“Defeat MSA Announces Global Research Consortium”

07/16/2020

DETROIT, MI—Defeat MSA Alliance announces the formation of a new global consortium of charities for people living with Multiple System Atrophy. The consortium, officially named “Defeat Multiple System Atrophy United International,” is comprised of six diverse organizations that span the globe. Each member organization is operated solely by volunteers, without relying on salaried staff or contracts for administrative services from profit driven businesses. Consortium members include:

- Defeat MSA Alliance – USA
- Defeat Multiple System Atrophy – Vaincre L'Atrophie Multisystématisée - Canada
- Defeat Multiple System Atrophy – Australia and New Zealand
- Combattiamo l'Atrofia Multisistemica – Italy
- Asociación Síndrome Shy-Drager Atrofia Multisistémica – Spain
- Defeat MSA Awareness Shoe, A Global Awareness Campaign – USA
The leaders of the consortium’s six charities have entered into a cooperative agreement to work as one united front to support patients, educate health professionals, raise public awareness and fund promising research.

They have also affirmed a commitment to support the “Global MSA Research Roadmap” that developed out of a 2014 international research meeting held in Las Vegas, Nevada. The Consortium’s five charities now join Defeat MSA Alliance in adopting the Roadmap’s research plan.

Attendees at the initial Roadmap included many of the world’s experts on MSA, the leaders of several advocacy organizations (including Defeat MSA Alliance), pharmaceutical industry representatives, and other important stakeholders in the worldwide MSA community. The meeting was spearheaded by the fundraising efforts of Rock ’n’ Roll Chef Kerry Simon, a celebrity chef based in Las Vegas. Sadly, Chef Simon succumbed to Multiple System Atrophy in 2015.

Although several advocacy organizations participated in the Roadmap meetings, Defeat MSA Alliance remains the only US-based charity to officially adopt the Roadmap. The primary task of the meeting was “to identify critical research areas where consensus and progress were needed to improve understanding, diagnosis, and treatment of the disease” (Neurology. 2018 Jan 9; 74–82). The Roadmap also established a series of research and advocacy recommendations to be implemented in the coming years.

Further information about the Consortium, participating organizations and their collective research philosophy is available by visiting www.MSAunited.org
The website is multilingual.

Contact: info@msaunited.org