



MSA NJ

MOVEMENT FOR SUPPORT & AWARENESS FOR
MULTIPLE SYSTEM ATROPHY
#ConquerMSA



**2018
Regional
Patient & Caregiver
Support Conference**

March 24, 2018

**Held At
Brookdale Community College
Lincroft, NJ**



OUR MISSION

MSA NJ is a non-profit organization founded by the Roemer Family to provide support for patients, families, caregivers, medical personnel, and any other affected persons or interested parties in the tri-state area impacted by Multiple System Atrophy or related neurological disorders. Additionally, our goals include providing education about this disease and related issues, raising public awareness, and supporting research for treatment and a cure. Fundraising efforts are to support realization of these goals.

OUR WORK

MSA NJ hosts monthly support group meetings, an annual patient-support conference, awareness/fundraising events, contributes to research programs, and represents its constituents in global MSA activities. Your donations help to support these activities.

OUR BOARD

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Joellyn Fox, DPT

Michelle Lowry, M.S., CCC-SLP

Lucy Norcliffe-Kaufmann, PhD

Victoria Pena-Cardinali, MSW—LCSW

Cynthia Roemer—Support Services Volunteer

MSA NJ is a registered non-profit corporation in New Jersey and a federally recognized 501(c)(3) charity.

MSA NJ 2018 Regional Patient & Caregiver Conference Schedule

Twin Lights Rooms I & II

9:00 a.m. – 9:30 a.m.	Registration and Breakfast Mix & Mingle Exhibits
9:30 - 11:00 a.m.	Welcome & Medical Presentations <i>Welcome</i> —Kym Roemer, MSA NJ Board Chair <i>Living with MSA</i> —Amy Colcher, MD <i>Sleep Dysfunction in Multiple System Atrophy</i> —Callum Dupré, MD
11:00 – 11:15 a.m.	Break/Exhibits
11:15 a.m. – 12:30 p.m.	Medical Panel Q & A
12:30 p.m. 1:30 p.m.	Lunch Exhibits & Chair Massage
1:30 p.m. – 1:45 p.m.	<i>Hot Topics: From a Therapeutic Perspective</i> – Joellyn Fox, DPT Remote Presentation
1:45 p.m. – 2:45 p.m.	<i>Clinical Research Update</i> — Lucy Norcliffe-Kaufmann, PhD
2:45 p.m. – 3:00 p.m.	MSA Advocacy Updates
3:00 p.m. – 3:15 p.m.	Break/Exhibits
3:15 p.m. – 4:15 p.m.	<i>Toolbox Kit: Self-Management & Prevention</i> — Victoria Pena-Cardinali, MSW, LCSW
4:15 p.m. – 5:00 p.m.	Support Group Meeting Facilitators: Victoria Pena-Cardinali & Cynthia Roemer

Exhibits:

*Accomplished Brain

Home Care & Hospice Association of NJ

*Lundbeck LLC

*Mobility Works—Wall Township, NJ

Monmouth County Office on Aging

Monmouth County Veterans and Disabilities Office

MSA Coalition

*Theravance Biopharma

*Tobii Dynavox

Kick Back & Relax— Barbara Rodgers, NJ Licensed Massage Therapist

Available during lunch and throughout the afternoon in the Monmouth Battleground Room.

*Conference Sponsor

NOTE: Please remember that the proceedings are being recorded.

Presentations

Living with MSA – Amy Colcher, MD

Director, Movement Disorders Program, Cooper University Health System

Multiple System Atrophy is a rare and complex disorder that requires careful management and efforts to maintain the best possible general and mental health. This presentation will address self-management, mindfulness, the importance of a team, and education in MSA care.

Sleep Dysfunction in Multiple System Atrophy – Callum Dupré, MD

Lead Physician & Sleep Center Medical Director, Capital Health System

Sleep disturbances are rampant in patients with Multiple System Atrophy and can encompass a host of different sleep disorders. These range from neurological manifestations of sleep dysfunction such as acting out of dreams, to pulmonary issues such as sleep disordered breathing and everywhere in between. These disorders disrupt not only the sleep of the patient, but their caregivers as well. They are, however, usually treatable and we aim during our session to discuss not only what sleep disorders are present in the MSA population, but also what we can do about them. We can "deal" with poor quality and quantity of sleep, but we shouldn't have to.

Hot Topics: From a Therapeutic Perspective—Dr. Joellyn Fox

PT, Dan Aaron Parkinson's Rehabilitation Center

A short but comprehensive remote presentation that highlights some key points about staying safe and strong. This session will offer practical strategies for functioning at home as the disease progresses. Home exercises and new technology resources to support the needs of MSA patients will be provided.

Clinical Research Update – Lucy Norcliffe-Kaufmann, PhD

Assistant Professor in Neurology and Neuroscience, New York University School of Medicine

The 6th International MSA Congress, in which renowned MSA researchers from around the world gathered, was held in the United States for the first time on March 1 – 3, 2018 in New York City. This session will provide a brief overview of this meeting, covering main themes of each of the sessions. The MSA NJ Community will learn that there is a lot happening when it comes to new treatments in the pipeline and planning for clinical trials.

Toolbox Kit: Self-Management and Prevention – Victoria Pena-Cardinali, MSW, LCSW

Outpatient Social Worker, Capital Institute for Neurosciences

One of the most difficult situations we all face throughout our lives is adapting to change. We lose our sense of control and may feel lost as we try to figure things out. Oftentimes we find ourselves in a state of crisis as we are forced to make important decisions about our lives and our future without having all the information we need in order to make an informed decision. However, this does not have to be the way if we are prepared by planning ahead, and if we surround ourselves with a network of support that will assist us to lead our future with confidence and determination. So, what do I need to know and how do I get there? This session will teach you the methods, skills, strategies and resources to take control of your life and take steps to prevent unnecessary crisis situations in your life.

Kick Back and Relax—Monmouth Battleground Room

Barbara Rodgers, NJ Licensed Massage Therapist

Who doesn't want to reduce the stress in their life? A chair massage can work wonders for your body and your mental state. Energize, rejuvenate, and relax.

Conference Presenters

Amy Colcher, MD is the director of the movement disorders division and Professor of Neurology at Cooper University Health System in Camden, NJ. She teaches at Cooper Medical School of Rowan University. She conducts clinical research in Movement Disorders and has participated in many clinical trials on Parkinson's disease, MSA, Huntington's disease, dystonia, and Essential tremor. She has authored over 40 articles in peer review journals and multiple book chapters on movement disorders. She was a Clinical Associate professor of neurology at the University of Pennsylvania from 1997-2012 and taught at the Medical School there. She did her Neurology training at Georgetown University and a Movement Disorder fellowship at the University of Pennsylvania. She got her medical degree from Jefferson Medical College and her BA and MS from the University of Pennsylvania.

Callum Dupré, MD, completed his B.A. in Neuroscience with a minor in Biochemistry from Drew University where he was inducted into the Tri-Beta Biology Honor Society. He completed his residency in the Department of Neurology at North Shore Long Island Jewish Medical Center in Manhasset, NY and served as Chief Resident. He was a fellow at the Center for Sleep Medicine at the Mayo Clinic in Rochester, MN before accepting the appointment to his current position as lead physician and director in the Capital Health System. He is also a physician with Comprehensive Sleep Associates in Hamilton.

Joellyn Fox, DPT, is a physical therapist at the Dan Aaron Parkinson's Rehabilitation Center in Philadelphia. She graduated from Lehigh University with a Bachelor's degree in Biology and Psychology and then earned her DPT from Temple University. Dr. Fox has more than a decade of professional experience within the University of Pennsylvania Health System. Her professional accreditations include: ATP Clinician Trained, LSVT Big Certification, Parkinson's Wellness and Recovery (PWR!) certification and Rock Steady certification. Dr. Fox has been an adjunct at Widener University, Drexel University and Rutgers for over 6 years and has taught seminars on behalf of the PPTA and CurePSP both nationally and internationally.

Lucy Norcliffe-Kaufmann, PhD, is an Assistant Professor in Neurology and Neuroscience at New York University School of Medicine. She gained her PhD in autonomic physiology in England. She is currently the Associate Director of the NYU Dysautonomia Center, which focuses on research and treatment of rare autonomic disorders. She has been working in MSA clinical research for the past decade. Dr. Norcliffe-Kaufmann trained within the Autonomic Disorder's Consortium and is a lead investigator in the Natural History Study of MSA; a global effort to unite the MSA research community. Her research work is funded by the MSA Coalition, the Dysautonomia Foundation, the National Institute of Health, the Food and Drug Administration and the Michael J Fox Foundation. Dr. Norcliffe-Kaufmann lives in New York City with her husband and two children.

Victoria Pena-Cardinali, MSW/LCSW, has a Masters Degree in Social Work with a clinical concentration from New York University. She has fifteen years experience in the social work areas of family preservation services, crisis intervention, child welfare, case management and counseling and six years of experience in the area of Medical Social Work at Capital Health Systems. In her newest role, as the Outpatient Social Worker at the Capital Institute for Neurosciences., Victoria has been able to work closely with patients and their families to address their unique and personal needs related to management of chronic diseases such as adjustment issues, community reintegration, service connection, advocacy, collaboration, support counseling and transitions of care among many others. Victoria facilitates three caregivers' support groups at Capital Health Hopewell and is a provider of psychotherapy services at the institute.

Barbara Rodgers, NJ licensed massage therapist, has been a massage therapist since 1998. Her specialties include relaxation, stress reduction and Reiki. She is experienced in working with Parkinson's patients and their caregivers.

MSA NJ extends its thanks to all the sponsors, exhibitors, support staff, and volunteers who helped to make this conference possible.



Monmouth County Office on Aging
Monmouth County Veterans and Disabilities



Barbara Rodgers,
NJ Licensed Massage Therapist



Special recognition for Alex Khachatryan,
our videographer, for always making time for MSA.



Union County College PTK student volunteers!

Happy Birthday, Alex!



Thank you, volunteer, Kara Vlahos!

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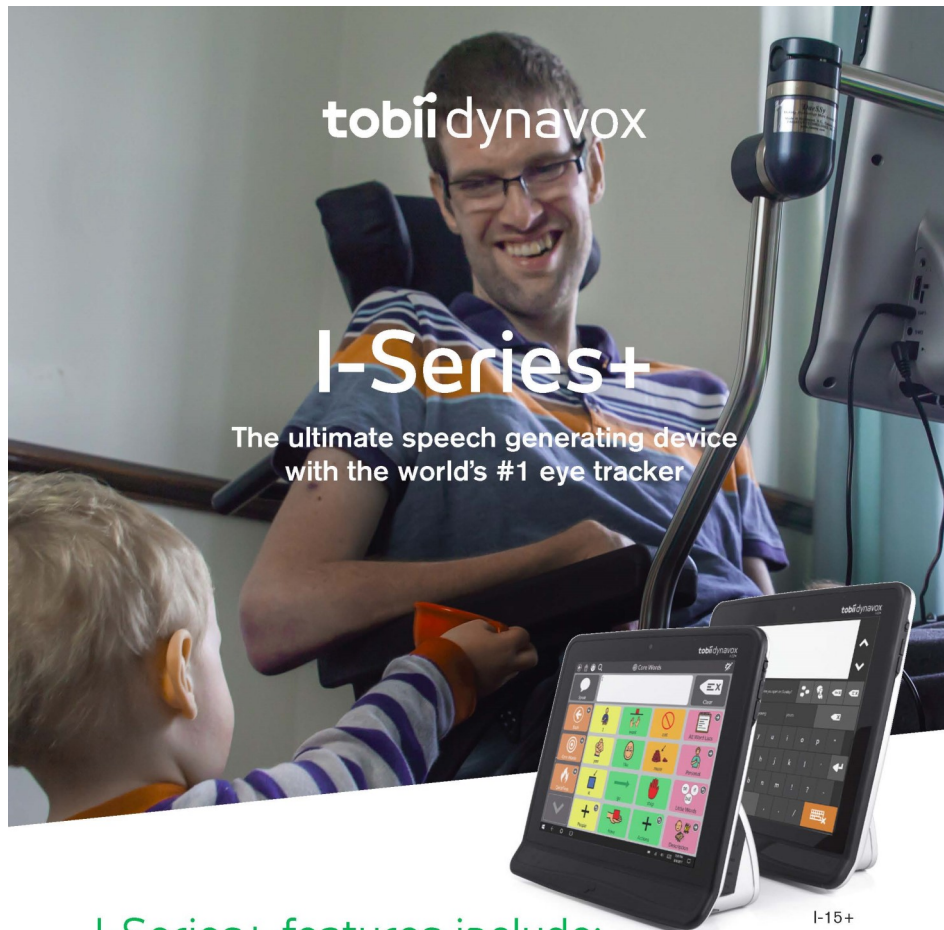
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when standing?

About



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blood pressure when standing.

Ask your healthcare provider if your
dizziness when standing could be due to nOH.

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



Nite, love you...



The MSA NJ logo ribbon, especially designed by Cyndi Roemer and Kym Roemer with graphic art by Jordan Ortiz, is a blend of zebra print to reflect the rareness of the disease with the purple color for MSA.

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