NEWS & VIEWS

FEBRUARY & MARCH 2024



Join the #MOVE4MSA with Defeat MSA/Vaincre AMS Canada!

#Move4MSA Awareness Campaign



March is Multiple System Atrophy Awareness Month. MSA is a rare, fast and fatal brain disease.

Please join us this month by "Moving for Those Who Can't" each day.
Help us by sharing photos, videos, exercise tips and facts about MSA on social media to raise awareness about this devastating disease!

Use these hashtags with every post:
#Move4MSA #MoveForThoseWhoCant #DefeatMSA #KickMSA

"With awareness comes funding, with funding comes research and with research comes treatment and a cure!" – Kelly Murphy, MSA Patient Advocate, Canada

MSA Research Trial Updates

GREAT NEWS

- REPORTED FIRST DISEASE MODIFYING THERAPY FOR MSA!

Lundbeck Pharmaceutical announced supportive phase II results with Lu AF82422 in the treatment of Multiple System Atrophy from the AMULET trial.

To quote Lundbeck :

"Signals of efficacy were observed across clinical and biomarker endpoints in a small exploratory proof-of-concept trial of 61 Multiple System Atrophy (MSA) patients (40 on Lu AF82422 versus 21 on placebo)."

"Although the AMULET trial did not show statistical significance on its primary endpoint in slowing the rate of progression of MSA as measured by UMSARS Total Score, a trend of a slowing MSA progression was observed in the group exposed to Lu AF82422."

WATCH LUNDBECK'S ANNOUNCEMENT HERE:
https://getvisualtv.net/stream/?lundbeck-o3zxgjk1hd

WE ARE ADVOCATING FOR MSA PATIENTS EVERYWHERE, FOR MORE MONEY & ATTENTION FROM THE PHARMA SECTOR!

DONATE TO OUR RESEARCH FUND -
www.defeatmsa.org/donate-to-us



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.

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

cypress@theravance.com,

or Call 1-650-808-3737,

or Visit: 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

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



🍩 Doughnuts for a cause!! 🍩 Defeat MSA Alliance is giving you the best reason to indulge in a dozen (or two) Krispy Kreme doughnuts. Starting February 14, 2024 until March 14, 2024,

50% of your order will be donated back to Defeat MSA Alliance when you purchase via our fundraising sales page!

Simply buy online, visit your local store & redeem using your code.

Treat yourself or even gift them to friends and family here:

https://www.groupraise.com/offer-campaigns/38394?utm_source=...

Keep watch on all social media for updates, links to order and more!

AMERICAN AUTONOMIC SOCIETY (AAS) MEETING 2023 in PUERTO RICO



Volunteer Defeat MSA Alliance & MSA United Consortium Board Members **Jennifer Huzar Frost** & **Philip M Fortier** attended the 2023 American Autonomic Society meeting in Puerto Rico. Defeat MSA Alliance was the **only MSA organization** exhibiting. Lots of great connections, talks and information was gathered and shares. **Thank you to our volunteers!**

Announcing the MSA Drug Repurposing Exploratory Fund!



Modeling the Linked Clinical Trials (iLCT) program supported by Cure Parkinson's UK, this exploratory research fund aims to support efforts to evaluate and prioritise existing drugs for further study in MSA. Repurposed drugs offer a unique advantage because they tend to already have extensive safety data and clinical evidence from other diseases. If repurposing drug research is successful, pharma companies will then be able to accelerate these drugs into clinical trials, thus helping to speed up the process of identifying new treatments. Defeat MSA Alliance (USA) and its partners continue to strongly advocate for more drug trials and a more equitable implementation of them worldwide.

Defeat MSA Alliance and its partners cannot conduct drug trials

or recommend treatments, experimental or otherwise, but we continue to advocate for more promising MSA treatments. All patients are advised to consult with their health care providers first before participating in any drug trials or experimental research. For any questions pertaining to diagnosis or treatment, please consult with your physician.

Earmark your donation to the Drug Repurposing Research Fund!

CLICK TO DONATE TO THE MSA DRUG REPURPOSING EXPLORATORY FUND

-About the first Cure Parkinson's UK iLCT Program, a pioneering drug repurposing program for Parkinson's - explained by Dr Patrik Brundin:

https://youtu.be/zzJaEg_NKkM?feature=shared

CHECK OUT OUR NEW SPANISH CONSORTIUM BROCHURE!

¡Click aqui para descargar ahora!

Investigación internacional Centro de apoyo y registro

Las personas con AMS no lo tienen nada fácil cuando se trata de encontrar apoyo o de estar al día sobre investigación. El Centro de apoyo y registro se ha creado para facilitar que tanto pacientes como cuidadores/as encuentren formas de crear redes de apoyo y de mantenerse informados/as sobre las oportunidades de investigación. Visita este registro para estar al día de los programas de apoyo y de las oportunidades que brinda la investigación:

msaunited.org/research-registry/

Este panfleto tiene únicamente fines publicitarios. No se debe utilizar para diagnóstico ni tratamiento.

Cualquiera que albergue dudas sobre AMS debería consultar con su médico o cualquier otro profesional sanitario sobre cuestiones de diagnóstico o tratamiento.

¡Ayudemos a quienes sufren AMS!

Ayúdanos con un cheque:
Defeat MSA Alliance
29924 Jefferson Avenue
Saint Clair Shores, Michigan 48082 USA

Email: info@defeatmsa.org

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**Marzo es el mes de la consciencia de la AMS.
El 28 de febrero es el Día Mundial
de las Enfermedades Raras.
Mayo es nuestro mes
para obtener financiación.**

Visita nuestras organizaciones integrantes:

Defeat MSA Alliance (United States)
www.defeatmsa.org

Defeat Multiple System Atrophy – Vaincre L'Atrophie Multisystématisée (Canada)
www.msacanada.ca

Atrofia Multisistémica (ASYD)
www.asyd.es

Defeat MSA Australia (Defeat MSA Down Under)
www.msadownunder.org.au

Defeat MSA New Zealand
www.defeatmsa.org.nz

Combattiamo l'Atrofia Multisistemica
www.msa-italia.org

Landsforeningen Multipel System Atrofi
www.msa-danmark.dk

Defeat MSA Awareness Shoe
www.msashoe.org

Muchas vidas, una esperanza

CONSORCIO MSA UNITED

www.MSAUnited.org

¿Qué es la AMS?

La AMS es una enfermedad cerebral incurable, rara, y con un desarrollo muy rápido. La AMS daña los sistemas que regulan la presión sanguínea, el pulso cardiaco y el control de la vejiga, que regulan muchas de las funciones vitales que todo el mundo da por sentadas a diario. Quienes padecen AMS presentan cada día una presión sanguínea peligrosamente baja, dificultades al hablar o tragar, trastornos del sueño, problemas de respiración, rigidez muscular y temblores. La esperanza de vida suele ser de 5 o 10 años. Las personas con un estadio avanzado de AMS suelen estar en cama, con imposibilidad para hablar o moverse. En estos momentos no existe cura para la AMS, ni tests genéticos para detectarla, ni terapia para ralentizarla. Los tratamientos para gestionar las debilidades que genera también son muy escasos.

Nuestra misión

MSA United International es un consorcio global de organizaciones caritativas que se unen en su lucha contra la atrofia multisistémica. Los objetivos del Consorcio son el apoyo a pacientes, la formación de profesionales en medicina, la concienciación pública sobre la enfermedad, la investigación científica, y la defensa de la comunidad. Todas las organizaciones que forman MSA United trabajan únicamente con voluntarios.

Consultoría de investigación

Pratik D. Bhattacharya, MD, MPH (EE.UU.)
Alessio Di Fonzo, MD, PhD (Italia)
Victor Dieriks, PhD (Nueva Zelanda)
Ziv Gan-Or, MD, PhD (Canadá)
Edwin B. George II, MD, PhD (EE.UU.)
Glenda Halliday, PhD (Australia)
Anne-Mette Hejl, MD (Dinamarca)
Henry Houlden, MD, PhD (Reino Unido)
Jeffrey Kordower, PhD (EE.UU.)
Anthony E. Lang, MD (Canadá)
Giulia Lazzeri, MD (Italia)
Peter A. LeWitt, MD (EE.UU.)
Wouter Peelaerts, PhD (Bélgica)
Alexandra Pérez Soriano, MD (España)
Michael G. Schlossmacher, MD (Canadá)
Enrique Urrea-Mendoza, MD (EE.UU.)
Steven Vernino, MD, PhD (EE.UU.)

* Expertos voluntarios ayudan de manera adicional revisando propuestas de investigación.

"Una semilla que se esconde en el corazón de una manzana es un frutal invisible"
(Kahlil Gibran)

Consejo de representantes

Rosemary Arbuthnot (Irlanda del Norte/Irlanda)
Miguel Ángel del Pino Esteban (España)
Brent Evans (Nueva Zelanda)
Philip M. Fortier, MA (EE.UU./Canadá)
Beth Foster (Canadá)
Jennifer Frost (EE.UU.)
Val Harper (Canadá)
Nadia Di Iorio (Italia)
Sergei Povaliaev (Rusia)
Olivia Romano (Australia)
Inge Vium (Dinamarca)

INVESTIGACIÓN. FORMACIÓN. APOYO. CONCIENCIACIÓN. DEFENSA.

IN MEMORIAM: PROF. G. K. WENNING



Defeat MSA Alliance was saddened to learn that **Professor Gregor Wenning** passed away 11th of February, 2024. Professor Wenning was director of the Clinical Neurobiology division at the University of Innsbruck in Austria. He was one of the greatest movement disorder experts of his generation, with particular interest in Multiple System Atrophy.

Professor Wenning was a brilliant mind and completely dedicated to the defeat of MSA. He spent

over 30 years in the discipline and published numerous articles and books on MSA. In 2012, he volunteered to serve on Defeat MSA's Scientific and Medical Advisory Board. His passing is a tremendous loss to the MSA community. We will miss him greatly.

Phil Fortier, who knew Professor Wenning since 2009 and founded Defeat MSA Alliance (USA), MSA United International Consortium and four other nonprofits within the Consortium, has announced a Consortium-wide legacy fund in his honor.

Professor Wenning's sincere hope was always to unite the world community and to ultimately defeat MSA forever. We endeavor to continue toward that goal in his memory.

Visit Defeat MSA Alliance (USA) to Donate

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+ May the Angels welcome Gregor to Paradise +

Eternal rest grant unto him, O Lord,

and let perpetual light shine upon him.

May he rest in peace. Amen.

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. **No donor dollars are used pay out high salaries for executives and staff.**

Lastly, the **MSA United International Consortium** is the only existing research consortium of MSA organizations in the world today.

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

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info@defeatmsa.org

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MSA United International Consortium: www.msaunited.org



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