

Introducing MSACONNECT

An Online Community for
Those Affected by MSA

[JOIN OUR COMMUNITY](#)

Building Hope For People Affected By Multiple System Atrophy

The Multiple System Atrophy (MSA) Coalition is a 501(c)(3) charitable organization with a 30-year history of devotion to improving the quality of life and building hope for people living with MSA.

The Four Pillars Of Our Mission



Credible & Relevant Education

Educating patients, care-partners and healthcare professionals with credible, critically important and relevant information



Trusted Emotional Support

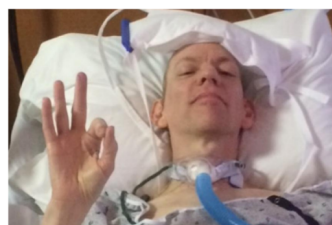
Providing patients and caregivers with trusted and compassionate emotional support



6th International Multiple System Atrophy Congress March 1 - 3, 2018

Building A Unified MSA Community

Building a sense of community by connecting and unifying people affected by MSA.



Funding Patient-Centric MSA Research

Funding patient-centric collaborative research aimed at alleviating symptoms, slowing disease progression and discovering a cure

MEET ALAN & ROCIO

We exist to support people like Alan and Rocio. Watch their story of how MSA connected them to others and how they're planning on paying it forward. Then visit our YouTube channel for more inspiration and information.



Testimonials About Our Work

Kara Byron - Daughter of an MSA Patient

"My dad, Marc, was diagnosed with MSA-C in 2015. At the time, my family essentially knew nothing about this rare disease and we needed to better understand his diagnosis. When we learned that there is no curative treatment for MSA, we committed our time to understanding his symptoms, collaborating with doctors and finding ways to improve my dad's quality of life.

Over the last four years, we've established the best symptom management care plan for my dad, of which we completely attribute to the MSA Coalition.

As a soon-to-be graduate with a Masters in Social Work, I see first-hand the efficiency and dedication of the MSA Coalition in providing MSA patients, families and caregivers with the most optimal resources, research, support and education.

When you really pause to consider how rare and complex this disease is, it feels reassuring and comforting to know that the coalition is wholeheartedly focused on helping those affected by MSA navigate this journey. Each conference, webinar, support group and fundraising effort is thoroughly thought through and the information and wealth of knowledge the coalition shares with the community is unparalleled.



For my dad and our family, the MSA Coalition also provides guidance on all things MSA-related, from the most durable medical equipment to recommendations for specific therapies. The sense of hope and abundance of resources our family has received from the coalition has completely changed our lives. I encourage anyone impacted by MSA to become involved with this wonderful organization because the MSA Coalition will change your life, too!"

HOW YOU CAN HELP



Make a Generous



Set Up a



Start a Live



About the Multiple System Atrophy Coalition

Mission – Programs – History

OUR MISSION

The Multiple System Atrophy (MSA) Coalition is devoted to improving quality of life and building hope for people affected by multiple system atrophy through:

- Providing patients and care partners with trusted and compassionate emotional support.
- Educating patients, care partners, and healthcare professionals with credible, critically important, and relevant information.
- Building a sense of community by connecting and unifying people affected by MSA.
- Funding patient-centric collaborative research aimed at alleviating symptoms, slowing disease progression, and discovering a cure.
- Playing a leading role in raising awareness and advocating for those impacted by the disease.

More Ways To Help

[Participate in MSA Research](#)

[Donate Now](#)

[Raise Money](#)

[Buy MSA Gear](#)

OUR VISION

Improve quality of life for the multiple system atrophy community by expanding access to care and support while advancing research toward treatment and a cure.

OUR PROGRAMS

Offering assistance to patients and their families with vital emotional support, information and guidance ...

Toll Free Helpline – 866-737-5999:

Our volunteer board members spend many hours on the telephone with patients and caregivers, staying in touch over weeks and months to provide encouragement and a listening ear. We connect them with sources of information, mailing packets and emailing links. Nothing is more important to us than helping MSA families. We have walked this path too.

Educational materials:

The MSA Coalition offers print, DVD, online and downloadable resources for patients, caregivers and families. We recommend downloading our new edition of *MSA: What You Need to Know*. For other downloadable items visit the [MSA Coalition resources page](#).

To self-order printed materials and DVDs [CLICK HERE](#).

View videos on our [YouTube channel](#).

STRATEGIC PLAN 2023-2025

Advocacy & Awareness	Education & Support	Research
Establish an actionable advocacy agenda	Define and develop tailored patient and care partner centric support communities and educational resources.	Engage the MSA Community with current MSA research and clinical trials that delivers action and hope.
Increase awareness of multiple system atrophy with the general public, medical and scientific communities, and elected officials.	Establish a standard of interdisciplinary care for MSA health care facilities and build a support framework to promote access to care, education, community, and clinical studies.	Enhance, evolve, and broaden diverse research expertise inside the MSA Coalition.
Create and mobilize a global MSA advocate network to enhance visibility and voice of the MSA Coalition to effect change.	Define and develop tailored education for medical professionals.	Strengthen sustainable research strategies with identified goals and objectives.
		Identify new and evolve existing external relationships to facilitate global innovation and provision of resources in the MSA research and clinical trial space.

GET CONNECTED

Contact us directly for assistance:

Email: info@multiplesystematrophy.org

Support Line: 866-737-5999

Office Line: 866-737-4999

By Mail: 1660 International Drive, Suite 600, McLean, VA 22102

In-person Support Groups:

The MSA Coalition maintains contact with over 50 support groups all around the USA and Canada which welcome MSA families. A list of these support groups can be [downloaded from our resources page](#). We work closely with several individuals and organizations that facilitate MSA specific support groups. Those seeking to start a local group are encouraged to be in touch with us for advice and a supply of educational materials.

Online Support Groups:

The MSA Coalition sponsors several online discussion groups for MSA families including the public "MSA Coalition discussion group", the private groups "MSA Buddies & Care Partners" and "MSA A Patient's Journey" as well as "MSA Research News". In addition there are 9 private regional online discussion groups covering the United States listed on our [resource page](#).

Newsletter: The MSA Coalition produces a monthly e-Newsletter. View the archives and [subscribe here](#).

The Annual Patient and Family Conference:

Each year researchers and medical professionals make presentations that provide real-world assistance and valuable information to people whose lives have been impacted by multiple system atrophy. For those who are unable to travel, we live-stream the conference online and make the sessions available for later viewing. Expert MSA clinicians and research scientists as well as other health professionals (occupational therapists, speech therapists, physiotherapists etc) attend and present up to date information to MSA families on how to cope with the disease. Separate breakout sessions among MSA patients and caregivers are the highlight of this meeting as each group shares their concerns, forming strong bonds and lifelong friendships. Watch video recordings from the [past 10 conferences here](#).

Offering support for investigators

Early Investigator Travel Awards:

The MSA Coalition provides travel awards to defray the costs of attending medical and scientific congresses in order to help attract talented early career investigators to the field of multiple system atrophy research. Many of the early career investigators who have received MSA Coalition Travel Awards are continuing to contribute important findings to the overall knowledge of MSA. Details and a list of past awardees are available [here](#).

Don Summers Memorial MSA Travel Award:

The Don Summers Memorial MSA Travel Award was established in 2014 in memory of past president Don Summers who led the organization from 1999 to 2010. Endowed by Sylvia Summers, the award consists of a \$2000 cash prize and a plaque which are given in recognition of outstanding MSA research by an early career investigator. Presented annually at the American Autonomic Society Congress, this award promotes and encourages MSA research by providing early career researchers an incentive to study this rare disease and to receive recognition and financial support for doing so. The award winner is selected in partnership with the American Autonomic Society. Details and a list of past awardees are available [here](#).

Funding vital research

MSA Coalition Research Grant Program:

The Multiple System Atrophy Research Fund is used to encourage and finance critically important MSA research leading to the identification of causes, improved diagnostic methods and more effective symptomatic and disease modifying treatments: Helping to bring us closer to a cure. Guided by the principles of the [MSA Global Research Roadmap](#), a vision that we helped to create, The Multiple System Atrophy Coalition seeks to fund the most promising MSA research anywhere in the world. To date, we have reviewed over 180 research grant proposals and awarded funding to 55 multiple system atrophy research project grants at 34 institutions in 11 countries. In total, these projects have received \$3.5 million in funding. Go [here](#) for a complete list of funded projects and the latest MSA research updates.

Sponsoring healthcare professional education and scientific conferences



MSA Research

Funding Research is Funding Hope. We've Funded 55 Research Projects with \$3.5 Million in Donations.

The Multiple System Atrophy Coalition® Research Fund

The MSA Coalition® has a dedicated Multiple System Atrophy Research Fund used to support scientific study into the cause, treatments and a cure for multiple system atrophy. As a federally registered 501(c)3 charity, donations made to the MSA Coalition may be tax deductible for U.S. taxpayers. Given that there are a small number of MSA patients in the U.S. and globally, a centralized MSA Research Fund is critical to pooling money so the funds can be used in the most effective way possible.

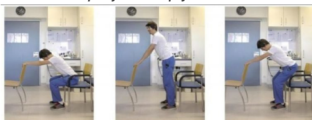
What the MSA Research Fund Supports

The Multiple System Atrophy Research Fund is used to encourage and finance critically important MSA research leading to the identification of causes, improved diagnostic methods and more effective symptomatic and disease modifying treatments: Helping to bring us closer to a cure. The Multiple System Atrophy Coalition seeks to fund the most promising MSA research anywhere in the world. To date, we have reviewed over 175 research grant proposals and awarded funding to 55 multiple system atrophy research project grants at 34 institutions in 11 countries. In total, these projects have received \$3.5 million in funding.

Research Dollars Making a Difference

Dr. Cecilia Raccagni, a researcher at Innsbruck Medical University, Austria, and colleagues there recently published the paper **"Physiotherapy improves motor function in patients with the Parkinson variant of multiple system atrophy: A prospective trial"**.

A research grant from the MSA Coalition helped support this trial, the results of which show that **"physiotherapy is feasible, safe and improves gait performance in patients with multiple system atrophy"**.



We are happy to be able to share this link with permission from the research team where you may [download the exercises](#) that proved helpful. Please feel free to share this protocol with your own physical therapists. We invite you to [learn more about other MSA Coalition funded projects](#).

[View Our Research Projects](#)

Patient & Family Conference

The Future Direction of Multiple System Atrophy Coalition Funded Research



Watch on YouTube

<p>The Future Direction of Multiple System Atrophy Coalition Funded Research</p> <p>The Future Direction of Multiple System Atrophy Coalition Funded Research Dr. Vik Khurana</p>	<p>Multiple System Atrophy Coalition Funded Research Over the Past 5 Years</p> <p>Multiple System Atrophy Coalition Funded Research Over the Past 5 Years Dr. Gregor Wenning</p>	<p>MSA Brain Bank (N=272)</p> <ul style="list-style-type: none"> Sex: 52% men Race: 85% Caucasian Region: 1 Hispanic, 2 Black, 2 Pacific Islander Age at death: median 58 years (range: 27 to 91) Disease duration: median 7 years (range: 1 to 19) Antemortem clinical diagnosis MSA: 1% PPS: 10% PD: 1% Other: 3% (CBS, FTD, PPA, ALS) Family history of neurodegenerative disorder: 8% <p>An Overview of Findings & Implications for MSA in Brain Pathology Dr. Dennis Dickson, Mayo Clinic</p>
<p>What Happens in Clinical Trials and Why MSA Patients Should Participate?</p> <p>What Happens in Clinical Trials and Why MSA Patients Should Participate? Dr. Daniel Claassen</p>	<p>and thank you</p> <p>Multiple System Atrophy Questions About MSA Research with Answers from World-Renowned Experts</p>	<p>What is a realistic timeline to identifying a treatment or cure for multiple system atrophy??</p> <p>What is a realistic timeline to identifying a treatment or cure for multiple system atrophy??</p>
<p>A serum miRNAs signature as potential biomarker for MSA</p> <p>An Interview With: Dr. Wassilos Meissner & Dr. Annamaria Yalilelunga</p> <p>Interviewed by: miRNA Biomarker for Multiple System Atrophy An Interview with the Researchers Episode 1</p>	<p>Multiple System Atrophy Coalition - MSA Research Overview</p>	<p>Funding Announcement Core G Genomics</p> <p>Vikram Khurana, MD PhD Scientific Liaison, MSA Coalition Board of Directors Chief, Division of Neurogenetics, Brigham & Women's Hospital and Harvard Medical School</p> <p>Dr. Vikram Khurana on Funding Announcement of Core G Genomics Multiple System Atrophy Coalition</p>

[View Our Research Projects](#)

About the MSA Coalition Research Grant Program

Launched in April of 2013, the MSA Research Grant Program is designed to kickstart promising Multiple System Atrophy research. To assist in this mission, the MSA Coalition relies on the expertise of a world-class Scientific Advisory Board (SAB) comprised of renowned globally-diverse researchers, scientists and physicians who are considered thought-leaders in the field of multiple system atrophy research. The SAB's mandate is to ensure independent and objective review of each research proposal application submitted to the MSA Coalition's Research Grant Program, to rank them by scientific merit and subsequently advise the Board of Directors about the top-ranked projects.

Under their guidance the MSA Coalition funds promising research that is directly applicable to identifying:

- A clear cause of MSA
- Improved methods leading to an earlier and more accurate diagnosis
- Better treatments to alleviate MSA symptoms and improve quality of life
- Interventions that slow, halt or reverse the progression of MSA
- A cure for MSA

Attention Scientists

The MSA Coalition will periodically solicit Requests for Applications / Letters of Intent as directed by the board. Check out our [grant opportunities page](#).

To ensure you are informed of the next RFA, please subscribe to our [Researcher Mailing List](#).

Supporting Early Career MSA Researchers

The MSA Coalition provides travel awards to defray the costs of attending medical and scientific congresses in order to help attract talented early career investigators to the field of multiple system atrophy research. Many of the early career investigators who have



Multiple System Atrophy (MSA)

What is Multiple System Atrophy?

Multiple System Atrophy (MSA) is a rare neurodegenerative disorder that can cause a multitude of symptoms in any combination including impairments to balance, difficulty with movement, poor coordination, bladder dysfunction, sleep disturbances and poor blood pressure control. The disease was first known as Shy-Drager Syndrome. Currently, it is believed that MSA is "sporadic," meaning that there are no established genetic or environmental factors that cause the disease. A few reports have described families with MSA, but this finding is probably very rare.

What are the symptoms of MSA?

Most often, the first clinical symptom a patient will note will be lightheadedness, dizziness, and episodes of passing out, but the first symptoms in some patients may include difficulty initiating movement, body stiffness, urinary incontinence, and increased falls. The autonomic nervous system is essential for controlling blood pressure, body temperature, digestion, urination, and sexual function, so MSA is largely a disease that impairs the autonomic nervous system. However, some patients don't seem to have severe autonomic symptoms, thus emphasizing the range of symptoms from person to person.

The difference between MSA and Parkinson's Disease

Although many clinical symptoms are also present in those with Parkinson's disease, patients with MSA typically show symptom onset at a younger age, with the average onset in the early 50s. The journey to a diagnosis can be long and difficult. Many patients are diagnosed with Parkinson's disease first, but over time, the extent, severity, and type of symptoms change, making a diagnosis of MSA more likely.

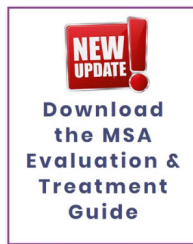
One of the most important symptoms in MSA patients is the presence of sleeping abnormalities such as snoring and apnea, stridor, and acting out dreams. Also, subtle changes to a person's speech such as low pitch or quivering voice can also be evident and the clinician may notice symptoms that look slightly different from those of Parkinson's disease. The diagnosis of MSA is made clinically, and neuroimaging can sometimes assist with confirmation of a clinical suspicion.

Common and Distinguishing Features of MSA

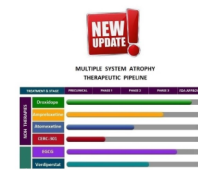
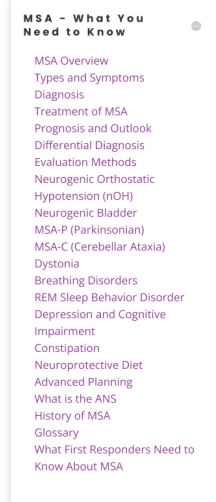
Similarities to Parkinsonism: Both Parkinson's disease and MSA are characterized by deposits of a type of protein known as alpha-synuclein in the nervous system. Both conditions also specifically affect cells that produce dopamine, a neurotransmitter that controls motor commands. As a result, many of the same motor dysfunctions occur in the two conditions.

Unique features: Important differences distinguish the symptoms and course of MSA from Parkinson's disease and other conditions of the nervous system, such as cerebellar ataxia or pure autonomic failure (PAF). Notably, MSA affects several areas of the brain, including the cerebellum, the brain's balance and coordination centers, and the autonomic nervous system, as mentioned above.

Another distinguishing feature of MSA is the types of cells involved. While Parkinson's disease affects the dopamine-producing neurons of a motor-controlling portion of the brain known as the nigro-striatal area, MSA affects both neurons and glial cells – the support cells that maintain the health of neurons and which outnumber neurons 10:1. Additionally, some of the glial cells affected in MSA produce myelin, the fatty substance that insulates neurons.



Atrofia Multisistémica: Que es lo que usted necesita saber



Recent Posts

- Saying Yes to Opportunities
- The Loving Sacrifice of Caregiving
- Learning to Navigate Life Changes
- You Walk Away? | A Poem from an MSA Patient
- From Parkinson's to MSA: My Path of Resilience and Faith
- MSA Instruction Manual
- The Lessons MSA has Taught Me
- Books, Treats, and Bingo: A Day with my Mother with MSA
- Miles for MSA Year 4: Updates from Austin Urban
- Making Adjustments for MSA

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For all references listed in the About MSA section please download the MSA Coalition's "MSA - What You Need to Know"

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