"Since 1989, improving quality of life and building hope for people affected by multiple system atrophy"

The Multiple System Atrophy (MSA) Coalition™ is a 501(c)3 charitable organization (EIN: 74-2926378) devoted to a four-pillar mission:

- Providing patients and caregivers with trusted and compassionate emotional support
- Educating patients, care-partners and healthcare professionals with credible, critically important and relevant information
- Funding patient-centric collaborative research aimed at alleviating symptoms, slowing disease progression and discovering a cure
- Building a sense of community by connecting and unifying people affected by MSA

Read more about our programs and services.

<table>
<thead>
<tr>
<th>SUPPORT</th>
<th>EDUCATION</th>
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</thead>
<tbody>
<tr>
<td>The Multiple System Atrophy Coalition offers a toll free support line staffed by former MSA caregivers.</td>
<td>The MSA Coalition hosts an annual conference for MSA patients and families (usually Sep or Oct) in a different US city each year.</td>
</tr>
</tbody>
</table>
| Contact: Larry Kellerman  
Toll free US and Canada: 866-737-5999  
lkellerman@msacoalition.org | Subscribe to our YouTube Channel for past conference recordings |
| Please Visit our MSA Resources Page | Download: “MSA - What you Need to Know” |

<table>
<thead>
<tr>
<th>RESEARCH</th>
<th>ADVOCACY &amp; AWARENESS</th>
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| The Multiple System Atrophy Coalition is the leading nonprofit funder of global MSA research. Since 2013 we have funded over $1.7 million in research projects. Find out more here. | March is MSA Awareness Month and October 3rd is World MSA Day. As a member of the National Organization for Rare Disorders and the Coalition of Patient Advocacy Groups the MSA Coalition stays abreast of issues important to the MSA community.  
Interested in Volunteering? Join our MSA Coalition Volunteers group on facebook |
| For Research and other news updates subscribe to our Monthly e-Newsletter | |
| Join our MSA Research News group on facebook | |
# MSA COALITION BOARD OF DIRECTORS

<table>
<thead>
<tr>
<th>Role</th>
<th>Name</th>
<th>Location</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chair</td>
<td>Cynthia Roemer EdD</td>
<td>Howell NJ</td>
<td>866-737-4999 x207 [<a href="mailto:croemer@msacoalition.org">croemer@msacoalition.org</a>]</td>
</tr>
<tr>
<td>Vice Chair</td>
<td>Pam Bower</td>
<td>Halifax NS CANADA</td>
<td>866-737-4999 x204 [<a href="mailto:pbower@msacoalition.org">pbower@msacoalition.org</a>]</td>
</tr>
<tr>
<td>Treasurer</td>
<td>Carol Langer CPA</td>
<td>Boston MA</td>
<td>866-737-4999 x205 [<a href="mailto:clanger@msacoalition.org">clanger@msacoalition.org</a>]</td>
</tr>
<tr>
<td>Secretary</td>
<td>Patricia Libby</td>
<td>Altadena CA</td>
<td>866-737-4999 x205 [<a href="mailto:plibby@msacoalition.org">plibby@msacoalition.org</a>]</td>
</tr>
<tr>
<td>Patient Representative</td>
<td>Cathy Chapman</td>
<td>Lander WY</td>
<td>866-737-4999 x204 [<a href="mailto:chapman@msacoalition.org">chapman@msacoalition.org</a>]</td>
</tr>
<tr>
<td>Caregiver Representative</td>
<td>Topher Schott</td>
<td>Arlington VA</td>
<td>866-737-4999 x204 [<a href="mailto:tschott@msacoalition.org">tschott@msacoalition.org</a>]</td>
</tr>
<tr>
<td>Global Research Strategy</td>
<td>Gregor Wenning MD, PhD</td>
<td>Innsbruck, Tyrol AUSTRIA</td>
<td>866-737-4999 x204 [<a href="mailto:gregor.wenning@i-med.ac.at">gregor.wenning@i-med.ac.at</a>]</td>
</tr>
<tr>
<td>Scientific Advisory Liaison</td>
<td>Vik Khurana MD, PhD</td>
<td>Boston MA</td>
<td>866-737-4999 x205 [<a href="mailto:vkhurana@msacoalition.org">vkhurana@msacoalition.org</a>]</td>
</tr>
<tr>
<td>Medical Advisory Liaison</td>
<td>Daniel Claassen MD</td>
<td>Nashville TN</td>
<td>866-737-4999 x205 [<a href="mailto:daniel.claassen@vumc.org">daniel.claassen@vumc.org</a>]</td>
</tr>
<tr>
<td>Director at large</td>
<td>Larry Kellerman PhD</td>
<td>Washington IL</td>
<td>866-737-4999 x209 [<a href="mailto:lkellerman@msacoalition.org">lkellerman@msacoalition.org</a>]</td>
</tr>
<tr>
<td>Director at large</td>
<td>Neil Versel</td>
<td>Chicago IL</td>
<td>866-737-4999 x210 [<a href="mailto:nversel@msacoalition.org">nversel@msacoalition.org</a>]</td>
</tr>
<tr>
<td>Director at large</td>
<td>Elaine Douglas</td>
<td>Seattle WA</td>
<td>866-737-4999 x210 [<a href="mailto:edouglas@msacoalition.org">edouglas@msacoalition.org</a>]</td>
</tr>
<tr>
<td>Director at large</td>
<td>Elizabeth Dyas</td>
<td>NETHERLANDS</td>
<td>866-737-4999 x210 [<a href="mailto:edyas@msacoalition.org">edyas@msacoalition.org</a>]</td>
</tr>
<tr>
<td>Director at large</td>
<td>Adrienne Glusman</td>
<td>FL</td>
<td>866-737-4999 x210 [<a href="mailto:aglusman@msacoalition.org">aglusman@msacoalition.org</a>]</td>
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<tr>
<td>Emeritus</td>
<td>David Robertson, MD</td>
<td>Nashville TN</td>
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<td>Emeritus</td>
<td>Don Crouse</td>
<td>Charlotte NC</td>
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<tr>
<td>Emeritus</td>
<td>Vera James</td>
<td>Walnut CA</td>
<td>866-737-4999 x210 [<a href="mailto:granmaj@gmail.com">granmaj@gmail.com</a>]</td>
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<tr>
<td>Emeritus</td>
<td>Judy Biedenharn</td>
<td>Grove City OH</td>
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<td>Emeritus</td>
<td>Thomas Cheilimsy MD</td>
<td>Richmond VA</td>
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<td>Emeritus</td>
<td>Hadley Ferguson</td>
<td>Missoula MT</td>
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<tr>
<td>Emeritus</td>
<td>Diane Adkins</td>
<td>Stephens City VA</td>
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This list is maintained by Pam Bower [pbower@msacoalition.org] Updated: March 13, 2022
In Person and Online Support Resources

**SCIENTIFIC/MEDICAL ADVISORY BOARD**

<table>
<thead>
<tr>
<th>Scientific Advisor</th>
<th>Bordeaux FRANCE</th>
<th>Email</th>
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<tbody>
<tr>
<td>Wassilios Meissner MD, PhD</td>
<td><a href="mailto:wassilios.meissner@chu-bordeaux.fr">wassilios.meissner@chu-bordeaux.fr</a></td>
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<tr>
<th>Scientific Advisor</th>
<th>Rochester MN USA</th>
<th>Email</th>
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<tbody>
<tr>
<td>Phillip Low MD</td>
<td><a href="mailto:low@mayo.edu">low@mayo.edu</a></td>
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<tr>
<th>Scientific Advisor</th>
<th>Toronto ON CANADA</th>
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<tr>
<td>Anthony Lang MD</td>
<td><a href="mailto:anthony.lang@uhnresearch.ca">anthony.lang@uhnresearch.ca</a></td>
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<tr>
<th>Medical Advisor</th>
<th>Gainesville FL USA</th>
<th>Email</th>
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<tr>
<td>Nikolaus McFarland, MD, PhD</td>
<td><a href="mailto:nikolaus.mcfarland@neurology.ufl.edu">nikolaus.mcfarland@neurology.ufl.edu</a></td>
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<tr>
<th>Medical Advisor</th>
<th>Richmond VA USA</th>
<th>Email</th>
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<tr>
<td>Thomas Chelimsky MD</td>
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<tr>
<th>Medical Advisor</th>
<th>Dallas TX USA</th>
<th>Email</th>
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<tr>
<td>Steven Vernino MD, PhD</td>
<td><a href="mailto:steven.vernino@utsouthwestern.edu">steven.vernino@utsouthwestern.edu</a></td>
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<tr>
<td>Elizabeth Coon</td>
<td><a href="mailto:Coon.Elizabeth@mayo.edu">Coon.Elizabeth@mayo.edu</a></td>
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<tr>
<th>Medical Advisor</th>
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<tr>
<td>Bonnie Black</td>
<td><a href="mailto:bonnie.black@vumc.org">bonnie.black@vumc.org</a></td>
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<tr>
<th>Medical Advisor</th>
<th>Boston MA USA</th>
<th>Email</th>
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<tr>
<td>Roy Freeman, MD</td>
<td><a href="mailto:rfreeman@bidmc.harvard.edu">rfreeman@bidmc.harvard.edu</a></td>
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<tr>
<th>Medical Advisor</th>
<th>Stanford CA USA</th>
<th>Email</th>
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<tbody>
<tr>
<td>Mitch Miglis, MD</td>
<td><a href="mailto:mmiglis@stanford.edu">mmiglis@stanford.edu</a></td>
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**UNITED STATES**

**ALABAMA**

**CHICKASAW**
Info updated as of Apr 2019: **No Meeting** Phone/email Support Only
Contact: Janiece Naber Martindale 251-689-4445 janiecenjim@gmail.com

**ARKANSAS**

**LITTLE ROCK**
Info updated as of Nov 2019: For anyone affected by PSP, CBD or MSA
Location: Faith United Methodist Church 9820 W. Markham Street Little Rock, AR 72205
Meeting Time: January to October 4th Thursday of every months at 11:00am

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Note: The following list represents support groups compiled by the MSA Coalition that are designated for individuals dealing with MSA and/or other related neurological disorders. In our effort to support MSA patients and their care partners everywhere, we are pleased to provide information and resources about MSA to all the groups listed. We welcome friendships with all, especially groups and organizations that offer support to those diagnosed with autonomic and movement disorders. Every effort is made to ensure meeting times & dates are accurate, however we do suggest that you contact the facilitator first before attending a meeting for the first time.
In Person and Online Support Resources

Meeting Time: November & December 3rd Thursday of these month at 1:00pm
Facilitator: Randi Haley 870-703-6417 randirhaley@yahoo.com

CALIFORNIA

BURLINGAME
Info updated as of Nov 2019: No Meeting Phone/email Support Only
Contact: Candy Welsh 650-218-5858 cortez1us@yahoo.com

FREMONT
Info updated as of Oct 2019: Non-profit for MSA
Cure MSA – Kathy Shih Memorial Foundation
P.O. Box 15088
Fremont, CA 94539 USA
www.curemsa.org
Contact: Lily Shih (Executive Director) 510-226-0453 lily@curemsa.org

GOLETA
Info updated as of Apr 2019: No Meeting Phone/email Support Only after 11am EST
Contact: George Relles 805-683-4829 grelles@cox.net

LOS ANGELES
Info updated as of Apr 2019: The Los Angeles Parkinsonian Disorders Support for people with PSP, CBD, MSA, and PD and their family members & friends
Location: UCLA Medical Plaza Bldg. 300 in the Marisa Leif Conference Room on the 3rd floor, Los Angeles, Calif.
Meeting Time: 1st Friday of every month from 2:00pm-4:00pm
Facilitator: Dr. Arik Johnson acjohnson@mednet.ucla.edu
To RSVP and for Further Information contact Dolly West dwest@mednet.ucla.edu or phone: 310-206-2154.

NORTHERN/SAN MATEO
Info updated as of March 2022: MSA caregivers (who live in Northern California) only. Contact facilitator for more info.
Location (even months): outdoors at a restaurant in San Mateo, CA
Location (odd months): virtual
Meeting Time(s): 2nd Sunday, 5:00pm - 7:00pm (February and May: 3rd Sunday)
Facilitator: Robin Riddle, 650-814-0848, robin.riddle@brainsupportnetwork.org

NORTHERN CALIFORNIA
Info updated as of March 2022: Those with MSA (who live in Northern California) only. Contact facilitator for more info.
Location: virtual
In Person and Online Support Resources

Meeting Time(s): 1st Sunday, 3:00pm - 4:00pm
Facilitator: Robin Riddle, 650-814-0848, robin.riddle@brainsupportnetwork.org

SACRAMENTO
Info updated as of Apr 2019: For caregivers dealing with PSP, CBD, MSA and Parkinson’s
Location: Shriner’s Hospital on the UC Davis Medical Center Campus, 7th Floor Board Room, 2425 Stockton Blvd, Sacramento, CA
Meeting Time 4th Wednesday of every month 7:00pm-8:30pm
Facilitator: Edward Fargusson. He can be reached through the Alzheimers Association Sacramento Phone: 916-930-9080 efargusson@gmail.com

SAN DIEGO/LA JOLLA
Info updated as of Mar 2019: Atypical Parkinson's Disease Support Group 
(for patients and caregivers with PSP, MSA, CBD, FTLD, LBD, VP)
Location: University of California San Diego (UCSD), East Campus, Medical Center Modular 1 (MCM1) Room 140 (conference room) 9423 Health Sciences Dr, La Jolla, CA 92037
Meeting Time(s): Third Monday of each month 1 - 3 pm
Facilitator: Darlene Gerow 619-806-9649 darlene.gerow@gmail.com

SAN DIEGO/CARLSBAD
Info updated as of Mar 2019: Atypical Parkinson's Disease Caregivers-Only Support Group 
(for caregivers of patients with PSP, MSA, CBD, FTLD, LBD, VP)
Location: Tri-City Wellness & Fitness Center, 6250 El Camino Real, Carlsbad, CA 92009
Meeting Time(s): Every other month on the first Wednesday from 11am – 1pm (Jan, Mar, May, Jul, Sep, Nov)
Facilitator: Darlene Gerow 619-806-9649 darlene.gerow@gmail.com

SANTA BARBARA
Info updated as of Nov 2019: No Meeting Phone/email Support Only
Contact: Suzanne Grimmesey 805-455-5194 sgrimmesey@gmail.com

COLORADO

DENVER/ENGLEWOOD
Info updated as of Mar 2019: Neurodegenerative movement disorder group (MSA, PSP, CBD) – For Patients/Caregivers
Location: 1st Plymouth Church, 3501 Hampden Ave, Englewood CO 80113 (New people must call leader ahead of time as church doors need to be unlocked for you)
Meeting Time(s): 2nd Friday of each month from 10:00am - 12:00pm for Patients/Caregivers
Facilitator: Helenn Franzgrote 303-789-9900 jhfranzgrote@comcast.net
DENVER/ENGLEWOOD
Info updated as of Mar 2019: Neurodegenerative movement disorder group (MSA, PSP, CBD) – For Caregivers ONLY
Location: Johnson Adult Day Center, 3444 South Emerson St., Englewood, CO 80113
Meeting Time(s): 4th Friday of each month from 10:00am-12:00pm for Caregivers only
Facilitator: Helenn Franzgrote 303-789-9900 jhfranzgrote@comcast.net

JOHNSTOWN/LOVELAND
Info updated as of Mar 2019: MSA, PSP, CBD Support Group
Location: Northern Colorado Rehabilitation Hospital 4401 Union Street
Johnstown CO 80528
Meeting Time: 2nd Friday of each month from 1:30pm - 3:30pm
Facilitator: Ruth Fletcher-Carter 970-391-8898 chantillylace3@usa.net

CONNECTICUT

CHESHIRE/VERNON
Info added as of Nov 2019: For patients and caregivers affected by PSP, CBD, MSA
Meeting Time: 4th Thursday of the month at 6:30pm
Location: There are two different locations that are alternated on the 4th Thursday
On the odd numbered months meet at Hartford Health Care 35 Talcottville Rd. Vernon, CT 06066
On the even numbered months meet at Hartford Health Care 280 South Main St. Cheshire, Ct 06410
Facilitator: Bill Johnson 860-417-8146 billjohnson1123@gmail.com
Meeting is hosted by CurePSP

FLORIDA

SOUTHEAST FLORIDA
Info updated as of Mar 2019: For patients/caregivers/families affected by MSA, PSP, CBD and related diseases
Location: North Broward Medical Center, 201 E. Sample Road, Deerfield Beach, FL 33064
1st Floor, Classrooms 7&8 (for directions only: 954-941-8300)
Meeting Time(s): Contact Facilitator for more info
Facilitator: Paul Freeman 305-970-0805 freemanph@aol.com

SOUTHWEST FLORIDA
Info updated as of Nov 2019: For patients/caregivers/families affected by MSA, PSP, CBD
Location: Terracina Grand 6825 Davis Blvd Naple, FL 34104 in the Garden Building
Meeting Time(s): 2nd Saturday of each month from 2:00pm – 4:00pm
Facilitator: Cindy MacDonald 239-353-3960/239-404-4429 hotrdh@hotmail.com
In Person and Online Support Resources

**NAPLES**
Info updated as of Nov 2019: **No Meeting** Phone/email Support Only
Contact: Tenley Smith 630-337-1314 Tenswims@gmail.com

**WINTER PARK / ORLANDO**
Info updated as of Jan 2020: **NEW!** MSA-Multiple System Atrophy Support Group

Attention, all those affected by MSA in Central Florida: The Parkinson Outreach Center at AdventHealth Central Florida is starting an MSA-Multiple System Atrophy Support Group. It will meet quarterly, starting this month! AdventHealth’s Parkinson programs are wonderful, and many are relevant to those with MSA, such as the twice-monthly Art & Exercise classes. Check it all out at www.adventhealthneuroinstitute.com/resources/support-groups-programs/parkinsons-outreach-center-support-groups

Location: Center for Health and Wellbeing, 2005 Mizell Ave. Winter Park, FL 32792
Registration Required. Please call 407-303-5295
Meeting Time(s): Quarterly - 2020 dates: Jan 29, Apr 29, Jul 29 & Oct 28 @ 1:00pm – 3:00pm
Upcoming Topics:

April 29: Meditation for stress management followed by drumming and caregiver breakout
July 29: PT/OT and ST for MSA followed by art and caregiver breakout
Oct 28: Brain donation followed by drumming and caregiver breakout

**GEORGIA**

**ATLANTA**
Info updated as of Nov 2019: For care partners only of those living with Atypical Parkinsonism’s, PSP, CBD
Location: Emory Brain Health Center. 12 Executive Park Dr. Room 144 Atlanta, GA
Meeting Time(s): 2nd Saturday of each month from 10:00am – 11:00am
Facilitator: Christabelle Auguste 404-712-7091 christabelle.auguste@emory.edu

**ELLIJAY**
Info updated as of Apr 2019: **No Meeting** Phone/email Support Only
Contact: Paula Davis 706-669-1978 jimandpaula@ellijay.com

**WOODSTOCK**
Info added as of Dec 2019: Meeting for PSP/MSA/CBD
Location: Resurection Anglican Church 231 Arnold Mill Road Woodstock, GA
In Person and Online Support Resources

Meeting Time: 2nd Sunday of each month 3:00pm -5:00pm  
Facilitator: Jackie Green 678-780-5576  jackie.greenpsp@gmail.com  
Sponsored through CurePSP

IDAHO

BOISE
Info updated as of Apr 2019:

Move Over MSA (Nonprofit support group)  
12847 W. Silverbrook Ct., Boise ID 83713  
www.moveovermsa.org  
Contact: Tiffany Christensen 208-389-8022 moveovermsa@gmail.com  
Closed Facebook Support Group for Move Over MSA online support:  
https://www.facebook.com/groups/467331547019226/  
Meeting Times: Meetings held quarterly, usually on the 3rd Saturday of the month that it is held.

LEWISTON
Info updated as of Nov 2019  No meeting Phone/email Support only  
Contact: Joe Turner  208-816-2057  jpturner2011@gmail.com

ILLINOIS

CHICAGO AREA
Info updated as of March 2022: MSA Support Meeting for Patients/Caregivers  
Meeting Time(s): Quarterly meetings. Time and place will be announced when cleared for in person meetings; current meetings bi-weekly via Zoom. Contact Facilitator for information.  
Facilitator: Lawrence Kellerman (309) 634-6357 rurlfolk1@yahoo.com

GLENVIEW
Info added as of Dec 2019: For PSP/MSA/CBD  
Location: The Abington of Glenview  3901 Glenview Road Glenview, IL 60025  
Meeting Time: 1st Saturday of each month  1:30pm-3:30pm  
Facilitator: David Takehara 847-452-1609 davidtakehara@gmail.com  
Hosted by CurePSP

INDIANA
WARSAW
Info updated as of Dec 2019: No Meeting Phone/email Support Only
Contact: Terry Shepherd 574-306-8290 tellmenolies2004@yahoo.com

IOWA

WESTERN IOWA AREA
Info updated as of Nov 2019: No Meeting Phone/email Support Only
Contact: Keryn Paul 402-813-7315 kmpaul@cox.net

DES MOINES
Info updated as of Jan 2020: Our group is new, open to anyone living with Multiple System Atrophy, including patients, caregivers, spouses and loved ones. Share with others making the MSA journey.
Location: Temple B’Nai Jeshurun 5101 Grand Ave, Des Moines - Parking is in the rear, with easy access to the main conference room
Next Meeting time: Wednesday, Feb 5, 2020 at 1 p.m.
Our program features Chris Scott, occupational therapist with Suncrest Home Health and Hospice. Chris will talk about the variety of services available through private home care companies including physical therapy, occupational therapy and nurses aides. He’ll explain when and how such services can be covered by Medicare, too. Chris has worked with Dave and Jan Miller to, among other things, help make their home more accessible.

As always, we’ll have time to go around the table and talk about what’s on everyone’s mind. I’m open to topics for future meetings, too.
Facilitator: Diane Graham 515-490-9026 dianeegraham@gmail.com
Please join our Facebook group, too, at https://www.facebook.com/groups/MSAIowa/

KENTUCKY

LOUISVILLE
Info updated as of Apr 2019: Atypical Parkinsonian Disorders (MSA, PSP, CBD)
Location: Parkinson Center, 315 Townepark Circle, Suite 100
Meeting Time: 1st Tuesday of every month 3:00pm – 4:30pm
Facilitator: Dan Heins 502-216-4563 danheins@gmail.com

MAINE

WELLS
Info updated as of Apr 2019: No Meeting Email Support Only
Contact: Gayle Gardner nauticalmile102@gmail.com or message on facebook www.facebook.com/ggcpteach
MARYLAND

COLUMBIA
Info updated as of Oct 2019:
Annual Symposium for MSA & PSP: Stephen K. Myers Memorial Symposium
Date: Usually held in mid-October
Location: Hotel in Columbia or Baltimore
Meeting Format: Half day event, speakers from 1 – 5pm with a reception following. Usually a keynote speaker presents on medical aspects of MSA & PSP. Panel discussion and reception follow. Speakers may also present from the patient and care-partner perspective.
Representatives from the MSA Coalition and CurePSP usually attend.
Contact: Emily Greene 410-706-5269 egreene@som.umaryland.edu

BEL AIR
Info updated as of Jan 2019: For caregiver affected by MSA, PSP, CBD & other neurodegenerative diseases
Location: William McFaul Activities Center 525 West McPhail Road, Bel Air, MD 21014
Meeting Times: 4th Thursday of every month from 2pm-4pm
Facilitator: Bailey Vernon 410-616-2811

EASTON
Info updated as of Jan 2019: for caregivers affected by Parkinson’s PSP, CBD, MSA and other Neuro diseases
Location: Eastern Shore Smile Solutions 29267 Erickson Dr. Easton, MD 21601
Meeting Time: 3rd Wednesday of every month from 3:30pm-5:00 pm
Facilitator: Bailey Vernon 410-616-2811

PARKVILLE
Info updated as of Nov 2019: For Caregivers & patients affect by Neurodegenerative diseases
Location: Saint John’s Lutheran Church 8808 Harford Rd Parkville, MD 21234
Meeting Time: 4th Thursday of every month from 2:00pm-4:00pm
Facilitator:Chelsea Ganc 410-955-6684 cganc1@jhmi.edu

TANEYTOWN
Info updated as of Dec 2020: **No Meeting** Phone/email Support Only
Contact: Shirley Snyder 904-207-5501 ses.msaflorida@gmail.com

MASSACHUSETTS

BOSTON
Info updated as of Mar 2019: For MSA, PSP, CBD Patients and Carepartners
Location: Encompass Braintree Rehabilitation Hospital, Conference Room A/B, 250 Pond Street,
In Person and Online Support Resources

Braintree, MA
Meeting Time: 12:30pm – 2:00pm
2019 meeting dates: Mar 9 May 11 July 13 Sep 14 Nov 9
Facilitator: Melissa Diggin 339-927-5468 m_diggin@hotmail.com

MICHIGAN
DELTON
Info updated as of Nov 2019: For patients, caregivers and families with PSP, CBD, MSA and other atypical parkinsonian disorders
Location: 11137 Florida Drive, Delton, MI 49046 (park in church parking lot)
Meeting Time(s): 2nd Saturday of each month (March thru December only) 2:00pm-3:30 pm
Please contact facilitator if you plan to attend
Facilitator: Mary Meagher 269-267-3117 mmeagher@mei.net

MINNESOTA
MINNEAPOLIS
Info updated as of Dec 2019: No Meeting Phone/email Support Only
Contact: Jean Wayne 612-419-2573 Mnnightm@gmail.com

NEBRASKA
OMAHA
Info updated as of Dec 2019: No Meeting Phone/email Support Only
Contact: Keryn Paul 402-813-7315 kmpaul@cox.net

LINCOLN
Info updated as of Nov 2019: No Meeting Phone/email Support Only
Contact: Susie Luxford 402-525-7367 susie.luxford@homerealestate.com

NEVADA
LAS VEGAS
Info updated as of Nov 2019: No Meeting Phone/email Support Only
Contact: Marty Koppel 702-914-8041 please leave message if no answer

NEW JERSEY

TRI-STATE AREA
Info updated as of Oct 2019:
MSA NJ (Nonprofit support group covering the tri-state area)  
P.O. Box 773 Howell, NJ 07731  
www.msanj.org  
Phone MSA NJ: 732-903-8517

Private Facebook Support Group for MSA NJ community  
only: www.facebook.com/groups/MSANJSupport

Meeting Times: 2nd Saturday of the Month - 11 a.m. - 1:00 p.m.  
Location: Overlook Medical Center, 99 Beauvoir Ave, Summit NJ  
Conference Room #3, 5th Floor (near Neuroscience)  
Facilitator: Cynthia Roemer contact@msanj.org

CAPE MAY  
Info updated as of Nov 2019: For caregiver dealing with Atypical Parkinson+ disorders  
Location: Cape Regional Medical Center, 2 Stone Harbor Blvd, Cape May Court House, New Jersey (exit 10 off the Garden State Parkway, Maruchi Room (first floor of medical center)  
Meeting Time: 1st Tuesday of every month 3:00pm - 4:30 pm  
Facilitator: Bonnie Kratzer 609-463-4043 jkratzer@caperegional.com

NEW MEXICO  

ALBUQUERQUE  
Info updated as of Apr 2019: For patients, caregivers and families affected by PSP, CBD, MSA  
Location: The Flying Star 10700 Corrales Road, Albuquerque, NM  
Meeting Time(s): 1st Tuesday of each month from 6:30pm-8:00pm  
Facilitator: Roxi Padrid 312-485-9342 roxipadrid@gmail.com

NEW YORK  

NEW YORK CITY & TRI-STATE AREA  
Info updated as of Oct 2019:

MSA NJ (Nonprofit support group covering the tri-state area)  
P.O. Box 773 Howell, NJ 07731  
www.msanj.org  
Contact: Cynthia Roemer contact@msanj.org  
Phone MSA NJ: 732-903-8517

Private Facebook Support Group for MSA NJ community  
only: www.facebook.com/groups/MSANJSupport
Meeting Times: Quarterly - 11 a.m. - 1:00 p.m.
Location: NYU Langone Health, 530 First Ave, New York (Between 30th and 33rd Streets
(Use Main entrance on 1st Avenue)
MSB 194 (Yellow Pathway)
Facilitator: Kara Byron contact@msanj.org

NEW YORK
Info added as of Nov 2019: For Caregivers Only of PSP/CBD/MSA
Meeting Time: 3rd Tuesday of the month 6:00pm-7:30pm must contact facilitator in advance of coming
Location: St. James Parish House 865 Madison Ave (btw. 71-73rd St) NYC, Freeman Room, 3rd Fl
Facilitator: Jane Jensen 561-598-9839 Jensen@att.net Co-facilitator Janet Charleston
Hosted by CurePSP

NORTH CAROLINA

CHAPEL HILL
Info added as of Nov 2019: Meeting for MSA only
Meeting Time: quarterly meeting 3rd Wednesday of March, June, September, December 3:00pm-4:30pm
Location: UNC Center for Rehabilitation Care 1807 Fordham Blvd, Chapel Hill, NC 27514 Conference room.
Facilitator: Jessica Shurer MSW 919-843-1657 jshurer@neurology.unc.edu Please RSVP by Friday prior
Hosted by CurePSP & UNC school of medicine

ADVANCE
Info updated as of Nov 2019: No Meeting Phone/email Support Only
Contact: Tammy Hunt Hauser 336-998-2942 haustertammy@hotmail.com

HIGH POINT
Info updated as of Nov 2019: No Meeting Phone/email Support Only
Contact: Amy Nissen acnissen@northstate.net

OHIO

CLEVELAND
Info updated as of Nov 2019: For patients/families/friends/caregivers affected by PSP, CBD, MSA
Location: Southwest General Hospital, 18697 Bagley Road, Middleburg Heights, OH, Room 15C (basement level)
Meeting Time(s): 2nd Sunday of each month from 2:00pm - 4:00pm
Note In May the meeting is the First Sunday of the month
Directions/Parking: Hospital is easy accessed from I-480, I-71 and the Ohio Turnpike - free parking rear garage of hospital.
Facilitator: Dave Potter 440-263-5330 davepotter7@gmail.com Pat Beekman 440-234-0007
For New participants please call facilitator first
(Group sponsored by CurePSP)

COLUMBUS
Info updated as of Oct 2019: For all Progressive Supranuclear Palsy (PSP), Corticobasal Degeneration (CBD) and Multiple System Atrophy (MSA) patients and their care partners, family and support persons.
Location: Riverside Methodist Hospital, 3535 Olentangy River Road, Columbus, Ohio 43214.
We meet in The Dempsey Family Education and Resource Center – located on the first floor in the Silver Area.
Meeting Times: Third Saturday of the month Time: 11:30 am to 1:00 p.m.
Facilitator: Nancy: CentralOhioPSPgroup@gmail.com
Contact: For general questions, please call (614) 788.6115 or email DempseyCenter@OhioHealth.com.
(Group sponsored by CurePSP)

FAIRFIELD
Info updated as of Dec 2019: No Meeting Phone/email Support Only
Contact: Brenda Reams 513-860-2912 calvelageb@yahoo.com
Paul Reams preams1@yahoo.com

KETTERING
Info updated as of Dec 2019: For MSA patients/caregivers
Meeting Time(s): A get together is arranged in this area a couple times a year
Contact: Susan Cervone 937-369-9531 FrankunSusan@aol.com

WESTERVILLE
Info updated as of Nov 2019: For MSA caregivers
Meeting Time(s): No formalized meeting, however will meet with caregiver or family
Contact: Cathy Rapenport 614-403-1440 cathrapenport@gmail.com

OKLAHOMA
GROVE
Info updated as of Apr 2019: No Meeting Phone Support Only
Contact: Paul Nandico 918-786-4949
OREGON

BEND
Info updated as of Apr 2019: No Meeting Phone/email Support Only
Contact: Nena Close 541-419-6408(cell) nena.close@gmail.com

BEAVERTON
Info updated as of Apr 2019: For MSA/PSP Caregivers only
Location: Parkinson's Resources of Oregon 8880 SW Nimbus Ave, Beaverton, OR
Meeting time(s): 1st Friday of the month 10am-noon
Facilitator: Pat Robertson 503-310-9085 bookmole@comcast.net
Contact information for questions & updates 800-426-6806

PORTLAND
Info updated as of Apr 2019: For MSA and PSP Patients /Caregivers
Location: Marquis Care Center, 319 NE Russet ST, Portland, OR
Meeting Time: 3rd Saturday of each month 10:30 am to noon
Facilitator: Pat Robertson 503-310-9085 bookmole@comcast.net

PENNSYLVANIA

TRI-STATE AREA
Info updated as of Apr 2019:
MSA NJ (Nonprofit support group covering the tri-state area)
P.O. Box 773 Howell, NJ 07731 www.msanj.org
Contact: Cynthia Roemer contact@msanj.org
Phone MSA NJ: 732-903-8517

Email Support Available

Monthly and quarterly meetings currently available in NJ and NY, other locations considered.

Private Facebook Support Group for MSA NJ community
only: www.facebook.com/groups/MSANJSupport/

N. VERSAILLES
Info updated as of Nov 2019: No Meeting Phone/email Support Only
Contact: Carole Barber 412-678-8948 barber.carole@juno.com

PHILADEPLHIA
Info added as of Nov 2019: For person with Atypical Parkinsonism
Locations: Varies
Meeting Time: Varies, but meets on a quarterly basis only
Facilitator: Josue Etienne BSN 215-829-2347 josue.etienne@uphs.upenn.edu
Hosted by: Penn Medicine Parkinson’s Disease and Movement Disorder Center

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**PUERTO RICO**

Info updated as of Nov 2019: **No Meeting** Phone/email Support Only
Contact: Alexis Brewer 787-510-4690 alexis_brewer_200@yahoo.com

**SOUTH DAKOTA**

**SIOUX FALLS**

Info updated as of Nov 2019: **No Meeting** Phone/email Support Only
Contact: Dawn Koenig 605-759-6740 dkoenig@pompstire.com

**TEXAS**

**AUSTIN**

Info added as of Nov 2019: For PSP/CBD/MSA
Location: Isle at Cedar Ridge 2200 S. Lakeline Blvd, Cedar Park, TX 78613
Meeting Time: 4th Saturday of each month 10:00am-12:30pm
Facilitator: Judi Nudelman 512-964-1236 jnudelman51@gmail.com
Hosted by: CurePSP

**HOUSTON**

Info updated as of Apr 2019: For patients/families with PSP, CBD, MSA, LBD
Location: Memorial Hermann SW Hospital, Houston, TX, Learning Center B, Professional Building II
Meeting Time(s): 3rd Saturday of each month (except July and December) at 1:00pm
Facilitator: Karen Kennemer 281-358-2282 kmk1224@aol.com

**DALLAS/FT.WORTH**

Info updated as of May 2020: NeuroBrain Support Group for North Texas patients and caregivers
Location: Lower level Perot Building Meadows Classrooms B&C
Meeting Time(s): 3rd Saturday of the month from 10:30am - 11:30am
Facilitator: Ileen McFarland 410-271-1818 ileen@earthlink.net

**SAN ANTONIO**

Info updated as of Apr 2019: **No Meeting** Phone/email Support Only

This list is maintained by Pam Bower pbower@msacoalition.org Updated: March 13, 2022
VIRGINIA

AMISSVILLE
Info updated as of Nov 2019: Will meet with people if they want to travel to Amissville or will meet at other’s home if accessible and can arrange a time and date to have a meeting
Contact: Bill Werre 540-937-6092 rwwerre@comcast.net

BURKE
Info added as of Dec 2019: Social and Voice practice group for those with Parkinson's Plus Syndromes & Parkinson with separate spouse group
Location: Sundrise Silas Burke House 9619 Burke Lake Rd Burke, VA 22015
Meeting Time: Weekly on Wednesday 3:00pm -4:00pm
Facilitator : Matt McKeon 215-292-6674 Pdhelp4u@gmail.com
Hosted by PFNCA in partnership with Sundrise AL

WASHINGTON

SEATTLE
Info updated as of Sep 2020: For Atypical Parkinson's (includes MSA) patients and caregivers.
Location: Swedish Cherry Hill Medical Center, 500 17th Ave, Seattle WA
Meeting Time: 4th Monday of every month
Contact: Suzanna Eller 206-320-3494 SuzannaAPDA@gmail.com

WEST VIRGINIA

MARTINSBURG
Info updated as of Nov 2019: No Meeting Phone/email Support Only
Contact: Shelli Kuhn 717-830-6199 shelli.kuhn.sk@gmail.com

WISCONSIN

SPARTA
Info updated as of Nov 2019: No Meeting Phone/email Support Only
Contact: Kathy Griffin 513-208-6621 photodog4412@gmail.com
WYOMING

JOHNSTOWN/LOVELAND (COLORADO)
Info updated as of Apr 2019: MSA, PSP, CBD Support Group
Location: Northern Colorado Rehabilitation Hospital 4401 Union Street
Johnstown CO 80528
Meeting Time: 2nd Friday of each month from 1:30pm - 3:30pm
Facilitator: Ruth Fletcher-Carter 970-391-8898 chantillylace3@usa.net

LANDER
Info updated as of Apr 2019: No Meeting Phone/email Support Only
Contact: Cathy Chapman 307-332-4144 cec@wyoming.com

~~~~~~~~~~ End of USA In-Person Support Groups ~~~~~~~~~~
CANADA

ALL PROVINCES

Info updated as of Oct 2019: No Meeting Email Support Only
Contact: Pam Bower pbower@msaawareness.org

ALBERTA

EDMONTON
Info updated as of Dec 2016: No Meeting Phone/email Support Only - Contact for the northern region of Alberta Contact: Iris Kirschner 780-792-7732 ikirschner@shaw.ca

CALGARY
Info updated as of Dec 2016: For patients, caregiver and families with PSP, CBD, MSA and other Atypical PD
Location: Servus Credit Union- Creekside Branch 12662 Symons Valley RD NW, Calgary AB
Meeting time: 3rd Saturday of every month from 12:00pm -2:00pm
Facilitator: Kelly Clapham 403-803-3307 claphamk@telus.net

BRITISH COLUMBIA

SURREY
Info updated as of Dec 2016: For anyone affected by PSP, CBD, MSA
Location: Elim Village, Oasis Building, Meeting Room, 2nd Floor;
The address will get folks there, but because the address is difficult to access using 158 Street, I advise new people to use: ‘GPS’ to 9045 - 160 Street, Surrey, BC
Village signage will direct them to Oasis building, and the meeting room.
Meeting time: 10:00 am to 12:00 noon (We do NOT meet in December)
Facilitator: Bob Brett 604-930-8150 curepspbc@gmail.com
Robyn Heppner 604-584-7587 x2020 rheppner@elimvillage.com

SIDNEY
Info updated as of Dec 2016: No Meeting Phone/email Support Only
Contact: Ann Jeffrey 250-656-9799 island.view@shaw.ca
NOVA SCOTIA

HALIFAX
Info updated as of Oct 2019: **No Meeting** Email Support Only
Contact: Pam Bower pbower@msaawareness.org

ONTARIO

BURLINGTON
Info updated as of Dec 2016: For patients, caregivers, and families dealing with PSP/CBD/MSA and other atypical Parkinsonian disorders
Location: Appleby Place Retirement Residence, 500 Appleby Line, Burlington, ON
Meeting Time(s): Last Monday of the month from 1pm-3pm
Facilitator: Kimberley Adrovez kimberleyadrovez@yahoo.com

KINGSTON
Info updated as of Dec 2016: For patients and families affected by PSP, CBD and MSA
Location: Legion 560 (Fireside Room), 734 Montreal Street, Kingston, ON (free parking and handicap accessible)
Meeting Time(s): 1st Thursday of every month from 6:00pm - 8:00pm
Facilitator: MJ Overby 613-531-2685 hopematterspspkingston@gmail.com

TORONTO
Info updated as of Dec 2016: For care partners of PSP/CBD/MSA patients; hosted by Parkinson Canada
Location: 4211 Yonge Street, Suite 305, Toronto, ON
Meeting Time(s): 3rd Wednesday of every month from 6:00pm – 8:00pm
Facilitator: Robert TerSteege 416-227-3372/ 1-800-565-3000 x3372 robert.tersteege@parkinson.ca

~~~~~~~~~ End of Canada In-Person Support Groups ~~~~~~~

This list is maintained by Pam Bower pbower@msacoalition.org Updated: March 13, 2022
ONLINE SUPPORT GROUPS

MSA COALITION MODERATED GROUPS

PUBLIC DISCUSSION GROUPS (Facebook account required):

- 7000+ members, worldwide - MSA Coalition Public Discussion Group on MSA
  www.facebook.com/groups/MSACoalitionPublicGroup/

- 2000+ members, worldwide - Multiple System Atrophy Research News
  www.facebook.com/groups/MSANewsGroup/

PRIVATE DISCUSSION GROUPS (Facebook account required):

- 4000+ members, worldwide - Multiple System Atrophy (MSA) Buddies – Caregivers welcome
  www.facebook.com/groups/MSABuddies/

- 500+ members, worldwide - MSA: A Patient’s Journey – Patients only
  www.facebook.com/groups/MSAPatients

- 300+ members, worldwide - Children of MSA Warriors – Children/grandchildren welcome
  www.facebook.com/groups/ChildrenOfMSAWarriors

USA REGIONAL FACEBOOK SUPPORT GROUPS (Private discussion groups):

EAST COAST

- MSA Coalition - New England (ME-NH-VT-CT-RI-MA)
  www.facebook.com/groups/MSANewEngland/

- MSA Coalition - Middle Atlantic (NY-NJ-PA)
  www.facebook.com/groups/MSAMidAtl/

- MSA Coalition - South Atlantic (DE-DC-FL-GA-MD-NC-SC-VA-WV)
  www.facebook.com/groups/MSASOATL/

CENTRAL STATES

- MSA Coalition - Northeast Central (IN-IL-MI-WI-OH)
  www.facebook.com/groups/MSANECentralUS/
In Person and Online Support Resources

MSA Coalition - Northwest Central (IA-KS-MN-MO-ND-SD-NE)
www.facebook.com/groups/MSANWCentralUS/

MSA Coalition - Southeast Central (AL-KY-MS-TN)
www.facebook.com/groups/MSASECentralUS/

MSA Coalition - Southwest Central (TX-OK-LA-AR)
www.facebook.com/groups/MSASWCentral/

WESTERN STATES

MSA Coalition - Mountain States (AZ-CO-ID-NM-MT-UT-NV-WY)
www.facebook.com/groups/MSAMountainUS/

MSA Coalition - Pacific States (CA-OR-WA-HI-AK)
www.facebook.com/groups/MSAPacificUS/

OTHER ONLINE SUPPORT GROUPS (Created by MSAawareness)

MSA Canada
www.facebook.com/groups/MSACanada/

MSA Australia & New Zealand
www.facebook.com/groups/MSAOZNZ/

MSA UK and Ireland
www.facebook.com/groups/MSAUKIRELAND/

MSA Germany
https://www.facebook.com/groups/MSAGermany

MSA Spain
https://www.facebook.com/groups/MSASpain

MSA India
https://www.facebook.com/groups/MSAIndia
ONLINE SUPPORT WEBINARS (Sponsored by CurePSP)

Online Discussion webinar - For MSA Care Partners:

Care partners of People with MSA

Meeting Time: 1st Monday of each month from 8:00pm – 9:00pm Eastern
Meeting Link: https://us02web.zoom.us/meeting/register/tZIqf-uhrDgoHdfcY_XXwpyWe602VedTnWbK
Meeting Tel: +1 646 558 8656 Access Code: 867 8292 3273
Facilitator: Tom Tait, tom.tait@comcast.net, 856-725-3450

Online Discussion webinar - For MSA Patients:

People with MSA

Meeting Time: 3rd Monday of each month at 8:00pm Eastern
Meeting Link: https://us02web.zoom.us/meeting/register/tZUtf-CgrD0uG9CGa7yq3806EcOd8xhmUaqR
Meeting Tel: +1 646 558 8656 Access Code: 810 8982 6414
Facilitator: Cathy Chapman, Phone 307-332-4144, email cec@wyoming.com