



## In Person and Online Support Resources

### THE MULTIPLE SYSTEM ATROPHY (MSA) COALITION, INC.

7918 Jones Branch Drive, Suite 300, McLean, VA USA 22102

[www.MultipleSystemAtrophy.org](http://www.MultipleSystemAtrophy.org)

Toll free: 1-866-737-4999 or 1-866-737-5999

Email: [info@multiplesystematrophy.org](mailto:info@multiplesystematrophy.org) or [Find us on Facebook](#)

[DONATE NOW](#)

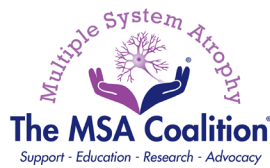
*"Since 1989, improving quality of life and building hope for people affected by multiple system atrophy"*

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](#).

<p><b>SUPPORT</b> The Multiple System Atrophy Coalition offers a toll free support line staffed by former MSA caregivers.</p> <p><b>Contact:</b> Larry Kellerman Toll free US and Canada: 866-737-5999 <a href="mailto:lkellerman@msacoalition.org">lkellerman@msacoalition.org</a></p> <p><a href="#">Please Visit our MSA Resources Page</a></p>	<p><b>EDUCATION</b> The MSA Coalition hosts an annual conference for MSA patients and families (usually Sep or Oct) in a different US city each year.</p> <p>Subscribe to our <a href="#">YouTube Channel</a> for past conference recordings</p> <p><a href="#">Download: "MSA - What you Need to Know"</a></p>
<p><b>RESEARCH</b> 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. <a href="#">Find out more here</a>.</p> <p><b>For Research and other news updates subscribe to our <a href="#">Monthly e-Newsletter</a></b></p> <p>Join our <a href="#">MSA Research News</a> group on facebook</p>	<p><b>ADVOCACY &amp; AWARENESS</b> March is MSA Awareness Month and October 3<sup>rd</sup> 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.</p> <p><b>Interested in Volunteering?</b> Join our <a href="#">MSA Coalition Volunteers</a> group on facebook</p>



## In Person and Online Support Resources

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### MSA COALITION BOARD OF DIRECTORS

Chair	Cynthia Roemer EdD	Howell NJ	866-737-4999 x207	<a href="mailto:croemer@msacoalition.org">croemer@msacoalition.org</a>
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Emeritus	Hadley Ferguson	Missoula MT		
Emeritus	Diane Adkins	Stephens City VA		



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### SCIENTIFIC/MEDICAL ADVISORY BOARD

Scientific Advisor	Wassilios Meissner MD, PhD	Bordeaux FRANCE	<a href="mailto:wassilios.meissner@chu-bordeaux.fr">wassilios.meissner@chu-bordeaux.fr</a>
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Medical Advisor	Steven Vernino MD, PhD	Dallas TX USA	<a href="mailto:steven.vernino@utsouthwestern.edu">steven.vernino@utsouthwestern.edu</a>
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Medical Advisor	Roy Freeman, MD	Boston MA USA	<a href="mailto:rfreeman@bidmc.harvard.edu">rfreeman@bidmc.harvard.edu</a>
Medical Advisor	Mitch Miglis, MD	Stanford CA USA	<a href="mailto:mmiglis@stanford.edu">mmiglis@stanford.edu</a>

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.

### 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](mailto: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 4<sup>th</sup> Thursday of every months at 11:00am



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Meeting Time: November & December 3<sup>rd</sup> Thursday of these month at 1:00pm

Facilitator: Randi Haley 870-703-6417 [randirhaley@yahoo.com](mailto: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](mailto: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](http://www.curemsa.org)

Contact: Lily Shih (Executive Director) 510-226-0453 [lily@curemsa.org](mailto: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](mailto: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 3<sup>rd</sup> floor, Los Angeles, Calif.

Meeting Time: 1<sup>st</sup> Friday of every month from 2:00pm-4:00pm

Facilitator: Dr. Arik Johnson [acjohnson@mednet.ucla.edu](mailto:acjohnson@mednet.ucla.edu)

To RSVP and for Further Information contact Dolly West [dwest@mednet.ucla.edu](mailto: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](mailto: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



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Meeting Time(s): 1st Sunday, 3:00pm - 4:00pm

Facilitator: Robin Riddle, 650-814-0848, [robin.riddle@brainsupportnetwork.org](mailto: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, 7<sup>th</sup> Floor Board Room, 2425 Stockton Blvd, Sacramento, CA

Meeting Time 4<sup>th</sup> Wednesday of every month 7:00pm-8:30pm

Facilitator: Edward Fergusson. He can be reached through the Alzheimers Association Sacramento Phone: 916-930-9080 [efergusson@gmail.com](mailto:efergusson@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, FTL, 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](mailto: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, FTL, 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](mailto: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](mailto:sgrimmesey@gmail.com)

## COLORADO

### DENVER/ENGLEWOOD

Info updated as of Mar 2019: Neurodegenerative movement disorder group (MSA, PSP, CBD) –  
For Patients/Caregivers

Location: 1<sup>st</sup> 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](mailto:jhfranzgrote@comcast.net)



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### **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): 4<sup>th</sup> Friday of each month from 10:00am-12:00pm for Caregivers only

Facilitator: Helenn Franzgrote 303-789-9900 [jhfranzgrote@comcast.net](mailto: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: 2<sup>nd</sup> Friday of each month from 1:30pm - 3:30pm

Facilitator: Ruth Fletcher-Carter 970-391-8898 [chantillylace3@usa.net](mailto:chantillylace3@usa.net)

### **CONNECTICUT**

#### **CHESHIRE/VERNON**

Info added as of Nov 2019: For patients and caregivers affected by PSP,CBD, MSA

Meeting Time: 4<sup>th</sup> Thursday of the month at 6:30pm

Location: There are two different locations that are alternated on the 4<sup>th</sup> 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](mailto: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

1<sup>st</sup> 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](mailto:freemanph@aol.com)

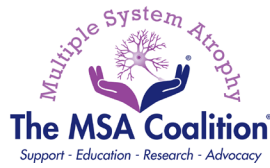
#### **SOUTHWEST FLORIDA**

Info updated as of Nov 2019: For patients/caregivers/families affected by MSA, PSP, CBD

Location: Terracina Grand 6825 Davis Blvd. Naples, 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](mailto:hotrdh@hotmail.com)



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### **NAPLES**

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

Contact: Tenley Smith 630-337-1314 [Tenswims@gmail.com](mailto: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](http://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](mailto:christabelle.auguste@emory.edu)

#### **ELLIJAY**

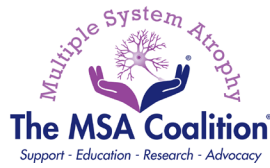
Info updated as of Apr 2019: **No Meeting** Phone/email Support Only

Contact: Paula Davis 706-669-1978 [jimandpaula@ellijay.com](mailto:jimandpaula@ellijay.com)

#### **WOODSTOCK**

Info added as of Dec 2019: Meeting for PSP/MSA/CBD

Location : Resurrection Anglican Church 231 Arnold Mill Road Woodstock, GA



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Meeting Time: 2<sup>nd</sup> Sunday of each month 3:00pm -5:00pm  
Facilitator: Jackie Green 678-780-5576 [jackie.greenpsp@gmail.com](mailto: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](http://www.moveovermsa.org)  
Contact: Tiffany Christensen 208-389-8022 [moveovermsa@gmail.com](mailto: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](mailto: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](mailto: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: 1<sup>st</sup> Saturday of each month 1:30pm-3:30pm  
Facilitator: David Takehara 847-452-1609 [davidtakehara@gmail.com](mailto:davidtakehara@gmail.com)  
Hosted by CurePSP

### INDIANA





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### **WARSAW**

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

Contact: Terry Shepherd 574-306-8290 [tellmenolies2004@yahoo.com](mailto: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](mailto: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](mailto:dianeegraham@gmail.com)

Please join our Facebook group, too, at <https://www.facebook.com/groups/MSAlowa/>

### **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](mailto:danheins@gmail.com)

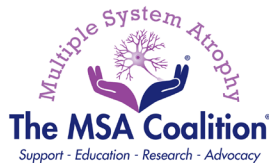
### **MAINE**

#### **WELLS**

Info updated as of Apr 2019: **No Meeting** Email Support Only

Contact: Gayle Gardner [nauticalmile102@gmail.com](mailto:nauticalmile102@gmail.com) or message on facebook

[www.facebook.com/ggcpteach](http://www.facebook.com/ggcpteach)



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### 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](mailto: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: 4<sup>th</sup> 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](mailto:cganc1@jhmi.edu)

#### **TANEYTOWN**

Info updated as of Dec 2020: **No Meeting** Phone/email Support Only

Contact: Shirley Snyder 904-207-5501 [ses.msafloida@gmail.com](mailto:ses.msafloida@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,



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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](mailto: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 Floria 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](mailto:mmeagher@mei.net)

### MINNESOTA

#### **MINNEAPOLIS**

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

Contact: Jean Wayne 612-419-2573 [Mnnightrn@gmail.com](mailto:Mnnightrn@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](mailto: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](mailto: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:



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MSA NJ (Nonprofit support group covering the tri-state area)

P.O. Box 773 Howell, NJ 07731

[www.msanj.org](http://www.msanj.org)

Phone MSA NJ: 732-903-8517

Private Facebook Support Group for MSA NJ community

only: [www.facebook.com/groups/MSANJSupport](https://www.facebook.com/groups/MSANJSupport)

Meeting Times: 2<sup>nd</sup> Saturday of the Month - 11 a.m. - 1:00 p.m.

Location: Overlook Medical Center, 99 Beauvoir Ave, Summit NJ

Conference Room #3, 5<sup>th</sup> Floor (near Neuroscience)

Facilitator: Cynthia Roemer [contact@msanj.org](mailto: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: 1<sup>st</sup> Tuesday of every month 3:00pm -4:30 pm

Facilitator: Bonnie Kratzer 609-463-4043 [jkratzer@caperegional.com](mailto: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](mailto: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](http://www.msanj.org)

Contact: Cynthia Roemer [contact@msanj.org](mailto:contact@msanj.org)

Phone MSA NJ: 732-903-8517

Private Facebook Support Group for MSA NJ community

only: [www.facebook.com/groups/MSANJSupport](https://www.facebook.com/groups/MSANJSupport)



## In Person and Online Support Resources

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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](mailto:contact@msanj.org)

### **NEW YORK**

Info added as of Nov 2019: For Caregivers Only of PSP/CBD/MSA

Meeting Time: 3<sup>rd</sup> Tuesday of the month 6:00pm-7:30pm must contact facilitator in advance of coming

Location: St. James Parish House 865 Madison Ave (btw. 71-73<sup>rd</sup> St) NYC, Freeman Room, 3<sup>rd</sup> Fl

Facilitator: Jane Jensen 561-598-9839 [Jensen@att.net](mailto: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 3<sup>rd</sup> 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](mailto: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 [hausertammy@hotmail.com](mailto:hausertammy@hotmail.com)

#### **HIGH POINT**

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

Contact: Amy Nissen [acnissen@northstate.net](mailto: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



## In Person and Online Support Resources

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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](mailto: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](mailto:CentralOhioPSPgroup@gmail.com)  
Contact: For general questions, please call (614) 788.6115 or email [DempseyCenter@OhioHealth.com](mailto: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](mailto:calvelageb@yahoo.com)  
Paul Reams [preams1@yahoo.com](mailto:preams1@yahoo.com)

### **KETTERING**

Info updated as of Dec2019: 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](mailto: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](mailto:cathrapenport@gmail.com)

### **OKLAHOMA**

#### **GROVE**

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



## In Person and Online Support Resources

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### OREGON

#### **BEND**

Info updated as of Apr 2019: **No Meeting** Phone/email Support Only  
Contact: Nena Close 541-419-6408(cell) [nenaclose@gmail.com](mailto:nenaclose@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): 1<sup>st</sup> Friday of the month 10am-noon  
Facilitator: Pat Robertson 503-310-9085 [bookmole@comcast.net](mailto: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](mailto: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](http://www.msanj.org)  
Contact: Cynthia Roemer [contact@msanj.org](mailto: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.

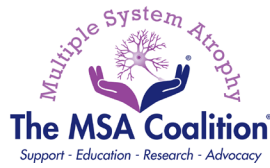
Private Facebook Support Group for MSA NJ community  
only: [www.facebook.com/groups/MSANJSupport/](https://www.facebook.com/groups/MSANJSupport/)

#### **N. VERSAILLES**

Info updated as of Nov 2019: **No Meeting** Phone/email Support Only  
Contact: Carole Barber 412-678-8948 [barber.carole@juno.com](mailto:barber.carole@juno.com)

#### **PHILADELPHIA**

Info added as of Nov 2019: For person with Atypical Parkinsonism  
Locations: Varies



## In Person and Online Support Resources

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Meeting Time: Varies, but meets on a quarterly basis only  
Facilitator: Josue Etienne BSN 215-829-2347 [josue.etienne@uphs.upenn.edu](mailto: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](mailto: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](mailto: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: 4<sup>th</sup> Saturday of each month 10:00am-12:30pm  
Facilitator: Judi Nudelman 512-964-1236 [jnudelman51@gmail.com](mailto: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](mailto: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](mailto:ileen@earthlink.net)

#### **SAN ANTONIO**

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





## In Person and Online Support Resources

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Contact: Sharon Sutton 210-296-4619 [saksutton@aol.com](mailto:saksutton@aol.com)  
Candice Hernandez 210-912-4530 [cleo0308@yahoo.com](mailto:cleo0308@yahoo.com)

### 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](mailto: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  
Facitator : Matt McKeon 215-292-6674 [Pdhelp4u@gmail.com](mailto: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](mailto: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](mailto: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](mailto:photodog4412@gmail.com)



## In Person and Online Support Resources

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### 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: 2<sup>nd</sup> Friday of each month from 1:30pm - 3:30pm

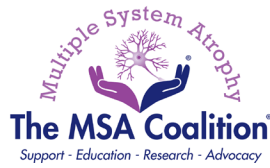
Facilitator: Ruth Fletcher-Carter 970-391-8898 [chantillylace3@usa.net](mailto:chantillylace3@usa.net)

#### **LANDER**

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

Contact: Cathy Chapman 307-332-4144 [cec@wyoming.com](mailto:cec@wyoming.com)

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



## In Person and Online Support Resources

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### CANADA

#### ALL PROVINCES

Info updated as of Oct 2019: **No Meeting** Email Support Only

Contact: Pam Bower [pbower@msaawareness.org](mailto: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](mailto: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: 3<sup>rd</sup> Saturday of every month from 12:00pm -2:00pm

Facilitator: Kelly Clapham 403-803-3307 [claphamk@telus.net](mailto: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](mailto:curepspbc@gmail.com)

Robyn Heppner 604-584-7587 x2020 [rheppner@elimvillage.com](mailto: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](mailto:island.view@shaw.ca)



## In Person and Online Support Resources

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### NOVA SCOTIA

#### **HALIFAX**

Info updated as of Oct 2019: **No Meeting** Email Support Only

Contact: Pam Bower [pbower@msaawareness.org](mailto: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](mailto: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 [hopenatterspspkingston@gmail.com](mailto:hopenatterspspkingston@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.terstege@parkinson.ca](mailto:robert.terstege@parkinson.ca)

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



## In Person and Online Support Resources

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### 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/](http://www.facebook.com/groups/MSACoalitionPublicGroup/)

2000+ members, worldwide - Multiple System Atrophy Research News

[www.facebook.com/groups/MSANewsGroup/](http://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/](http://www.facebook.com/groups/MSABuddies/)

500+ members, worldwide - MSA: A Patient's Journey – Patients only

[www.facebook.com/groups/MSAPatients](http://www.facebook.com/groups/MSAPatients/)

300+ members, worldwide - Children of MSA Warriors – Children/grandchildren welcome

[www.facebook.com/groups/ChildrenOfMSAWarriors](http://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/](http://www.facebook.com/groups/MSANewEngland/)

MSA Coalition - Middle Atlantic (NY-NJ-PA)

[www.facebook.com/groups/MSAMidAtl/](http://www.facebook.com/groups/MSAMidAtl/)

MSA Coalition - South Atlantic (DE-DC-FL-GA-MD-NC-SC-VA-WV)

[www.facebook.com/groups/MSASOATL/](http://www.facebook.com/groups/MSASOATL/)

###### CENTRAL STATES

MSA Coalition - Northeast Central (IN-IL-MI-WI-OH)

[www.facebook.com/groups/MSANECentralUS/](http://www.facebook.com/groups/MSANECentralUS/)



## In Person and Online Support Resources

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**MSA Coalition - Northwest Central (IA-KS-MN-MO-ND-SD-NE)**

[www.facebook.com/groups/MSANWCentralUS/](http://www.facebook.com/groups/MSANWCentralUS/)

**MSA Coalition - Southeast Central (AL-KY-MS-TN)**

[www.facebook.com/groups/MSASECentralUS/](http://www.facebook.com/groups/MSASECentralUS/)

**MSA Coalition - Southwest Central (TX-OK-LA-AR)**

[www.facebook.com/groups/MSASWCentral/](http://www.facebook.com/groups/MSASWCentral/)

### WESTERN STATES

**MSA Coalition - Mountain States (AZ-CO-ID-NM-MT-UT-NV-WY)**

[www.facebook.com/groups/MSAMountainUS/](http://www.facebook.com/groups/MSAMountainUS/)

**MSA Coalition - Pacific States (CA-OR-WA-HI-AK)**

[www.facebook.com/groups/MSAPacificUS/](http://www.facebook.com/groups/MSAPacificUS/)

### OTHER ONLINE SUPPORT GROUPS (Created by MSAawareness)

**MSA Canada**

[www.facebook.com/groups/MSACanada/](http://www.facebook.com/groups/MSACanada/)

**MSA Australia & New Zealand**

[www.facebook.com/groups/MSAOZNZ/](http://www.facebook.com/groups/MSAOZNZ/)

**MSA UK and Ireland**

[www.facebook.com/groups/MSAUKIRELAND/](http://www.facebook.com/groups/MSAUKIRELAND/)

**MSA Germany**

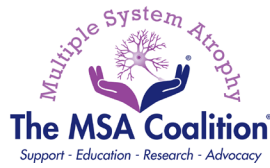
<https://www.facebook.com/groups/MSAGermany>

**MSA Spain**

<https://www.facebook.com/groups/MSASpain>

**MSA India**

<https://www.facebook.com/groups/MSAIndia>



## In Person and Online Support Resources

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### **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/tZlqf-uhrDgoHdfeY\\_XXwpyWe602VedTnWbK](https://us02web.zoom.us/meeting/register/tZlqf-uhrDgoHdfeY_XXwpyWe602VedTnWbK)

**Meeting Tel:** +1 646 558 8656 Access Code: 867 8292 3273

**Facilitator:** Tom Tait, [tom.tait@comcast.net](mailto: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/tZUf-CgrD0uG9CGa7yq3806EcOd8xhmUaqR>

**Meeting Tel:** +1 646 558 8656 Access Code: 810 8982 6414

**Facilitator:** Cathy Chapman, Phone 307-332-4144, email [cec@wyoming.com](mailto:cec@wyoming.com)