MSA NJ

ORGANIZATIONAL UPDATES



About MSA NJ

- MSA NJ is a registered 501(c) (3) charity.
- Founded in 2012 by the Roemer family after losing Mom to MSA in 2009.
- Goals:
 - Provide support services to those impacted by MSA through:
 - Monthly support group meetings
 - Annual Patient & Caregiver Conference
 - Sharing resources and information relevant to managing MSA
 - Educate about MSA
 - Raise awareness of MSA
 - Support research activities for treatment and a cure.
 - *Fundraising campaigns are to support realization of these goals*

MSA SUPPORT GROUPS

• Monthly sessions held at Overlook Hospital, Summit, NJ; 2nd Saturday of the month.

AND

• NEW! Quarterly sessions held in NYC at NYU Langone; 3rd Saturday of the month.

Open to future expansion!

MARCH AWARENESS ACTIVITY

2019 Proclamations:

- 2019 marks the 6th consecutive year The Multiple System Atrophy Coalition and MSA NJ have worked together to obtain state proclamations for Multiple System Atrophy Awareness Month.
- Six permanent bills: Alabama, Arkansas, Indiana, Ohio, Oregon, Washington
- 35 states requested; 19 approved so far, including NJ!



WHEREAS, Multiple System Atrophy (MSA) is a rare progressive neurodegenerative disorder characterized by a combination of symptoms that affect both the autonomic nervous system and novement; and

WHEREAS, according to the National Institute of Neurological Disorders and Stroke, MSA affects potentially 15,000 to 50,000 Americans, including men and women of all racial groups; and

WHEREAS, symptoms, including problems with heart rate, progressive loss of motor function and problems with balance, coordination, gait, bladder and bowel control, speech, swallowing, breathing and eventual confinement to bed, tend to appear in a person's 50s and advance rapidly over the course of five to 10 years; and

WHEREAS, there are some medications that treat the symptoms and some clinical trials for the development of improved treatment, nonetheless researchers continue to look for treatments with fever side effects, and methods to better manage the disease and ultimately a cure; and

WHEREAS, a multidisciplinary approach to MSA care includes physical, psychological and financial support for patients, caregivers, support groups, and MSA research foundations; and

WHEREAS, March has been proclaimed as Multiple System Atrophy Awareness Month among the worldwide MSA community to increase awareness of the devastating effects of MSA;

NOW, THEREFORE, I, Philip D. Murphy, Governor of the State of New Jersey, do hereby proclaim:

MARCH 2019 AS MULTIPLE SYSTEM ATROPHY AWARENESS MONTH

in New Jersey.



GIVEN, under my hand and the Great Seal of the State of New Jersey, this fifth day of March in the year two thousand nineteen, the two hundred forty-third year of the Independence of the United States.

Lt. GOVERNOR Y. Dein

GOVERNOR)

AWARENESS/FUNDRAISING EVENT

- 2019 Global MSA Walkathon
 - Charity organization partner to support The Multiple System Atrophy Coalition's initiative. More info on Charity Footprints website.
 - Two ways to help:

 Join the MSA NJ Team – registration costs \$50, link tracking device, share with friends and family to get donations. Please be sure you are selecting "Team MSA NJ: ConquerMSA.

https://www.charityfootprints.com/team?id=1041

• Make an individual contribution to the MSA NJ campaign. https://www.charityfootprints.com/.../goa.../index/5019/swikwmtx

MSA NJ PARTNERSHIPS

The Multiple System Atrophy community is a small, but close-knit family. Organizations work closely together in an effort to give this community a bigger voice. Our "Sister" charities:

- The Multiple System Atrophy Coalition
- Move Over MSA (Idaho)
- Cure MSA (California)
- Rex Griswold Foundation (Texas)
- Brain Support Network







WORKING TOGETHER

for greater awareness of

MULTIPLE SYSTEM ATROPHY



FUTURE OF MSA NJ

- Representing MSA NJ at The MSA Coalition's conference in September and currently serving on planning committee.
 - Looking forward to hosting a special event for this 30th anniversary celebration.
- Hoping to arrange an awareness event in the fall.
- 2020 marks the 5th anniversary conference. Planning an exciting program!
- Potential support group expansion.
- Stay connected by joining the MSA NJ email distribution list to receive important updates and information.
- Request to join on closed support group on Facebook to interact with the MSA NJ community.

HOW YOU CAN HELP

- Donations/Fundraisers
 - MSA NJ provides services to our community at no cost; all donations received help us to provide this
 crucial support.
- Shop AmazonSmile
 - Select MSA NJ as your charity, .5% of the total sale on eligible purchases will be donated directly to MSA NJ
- Attend and support MSA NJ sponsored events
 - To be successful, these events need your support; attend if you can, please! Share information with family and friends who can attend in honor of your battle with MSA. Turning out in numbers helps make s a statement that the MSA community is strong, which certainly helps when seeking sponsors, media attention, and legislative action.
- Share ideas & Volunteer!
 - If you have ideas for activities, locations for support group meetings, speakers for events, etc., please let us know. Also, we need reliable volunteers to help achieve our mission. If you believe you have the time and interest in working with MSA NJ, and can really commit to doing so, please let us know. We need help with social media posts, fundraising, secretarial duties, and periodic help with events. The more hands on board, the more we can do!
- "Like" us on Facebook & share MSA NJ posts: https://www.facebook.com/NJMSA/

MSA NJ Dedication

In loving memory of our Mom and MSA Angel, Dolores Roemer lost to MSA on May 10, 2009.

Throughout adversity, Mom maintained strength, dignity, grace, a sense of humor, and above all, love...

Nite, Mom. We love you...

#ConquerMSA

www.msanj.org

"My advice to other disabled people would be, concentrate on things your disability doesn't prevent you doing well, and don't regret the things it interferes with. Don't be disabled in spirit as well as physically." ~ Stephen Hawking

