

THE MULTIPLE SYSTEM ATROPHY (MSA) COALITION, INC.

9935-D Rea Road #212, Charlotte, NC 28277 USA www.MultipleSystemAtrophy.org

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

Email: <u>info@multiplesystematrophy.org</u> or <u>Find us on Facebook</u>

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

SUPPORT

The Multiple System Atrophy Coalition offers a toll free support line staffed by former MSA caregivers.

Contact: Larry Kellerman

Toll free US and Canada: 866-737-5999

Ikellerman@msacoalition.org

Please Visit our MSA Resources Page

EDUCATION

The MSA Coalition hosts an annual conference for MSA patients and families (usually Sep or Oct) in a different US city each year.

See our <u>YouTube Channel</u> for past conference recordings. DVD's of past conferences are

available to order, just Contact Us

Download: "MSA - What you Need to Know"

RESEARCH

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.

Patients please register in the **Global MSA Registry**

ADVOCACY & AWARENESS

The MSA Coalition highlights the month of March as MSA Awareness Month and October 3rd as World MSA Day. As a member of the National Organization for Rare Disorders and the Coalition of Patient Advocacy Groups we stay abreast of issues important to the MSA community.



MSA COALITION BOARD OF DIRECTORS

Chair	Cynthia Roemer EdD	Howell NJ	866-737-4999 x207	croemer@msacoalition.org
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Emeritus				

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Medical Advisor	Thomas Chelimsky MD	Milwaukee WI USA	tchelimsky@mcw.edu
Medical Advisor	Steven Vernino MD, PhD	Dallas TX USA	steven.vernino@utsouthwestern.edu



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

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 Octocber 4th Thursday of every months at 11:00am 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 <u>acjohnson@mednet.ucla.edu</u>

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 Apr 2019: Neurodegenerative movement disorder group (MSA PSP, CBD, etc.

- caregivers only. Contact facilitator for more info.

Location: A Café in San Mateo, CA

Meeting Time(s): Every six weeks (call or e-mail for schedule) from 5:00pm - 7:00pm 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

JACKSONVILLE

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

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

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/parkinsonsoutreach-center-support-groups

Updated: May 23, 2020

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

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 Oct 2019: MSA Support Meeting for Patients/Caregivers

Meeting Time(s): Quarterly meetings. Time and place announced on <u>Facebook NE Central USA</u>

Page or Contact Facilitator.

Facilitator: Pam Getz 847-414-5910 pgetz1019@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

кокомо

Info updated as of Nov 2019: For MSA Patients/caregivers

Contact: Renate Sharp 765-453-5351 rsbreslau@yahoo.com

Chris Markiewicz 765-513-5219 atacrew@aol.com

Francie Hutton 765-453-9020 huttondf20@aol.com

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/MSAlowa/

KANSAS

LEAWOOD

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

Location: Turning Point 8900 State Line Road Suite 240 Leawood, KS 66206

Meeting Time: 3rd Wednesday of the month beginning Jan 15, 2020 6:30pm-8:00pm

Facilitator: Tam Smith 913-645-5254 RSOFAN@aol.com

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 <u>nauticalmile102@gmail.com</u> 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 eggreene@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: 4thThursday of every month from 2:00pm-4:00pm

Facitlitator:Chelsea Ganc 410-955-6684 cganc1@jhmi.edu

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,

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 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

MINNESOTA

MINNEAPOLIS

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

Contact: Jean Wayne 612-419-2573 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

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

Updated: May 23, 2020

(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 hausertammy@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

<u>DempseyCenter@OhioHealth.com</u>. (Group sponsored by CurePSP)

FAIRFIELD

Info updated as of Dec 2019: **No Meeting** Phone/email Support Only Contact: Brenda Reams 513-860-2912 <u>calvelageb@yahoo.com</u>

Paul Reams 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

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 <u>alexis brewer 200@yahoo.com</u>

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 <u>inudelman51@gmail.com</u>

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

Contact: Sharon Sutton 210-296-4619 <u>saksutton@aol.com</u>

Candice Hernandez 210-912-4530 <u>cleo0308@yahoo.com</u>

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

Facitator: Matt McKeon 215-292-6674 Pdhelp4u@gmail.com

Hosted by PFNCA in partnership with Sundrise AL

WASHINGTON

SEATTLE

Info updated as of Apr 2019: 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 suzanna.eller@swedish.org

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 <a href="mailto:pbower@msaawareness.org">pbower@msaawareness.org</a>

### **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: 3<sup>rd</sup> 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 <u>rheppner@elimvillage.com</u>

## **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 <a href="mailto:pbower@msaawareness.org">pbower@msaawareness.org</a>

### **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 <u>kimberleyadrovez@yahoo.com</u>

#### **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 ~~~~~~



ONLINE SUPPORT GROUPS

MSA COALITION MODERATED GROUPS

PRIVATE EMAIL SUPPORT GROUP (Join via email only, no Facebook account required):

2000+ members, worldwide: Shydrager Yahoo Email Support Group for MSA Founded in 1995 by Vanderbilt University Autonomic Dysfunction Center staff

Subscribe: Send an email to $\underline{shydrager\text{-}subscribe@yahoogroups.com}$

Unsubscribe: Send an email to shydrager-unsubscribe@yahoogroups.com

Post a Message: Send an email to shydrager@yahoogroups.com

Contact the moderators: Send an email to shydrager-owner@yahoogroups.com

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 www.facebook.com/groups/MSABuddies/

MSA: A Patient's Journey – Patients only www.facebook.com/groups/MSAPatients

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/

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

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/



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://www2.gotomeeting.com/register/977578139

Meeting Tel: (415) 655-0060; Access Code: 950-759-636

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://attendee.gotowebinar.com/register/8182973838726361090

Meeting Tel: (914) 614-3221; Access Code: 500-058-061

Facilitator: Cathy Chapman, Phone 307-332-4144, email cec@wyoming.com