



UNLOCKING THE SECRETS OF BRAIN DISEASE®

## Northeast Region: Support for PSP/CBD/MSA

### Peer Supporters

If you are in search of one-on-one conversation about the journey you are on, please find the names and contact information of our peer supporters. Peer supporters are available to offer practical care tips, connect with local resources, and provide emotional support. Feel free to reach out to anyone on this or other regional lists, regardless of location.

### Support Groups

Support groups are safe and dedicated spaces to connect with and learn from individuals and families on similar journeys. CurePSP's network of regional support groups offers opportunities to meet others in your community impacted by PSP, CBD and MSA. You can also visit [www.psp.org/inneedssupport/online-support-groups](http://www.psp.org/inneedssupport/online-support-groups) for CurePSP's national support groups

### Connecticut

**Peer Supporter:** William Johnson **City:** Morris, CT  
**Email:** [billjohnson1123@gmail.com](mailto:billjohnson1123@gmail.com) **Phone:** 860-417-8146  
**Experience:** Cared for a spouse with PSP

**Peer Supporter:** Allen Nixon **City:** Farmington, CT  
**Email:** [aleinixon@comcast.net](mailto:aleinixon@comcast.net) **Phone:** 860-307-6862  
**Experience:** Cared for a spouse with PSP

### Connecticut Support Group for PSP/CBD/MSA carepartners

**Location:** Meeting virtually - contact facilitator for link  
**Meeting Time:** 4th Thursday of the month from 6:30pm - 8:00pm ET  
**Facilitator:** Bill Johnson, 860-417-3272, [billjohnson1123@gmail.com](mailto:billjohnson1123@gmail.com), Al Nixon, [aleinixon@comcast.net](mailto:aleinixon@comcast.net)

### Maine

**Peer Supporter:** Janet Edmunson **City:** South Portland, ME  
**Email:** [janet@janetedmunson.com](mailto:janet@janetedmunson.com) **Phone:** 508-308-4195 (m) / 207-799-1686 (h)  
**Experience:** Cared for a spouse with PSP/CBD

### Portland Support Group for PSP/CBD/MSA patients & carepartners

**Location:** <https://us02web.zoom.us/join/9123456789>  
**Meeting Time:** One Sunday per quarter from 1:00 - 3:00pm ET, contact facilitator for info  
**Facilitator:** Janet Edmunson, [janet@janetedmunson.com](mailto:janet@janetedmunson.com)

## Maryland

### **Maryland Support Group for Atypical Parkinsonism**

**Location:** Meeting virtually – contact facilitator for link

**Associated Medical Center:** Johns Hopkins Movement Disorders Center

**Meeting Time:** 4<sup>th</sup> Thursday of the month from 2:00 – 3:00pm ET

**Facilitator:** Sarah Phelan, MS, [sphelan2@jhmi.ed](mailto:sphelan2@jhmi.ed)

## Massachusetts

**Peer Supporter:** Kathryn Buckley **City:** Northbridge, MA

**Email:** [katbuckley31@aol.com](mailto:katbuckley31@aol.com) **Phone:** 508-246-1732

**Experience:** Cared for a parent with PSP

**Name:** Rev. Lee Riggs **City:** Natick, MA

**Email:** [rev.riggs@gmail.com](mailto:rev.riggs@gmail.com) **Phone:** 843-424-7658

**Experience:** Cared for a spouse with PSP

### **Boston Support Group for PSP/CBD/MSA patients & carepartners**

**Location:** Meeting virtually - contact facilitator for link

**Meeting Time:** Every other month, 2<sup>nd</sup> Saturday of the month from 12:00 – 1:00pm ET

**Facilitator:** Melissa Diggin, [m\\_diggin@hotmail.com](mailto:m_diggin@hotmail.com)

## New Jersey

**Peer Supporter:** MaryAnn Boyle **City:** Green Brook, NJ

**Email:** [kiwi3841@yahoo.com](mailto:kiwi3841@yahoo.com) **Phone:** 732-752-3841

**Experience:** Cared for a parent with PSP/MSA

**Peer Supporter:** Steve Garcia **City:** Ringwood, NJ

**Email:** [advancedstagespsp@gmail.com](mailto:advancedstagespsp@gmail.com) **Phone:** 973-962-9356

**Experience:** Cared for a parent with PSP

**Peer Supporter:** June Kestenbaum **City:** Moorestown, NJ

**Email:** [jkestenbaumhealth@gmail.com](mailto:jkestenbaumhealth@gmail.com) **Phone:** 609-410-9921

**Experience:** Cared for a parent with PSP

### **New Jersey Support Groups**

**Location:** Various meeting locations and times through MSA NJ - <https://www.msanj.org/resources-2/msa-support-group-listings/>

## New York

**Peer Supporter:** Kara Holisher **City:** Plainview, NY

**Email:** [kbhx2@optonline.net](mailto:kbhx2@optonline.net) **Phone:** 516-884-2601

**Experience:** Cared for a parent with PSP

**Peer Supporter:** Sarah Weingarten **City:** Forest Hills, NY

**Email:** [sarah.weingarten@gmail.com](mailto:sarah.weingarten@gmail.com) **Phone:** 518-248-2560

**Experience:** Cared for a parent with PSP

**Peer Supporter:** Jordan Reisner **City:** New York, NY

**Email:** [jordanreisner@gmail.com](mailto:jordanreisner@gmail.com) **Phone:** 917-841-3260

**Experience:** Caring for a parent with PSP

**Peer Supporter:** Amy Branch **City:** New York, NY

**Email:** [amybranch6@gmail.com](mailto:amybranch6@gmail.com) **Phone:** 919-614-3285

**Experience:** Cared for a parent with PSP

**Peer Supporter:** Raphael Stern **City:** New York, NY

**Email:** [rstern9@gmail.com](mailto:rstern9@gmail.com) **Phone:** 917-589-8660

**Experience:** Cared for a parent with PSP

#### **New York City Support Group for PSP/CBD/MSA carepartners**

**Location:** Meeting virtually - contact facilitator for link

**Meeting Time:** 3<sup>rd</sup> Tuesday of every month

**Facilitator:** Jane Jensen, [jensen@att.net](mailto:jensen@att.net), 561-598-9839

#### **Albany Support Group for PSP/CBD/MSA patients & carepartners**

**Location/Meeting Time:** Contact facilitator for location and meeting time

**Facilitators:** Brittany Buza, [brittanybuza@yahoo.com](mailto:brittanybuza@yahoo.com), 315-391-7891

### **Pennsylvania**

**Peer Supporter:** Susan McLaughlin **City:** Pittsburgh, PA

**Email:** [susan.mclaughlin37@icloud.com](mailto:susan.mclaughlin37@icloud.com) **Phone:** 412-352-9369

**Experience:** Cared for a parent with PSP

**Peer Supporter:** Shannon Heacock **City:** King of Prussia, PA

**Email:** [shannon.heacock@gmail.com](mailto:shannon.heacock@gmail.com) **Phone:** 215-260-3413

**Experience:** Cared for a parent with PSP

#### **Philadelphia Support Group for PSP/CBD/MSA/LBD patients & carepartners**

**Location:** Meeting virtually – contact facilitator for link

**Meeting Time:** 4<sup>th</sup> Monday of each month from 11:00am-12:00pm ET

**Facilitator:** Lauren Zelouf, MSW, LCSW, [lauren.zelouf@penmedicine.upenn.edu](mailto:lauren.zelouf@penmedicine.upenn.edu), (215) 829-3038

### **Vermont**

**Peer Supporter:** Janis Appel **City:** St. Albans, VT  
**Email:** [jappel1130@gmail.com](mailto:jappel1130@gmail.com) **Phone:** 802-527-7398  
**Experience:** Cared for a spouse with PSP/FTD

## **Washington DC**

**Washington DC Support Group for PSP/MSA/CBD patients & carepartners**

**Location:** [https://us02web.zoom.us/meeting/register/tZYocu-qqjwpHNTKm0FxpKt7LGigfDAry23Q](https://us02web.zoom.us/join/https://us02web.zoom.us/meeting/register/tZYocu-qqjwpHNTKm0FxpKt7LGigfDAry23Q)

**Meeting Time:** 3rd Saturday of each month from 2:00p-4:00pm ET

**Facilitator:** Kristen Weidner, [weidner.kristen@gmail.com](mailto:weidner.kristen@gmail.com)