



Northeast Region: Support for PSP/MSA/CBD

CurePSP encourages and organizes groups that foster face-to-face communication, exchange of ideas and information, and comforting interaction for families facing a diagnosis of prime of life neurodegeneration. Many people dealing with these feel that others in their lives cannot understand what they are going through, so talking with someone who has been on the journey, and who can provide insight and advice, is very beneficial. The groups are for carepartners, family members, friends, and people with PSP, CBD, MSA, or a related disease looking for comfort and support from others in the community. They are all facilitated by our dedicated volunteers, most of whom have been on this journey and can provide unique insight from a personal perspective. If you are not ready to communicate with a group or are looking for a more one-on-one conversation about the journey you are on, please find the names and contact information of our peer supporters listed state-by-state below. Peer supporters are available for practical conversations, recommendations for doctors, emotional support, or any other type of question. For any further information or to be added to this list, please contact Joanna Teters at teters@curepsp.org

Connecticut

Support Groups

Connecticut Support Group for PSP/MSA/CBD caregivers

Meeting Virtually: Yes

Meeting Registration Link: Contact facilitator for link

Meeting Time(s): 4th Thursday of the month from 6:30pm - 8:00pm

Contact the facilitator: Bill Johnson, 860-417-3272, billjohnson1123@gmail.com, Al Nixon, aleinixon@comcast.net

Peer Supporters

Name: William Johnson **City:** Morris **Disease Familiarity:** PSP

Email: billjohnson1123@gmail.com **Phone:** 860-417-8146

Name: Allen Nixon **City:** Farmington **Disease Familiarity:** PSP

Email: aleinixon@comcast.net **Phone:** 860-307-6862

Name: Nancy Frehill **City:** New Milford **Disease Familiarity:** PSP

Email: frehillnancy@gmail.com **Phone:** 914-715-5665

Maine

Support Groups

Portland Support Group for PSP/MSA/CBD patients and caregivers

Meeting Virtually: Yes

Meeting Registration Link:

<https://us02web.zoom.us/meeting/register/tZMvcOytqDisGNUZ6l2SaynOuWfc26UqdwS>

Meeting Time(s): One Sunday per quarter from 1:00 - 3:00pm, contact facilitator for more info

Contact the facilitator: Janet Edmunson janet@janetedmunson.com

Peer Supporters

Name: Janet Edmunson **City:** Portland **Disease Familiarity:** PSP/CBD

Email: janet@janetedmunson.com **Phone:** 207-799-4963

Maryland

Peer Supporters

Name: Martha Thomas **City:** Monkton **Disease Familiarity:** PSP

Email: martha.kenney75@gmail.com **Phone:** 443-414-0993

New Jersey

Peer Supporters

Name: MaryAnn Boyle **City:** Green Brook **Disease Familiarity:** PSP/MSA

Email: kiwi3841@yahoo.com **Phone:** 732-752-3841

Name: Steve Garcia **City:** Ringwood **Disease Familiarity:** PSP

Email: advancedstagespsp@gmail.com **Phone:** 973-962-9356

Name: June Kestenbaum **City:** Moorestown **Disease Familiarity:** PSP

Email: jkestenbaumhealth@gmail.com **Phone:** 609-410-9921

New York

Manhattan Support Group for PSP/MSA/CBD caregivers

Meeting Virtually: Yes

Meeting Registration Link: Contact facilitator for link

Meeting Time(s): 3rd Tuesday of every month

Contact the facilitator: Jane Jensen, 561-598-9839, jensen@att.net, Janet Charleston jlcharleston@gmail.com

Albany Support Group for PSP/MSA/CBD patients and caregivers

Meeting

Virtually: No

Information: For patients, caregivers and families affected by Parkinson's, PSP, CBD, MSA

Location: Contact facilitator to get on list for in-person support group meetings

Meeting Time(s): Contact facilitator for more details

Facilitators: Brittany Buza, 315-391-7891, brittanybuza@yahoo.com

Peer Supporters

Name: Kara Holisher **City:** Plainview **Disease Familiarity:** PSP/CBD

Email: kbhx2@optonline.net **Phone:** 516-884-2601

Name: Sarah Weingarten **City:** Forest Hills **Disease Familiarity:** PSP

Email: sarah.weingarten@gmail.com **Phone:** 518-248-2560

Name: Jordan Reisner **City:** New York City **Disease Familiarity:** PSP

Email: jordanreisner@gmail.com **Phone:** 917-841-3260

Name: Amy Branch **City:** New York City **Disease Familiarity:** PSP

Email: amybranch6@gmail.com **Phone:** 919-614-3285

Name: Nancy Frehill **City:** Bronxville **Disease Familiarity:** PSP

Email: frehillnancy@gmail.com **Phone:** 914-715-5665

Name: Raphael Stern **City:** New York City **Disease Familiarity:** PSP

Email: rstern9@gmail.com **Phone:** 917-589-8660

Pennsylvania

Peer Supporters

Name: Shannon Heacock **City:** King of Prussia **Disease Familiarity:** PSP
Email: shannon.heacock@gmail.com **Phone:** 215-260-3413

Name: Susan McLaughlin **City:** Pittsburgh **Disease Familiarity:** PSP
Email: susan.mclaughlin37@icloud.com **Phone:** 412-352-9369

Vermont

Support Groups

Burlington Support Group for PSP/MSA/CBD patients and caregivers

Meeting Virtually: Yes

Meeting Registration Link:

<https://us02web.zoom.us/meeting/register/tZAuceGsqs8iHNWCBFgrTsNmI25ZmbESWTEX>

Meeting Time(s): Every 3rd Thursday of the month from 7-8pm EST

Contact the facilitator: Janis Appel, jappel1130@gmail.com, 802-527-7398

Peer Supporters

Name: Janis Appel **City:** Burlington **Disease Familiarity:** PSP/FTD
Email: jappel1130@gmail.com **Phone:** 802-527-7398

Washington DC

Support Groups

Washington DC Support Group for PSP/MSA/CBD patients and caregivers

Meeting Virtually: Yes

Meeting Registration Link: Contact facilitator for link

Meeting Time(s): 3rd Saturday of each month from 2:00p-4:00pm EST

Contact the facilitator: Steve Goldman, goldmanskm@comcast.net, home (301)330-6954; cell (301) 367-4317