CUIEPSP

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 <u>www.psp.org/ineedsupport/online-support-groups</u> for CurePSP's national support groups

Connecticut

Peer Supporter: Susanne McAvoy **City:** Darien, CT **Email**: <u>susanne.mcavoy@gmail.com</u> **Phone:** 917-846-5102 **Experience:** Cared for a parent with PSP

Peer Supporter: Allen Nixon *City:* Farmington, CT *Email*: <u>aleinixon@comcast.net</u> *Phone:* 860-307-6862 *Experience:* Cared for a spouse with PSP

Connecticut Support Group for PSP/CBD/MSA care partners *Location:* Meeting virtually - contact facilitator for link

Meeting Time: 4th Thursday of the month from 6:30pm - 8:00pm ET *Facilitator:* Al Nixon, <u>aleinixon@comcast.net</u>

<u>Maine</u>

Peer Supporter: Janet Edmunson *City:* South Portland, ME *Email*: janet@janetedmunson.com *Phone:* 508-308-4195 *Experience:* Cared for a spouse with PSP/CBD

Maine Support Group for people with PSP/CBD/MSA and care partners Location: <u>https://uso2web.zoom.us/meeting/register/tZMvcOytqDIsGNUZ612SaynOuWfc26UqdwS</u>

Meeting Time: Bi-monthly from 1:00 - 3:00pm ET, 2024 dates are 2/4, 4/14, 6/9, 8/11, 10/13 and 12/1 *Facilitator:* Janet Edmunson, <u>janet@janetedmunson.com</u>, 508-308-4195

Maryland

Maryland Support Group for Atypical Parkinsonism Location: Meeting virtually – contact facilitator for link Associated Medical Center: Johns Hopkins Movement Disorders Center Meeting Time: 4th Monday of the month from 12:30-1:30pm ET Facilitator: Sarah Phelan, MS, <u>sphelan2@jhmi.edu</u>

Massachusetts

Peer Supporter: Kathryn Buckley **City:** Northbridge, MA **Email**: <u>katbuckley31@aol.com</u> **Phone:** 508-246-1732 **Experience:** Cared for a parent with PSP

Peer Supporter: Kat Fishman *City:* Newton, MA *Email*: <u>fishmank@bc.edu</u> *Experience:* Cared for a parent with PSP

Peer Supporter: Tom Loewald *City:* North Easton, MA *Email*: <u>thomas.loewald@gmail.com</u> *Phone:* 508-446-1920 *Experience:* Cared for a spouse with PSP

Peer Supporter: Rev. Lee Riggs *City:* Natick, MA *Email*: <u>rev.riggs@gmail.com</u> *Phone:* 843-424-7658 *Experience:* Cared for a spouse with PSP

Peer Supporter: Zach Rivers *City:* Somerville, MA *Email*: <u>zach_rivers@mac.com</u> *Phone:* 404-405-9296 *Experience:* Cared for a parent with PSP

Peer Supporter: Lauren Simon *City:* Millis, MA *Email*: <u>rev.riggs@gmail.com</u> *Phone:* 618-365-4984 *Experience:* Cared for a parent with PSP

Massachusetts Support Group for PSP/CBD/MSA care partners Location: <u>https://us02web.zoom.us/meeting/register/tZcudumrrTMtHt18pczS5IWW35TWxr4mJKaX</u> Meeting Time: 4th Tuesday of every month from 7:00-8:00pm ET Facilitator: Tom Loewald, <u>thomas.loewald@gmail.com</u>, 508-446-1920

New Jersey

Peer Supporter: MaryAnn Boyle *City:* Green Brook, NJ *Email*: <u>kiwi3841@yahoo.com</u> *Phone:* 732-752-3841

Experience: Cared for a parent with PSP/CBD

Peer Supporter: Steve Garcia *City:* Ringwood, NJ *Email*: <u>advancedstagespsp@gmail.com</u> *Phone:* 973-962-9356 *Experience:* Cared for a parent with PSP

Peer Supporter: June Kestenbaum *City:* Moorestown, NJ *Email*: <u>jkestenbaumhealth@gmail.com</u> *Phone:* 609-410-9921 *Experience:* Cared for a parent with PSP

Peer Supporter: Andreanna Whittle **City: Edison**, NJ **Email**: <u>Andreanna.Whittle@anthem.com</u>**Phone:** 732-810-6444 **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: Amy Branch *City:* New York, NY *Email*: <u>amybranch6@gmail.com</u> *Phone:* 919-614-3285 *Experience:* Cared for a parent with PSP

Peer Supporter: Brittany Buza *City:* Saratoga Springs, NY *Email*: brittanybuza@yahoo.com *Phone*: 315-391-7891 *Experience:* Cared for a parent with PSP

Peer Supporter: Jonathan Denby **City:** New York, NY **Email**: <u>jon@jondenby.com</u> **Experience:** Cared for a parent with PSP

Peer Supporter: Paola Mejia *City:* Flushing, NY *Email*: <u>paola.mejia6@gmail.com</u> *Phone:* 347-256-9437 *Experience:* Caring for a parent with PSP

Peer Supporter: Jordan Reisner **City:** New York, NY **Email**: <u>jordanreisner@gmail.com</u> **Phone:** 917-841-3260 **Experience:** Caring for a parent with PSP

Peer Supporter: Raphael Stern *City:* New York, NY *Email*: <u>rstern9@gmail.com</u> *Phone:* 917-589-8660 *Experience:* Cared for a parent with PSP

Peer Supporter: Sarah Weingarten *City:* Forest Hills, NY *Email*: <u>sarah.weingarten@gmail.com</u> *Phone:* 518-248-2560 *Experience:* Cared for a parent with PSP

New York City Support Group for PSP/CBD/MSA care partners Location: Meeting virtually - contact facilitator for link Meeting Time: 3rd Wednesday of every month from 7:00-8:00pm ET Facilitator: Jane Jensen, jensen@att.net 561-598-9839, Co-facilitator: Janet Charleston

Pennsylvania

Peer Supporter: Shannon Heacock *City:* King of Prussia, PA *Email*: <u>shannon.heacock@gmail.com</u> *Phone:* 215-260-3413 *Experience:* Cared for a parent with PSP

Peer Supporter: Susan McLaughlin *City:* Pittsburgh, PA *Email*: <u>susan.mclaughlin37@icloud.com</u> *Phone:* 412-352-9369 *Experience:* Cared for a parent with PSP

Philadelphia Support Group for people with PSP/CBD/MSA/LBD and care partners *Location:* Meeting virtually – contact facilitator for link *Meeting Time:* 4th Monday of each month from 11:00am-12:00pm ET *Facilitator:* Lauren Zelouf, MSW, LCSW, <u>lauren.zelouf@pennmedicine.upenn.edu</u>, 215-829-3038

<u>Vermont</u>

Peer Supporter: Janis Appel *City:* St. Albans, VT *Email*: <u>jappel1130@gmail.com</u> Phone: 802-527-7398 *Experience:* Cared for a spouse with PSP/FTD

Peer Supporter: Mary Ford Clarke *City:* Bennington, VT *Email*: <u>mary.clarke322@gmail.com</u> Phone: 516-361-2196 *Experience:* Caring for a spouse with PSP

Washington DC

Washington DC Support Group for PSP/MSA/CBD patients & care partners Location: <u>https://uso2web.zoom.us/meeting/register/tZYocu-qqjwpHNTKmoFxpKt7LGigfDAry23Q</u> Meeting Time: 3rd Saturday of each month from 2:00p-4:00pm ET Facilitator: Kristen Strader, <u>strader.kristen@gmail.com</u>