Long Sleeve Tee

CLICK HERE TO SEE 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): 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/
- Donate 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.

Defeat MSA (USA) is 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 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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