New research partnerships, global advocacy, caregiver support, conference news and ways to take action.

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**Defeat MSA Alliance (USA)**
**& MSA United Research Consortium**

***Defeat MSA Alliance & MSA United are U.S. based organizations geared toward global impact - and the only major MSA charities entirely operated by volunteers.***




# Join Us for the 7th Annual Virtual MSA Conference

Mark your calendar for **September 19–20, 2026**, and join the **7th Annual Virtual MSA Conference**, presented by the Defeat MSA Alliance and MSA United Research Consortium.

This year's theme, **"Hope for MSA: New Directions in Research & Advancing Care,"** brings together leading MSA researchers,

clinicians, and experts from around the world to share the latest developments in research, treatment, and patient care.

The conference is **free to attend**, with attendees from the U.S. receiving a **free conference awareness package**. Participants will have opportunities to hear from renowned speakers, learn about the latest promising research, and take part in **Ask the Doctor** and **Ask the Scientist** sessions.

**Register Today on the Hub**




Defeat MSA and MSA United are pleased to announce the **Garden of Blessing International Movement Disorders Memorial**, a unique new project bringing remembrance, nature and our community together.

Located at **1052 Manistique St, Detroit, MI 48215,** the Garden is a nonprofit hosted pollinator and wildflower garden using land purchased from the city for use by the community. Open to the public, it will provide a space to remember loved ones, gather as a community, raise awareness and connect with nature. Jointly sponsored by MSA consortium member organizations in United States and Canada, the garden will also unify communities nationally and internationally, via a live streaming webcam and website (under construction) which will mirror the physical garden.



## Become Part of the Garden Today

Individuals, families honoring lost loved ones and organizations (local, national and international) will have multiple opportunities to contribute to this unique community garden project. Tributes and dedications may be made to those impacted by any movement disorder.

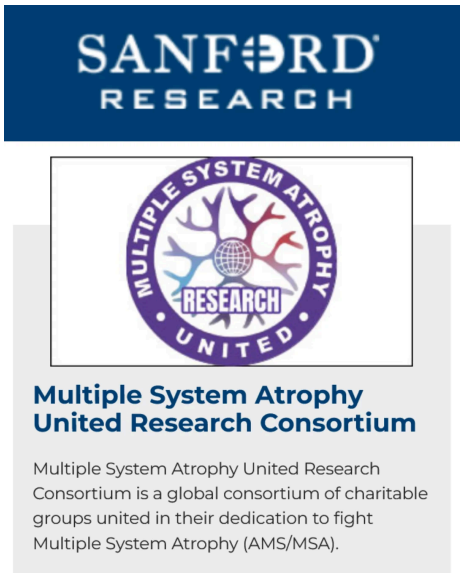
**Opportunities will include:**

- Memorial garden beds and flower groups
- Benches and tables
- Personalized bricks and plaques
- Remembrance Wall - which could include photos and names
- Memory capsules, helping us learn about the personal journeys
- Gathering structures and more

Support for future garden needs, include a rain catchment system and upgrading other garden areas.

**Interested in a dedication or supporting the Garden?**
Contact Defeat MSA to learn more: **garden@defeatmsa.org**






MSA United Research is partnering with **CoRDS, the Coordination of Rare Diseases at Sanford**, to help strengthen the connection between people affected by MSA and the researchers working on advances in biomarkers, genetics and new treatments.

Based at Sanford Research in Sioux Falls, South Dakota, **CoRDS** is a free international rare-disease registry that securely gathers information from patients and families. Qualified researchers can use de-identified registry data to better understand rare diseases, identify research needs and connect eligible participants for future study opportunities. CoRDS currently works with more than 130 patient organizations and includes participants from more than 100 countries.

> *"By participating in a registry, patients and families can turn their lived experiences into information that helps researchers ask better questions and design stronger studies."* ***- Philip Fortier, Chair, Defeat MSA***

Visit the CoRDS Rare Disease Registry

# THE HEART IN MSA: DR. SATISH RAJ

**Defeat MSA and its international partners are currently supporting eight research teams in 2026, with projects addressing disease mechanisms, biomarkers, diagnosis and supporting future clinical trials.**



Today we feature **Dr. Satish Raj**, a cardiologist and Professor of Cardiac Sciences at the University of Calgary in Alberta, Canada. Dr. Raj founded the Calgary Autonomic Investigation and Management Clinic and specializes in conditions involving blood-pressure regulation, heart rhythm and the autonomic nervous system.

MSA can disrupt automatic functions such as blood-pressure and heart-rate regulation. By examining the cardiovascular and autonomic effects of the disease, researchers can work toward better ways to understand Multiple System Atrophy.

Dr. Raj will also discuss **Cardiology and Autonomic Issues** during the upcoming Defeat MSA conference (Sept 19-20). Dr. Raj was the highest rated grant awardee, receiving full support for his heart related research from consortium member organization, **Defeat MSA/Vaincre AMS Canada** in 2026.

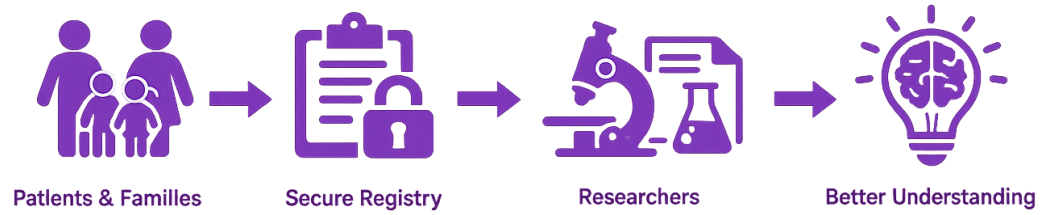
# PATIENT AND FAMILY VOICES AT IONIS




**Rodney Rastall,** Defeat MSA Board Member recently visited **Ionis Pharmaceuticals** to share perspectives on behalf of our community directly with Ionis upper management.

Ionis is developing ION464, an investigational RNA-targeted medicine being studied for Multiple System Atrophy and Parkinson's disease. Visits like this help researchers understand the experiences, priorities and urgency behind the scientific work.

For Rodney, who serves as Defeat MSA Board Secretary, the work is deeply personal. His wife, Regina, died from MSA, and her story continues to inspire his commitment to advocacy and research.




> *"Regina's journey with MSA is why I keep showing up. When researchers hear directly from families, they understand that every study represents the people, urgency and hope."*
>
> — ***Rodney Rastall,***
> *Defeat MSA Alliance, Board Secretary*





## EXPANDING GLOBAL COLLABORATION

During a recent visit to London, Philip and Rosemary Arbuthnot, (President, MSA Partnership Ireland) connected with colleagues at the MSA Trust, **Professor Henry Houlden of UCL Queen Square (Research Advisor, Defeat MSA and MSA United)** and other members of the research community.

The MSA Trust's research symposium, developed in collaboration with University College London (UCL), has brought together researchers, clinicians, advocacy organizations and industry representatives yearly to share early research findings and build

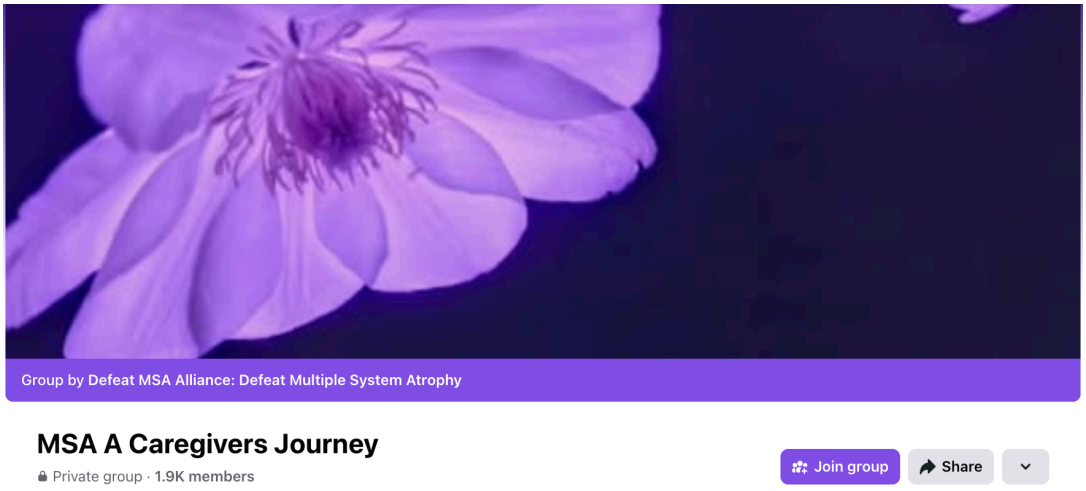
future collaborations. Its 2026 symposium welcomed nearly 150 participants.

This symposium has an added significance because **Professor Houlden** is among the researchers receiving 2026 research support from Defeat MSA and MSA United. His work focuses on identifying biomarkers that could support earlier diagnosis, disease staging and stronger clinical trials.




**Caring for someone living with MSA can be physically demanding, emotionally challenging and deeply isolating. No caregiver should have to navigate that experience alone.**

**If you are a current or former caregiver of someone with MSA, consider joining MSA: A Caregiver's Journey, one of many Defeat MSA Facebook Groups.**




**MSA: A Caregiver's Journey** is a private Facebook group where care partners can ask practical questions, exchange hard-earned lessons, tips and connect with people who understand the day-to-day realities of MSA.

| MSA A Caregivers Journey | | | |
|---|---|---|---|
| **13 Years Active** | **1.9K Members** | **1.3k Posts this Month** | **643 Reactions this Month** |

> *"In this group, I don't have to explain the hard parts. People already understand."* ***- group member***

**Why Caregiver Support Matters**

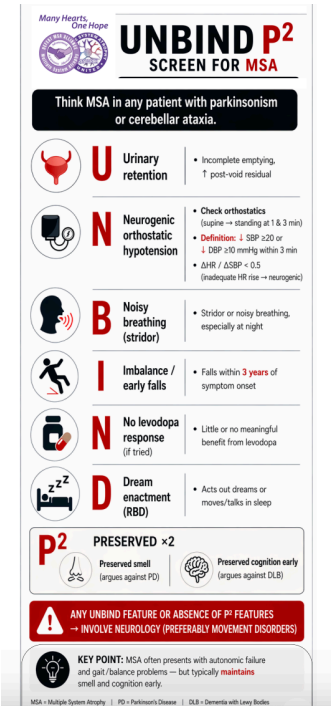
In one published survey, 90% of former MSA caregivers described mobility challenges as difficult or very difficult to manage, while 85% said the same about autonomic symptoms. Peer support cannot remove those challenges, but it can assist and help caregivers feel better informed, understood and connected.

Join Defeat MSA's Private Caregiver Group

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# A New Medical Advisor and a New MSA Recognition Tool






# Defeat MSA and MSA United are pleased to welcome Dr. Philip Tipton to its medical advisory team.

Dr. Tipton (Director of Research at the Cole Center for Parkinson's & Movement Disorders, Knoxville, TN) is a movement-disorders specialist and behavioral neurologist whose clinical and educational work focuses on helping healthcare professionals better recognize complex neurological conditions.

He is also the creator of **UNBIND P²**, the world's first practical recognition tool developed to help primary healthcare providers notice early symptoms that may help distinguish MSA from Parkinson's disease and other similar disorders. This helpful tool is downloadable from our website **here.**




Beyond research, we remain committed to practical support for individuals and families navigating MSA.

**Available resources include:**

- Defeat MSA Loaner Closet
- Support Groups
- MSA Hub Community

Join MSA Hub 2.0

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# Thank You for Supporting the Defeat MSA Raffle!



*Pictured left to right: Philip Fortier, Emma Martinez of Roseville, Michigan, and Mark Wood, board director, Defeat MSA and Move for MSA.*

After an incredible year, the **Defeat MSA Raffle, the world's first progressive gaming raffle for MSA, has officially come to a close!**

Thank you to everyone who purchased tickets, donated, volunteered, shared the raffle, and helped raise awareness of

Multiple System Atrophy (MSA). Your support helps shine a light on MSA and makes a meaningful difference for families affected by this devastating disease.

**Mark Is Our Raffle STAR!**

A special thank-you to **Mark Wood** (board member, Defeat MSA and Move for MSA, Inc.) who generously shared his time every week for an entire year, his energy, and connections to help make the raffle a success. After losing his father to Parkinson's disease, this mission is especially meaningful to Mark, and we are incredibly grateful for his dedication.

We also recognize **Vicki Moeller**, raffle volunteer, Move for MSA board member, and devoted caregiver for her mother. Her hard work and compassion were instrumental in this raffle effort.

**Thank You!**

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## Looking Ahead:

There are several important events ahead which show great promise:




**The 7th Annual All-Community Global Virtual Conference**

- **Sept 19: Clinical & Caregiving Topics**
- **Sept 20: Scientific & Research Topics**

In addition, Defeat MSA Alliance and MSA United Research Consortium will be advocating on behalf of MSA patients and caregivers at these conferences for the rest of the year, including:

- **Society of Neuroscience (SfN)**
  **(Nov 14-18, Washington D.C.)**
- **International Congress of Parkinson's Disease and Movement Disorders**
  **(Oct 4-8, Seoul, Korea)**

We'll be sharing additional information on these and other events soon.

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# Start a Fundraiser for Defeat MSA

A birthday, anniversary or personal milestone can become an opportunity to introduce more people to the MSA community.

Starting a Facebook fundraiser takes only a few minutes and gives friends and family a simple way to support research, education and programs for people affected by MSA.

### Step 1: Go to Facebook Fundraisers

On Facebook, click **Fundraisers** in the menu, or search "**Facebook Fundraisers**."

### Step 2: Choose "Raise Money for a Nonprofit"

Select **Defeat MSA Alliance (USA)** from the nonprofit list.

### Step 3: Set Your Goal

Choose a fundraising goal that feels meaningful and achievable — every dollar helps advance research.

### Step 4: Write a Short Personal Message

Example:

*I'm raising funds for Defeat MSA Alliance to support research, education and families affected by Multiple System Atrophy.*

*MSA is a rare and progressive neurological disease, but every donation helps strengthen the community working toward better answers, treatments and hope.*

*Please consider donating or sharing this fundraiser with your friends. Every gift makes a difference.*

### Step 5: Share It

Post your fundraiser.
Invite at least 5 friends to support or share.

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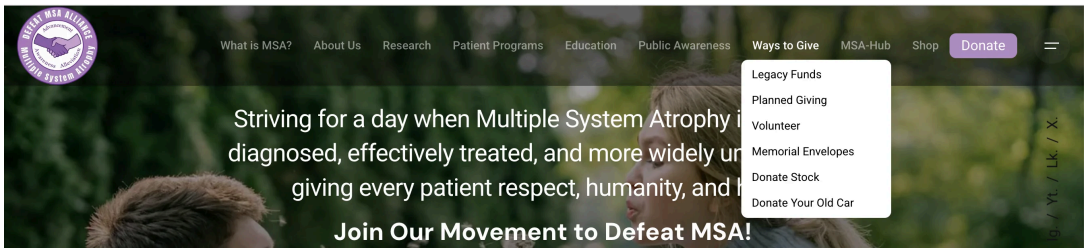
Start a Facebook Fundraiser

Sustained research progress requires long-term planning.

Through FreeWill, supporters can create a no-cost will and include Defeat MSA Alliance (USA) as a beneficiary — helping ensure research sustainability for years to come.

FreeWill

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## Support the mission in a way that works best for you.

You can make an impact through GoFundMe campaigns, Facebook birthday fundraisers, Legacy funds, planned giving, stock or vehicle donations, memorial gifts, personal fundraising, or by volunteering your time.

Every contribution helps move research forward and supports families affected by Multiple System Atrophy.

Visit Homepage > Ways to Give

# GIVE HELP, GIVE HOPE

**Defeat MSA** (USA), together with its affiliates in **MSA United**, stands apart as the world's only major MSA charity network operated entirely by volunteers—people personally impacted by MSA. We pay no management salaries to individuals unconnected to MSA, helping ensure that all donor dollars directly advance our mission of research, education, support and advocacy.

DONATE NOW

## TOLL FREE

**1 855 542-5672**

**(855 KICK-MSA)**


**Defeat MSA Alliance (USA) & MSA United Research Consortium**

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