

# **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 <a href="https://www.psp.org/ineedsupport/online-support-groups">www.psp.org/ineedsupport/online-support-groups</a> for CurePSP's national support groups

#### Connecticut

**Peer Supporter:** Susanne McAvoy **City:** Darien, CT

Email: susanne.mcavoy@gmail.com Phone: 917-846-5102

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

**Peer Supporter:** Allen Nixon **City:** Farmington, CT **Email**: aleinixon@comcast.net **Phone:** 860-307-6862

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

Peer Supporter: Joanna Rieger City: Darien, CT

*Email*: joannasweber@yahoo.com *Phone*: 917-509-0094

**Experience:** Cared for a parent 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 - 7:30pm ET

Facilitator: Al Nixon, aleinixon@comcast.net

#### Maine

**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:*https://uso2web.zoom.us/meeting/register/tZMvcOvtqDIsGNUZ6I2SavnOuWfc26UqdwS

**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, janet@janetedmunson.com, 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, sphelan2@jhmi.edu

#### **Massachusetts**

**Peer Supporter:** Kathryn Buckley Hanna **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*: fishmank@bc.edu

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

**Peer Supporter:** Tom Loewald **City:** North Easton, MA **Email**: <a href="mailto:thomas.loewald@gmail.com">thomas.loewald@gmail.com</a> **Phone:** 508-446-1920

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

**Peer Supporter:** Rev. Lee Riggs **City:** Natick, MA **Email**: rev.riggs@gmail.com **Phone:** 843-424-7658

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

**Peer Supporter:** Zach Rivers **City:** Somerville, MA **Email**: zach rivers@mac.com **Phone:** 404-405-9296

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

Peer Supporter: Lauren Simon City: Millis, MA Email: <a href="mailto:rev.riggs@gmail.com">rev.riggs@gmail.com</a> Phone: 618-365-4984

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

Massachusetts Support Group for PSP/CBD/MSA care partners

**Location:** https://us02web.zoom.us/meeting/register/tZcudumrrTMtHt18pczS51WW35TWxr4mJKaX

*Meeting Time:* 4<sup>th</sup> Tuesday of every month from 7:00-8:00pm ET *Facilitator:* Tom Loewald, thomas.loewald@gmail.com, 508-446-1920

# **New Jersey**

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

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

**Peer Supporter:** Erin Buterick **City:** Tuckerton, NJ *Email*: ebuterick@gmail.com *Phone*: 609-713-8337

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

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

*Email*: advancedstagespsp@gmail.com **Experience:** Cared for a parent with PSP

**Peer Supporter:** June Kestenbaum **City:** Moorestown, NJ Email: jkestenbaumhealth@gmail.com Phone: 609-410-9921

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

**Peer Supporter:** Andreanna Whittle **City: Edison**, NJ

Email: Andreanna. Whittle@anthem.comPhone: 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: amybranch6@gmail.com Phone: 919-614-3285

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

**Peer Supporter:** Jonathan Denby **City:** New York, NY

*Email*: jon@jondenby.com

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

**Peer Supporter:** Paola Mejia **City:** Flushing, NY

Email: paola.mejia6@gmail.com Phone: 347-256-9437

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

**Peer Supporter:** Jordan Reisner **City:** New York, NY Email: jordanreisner@gmail.com Phone: 917-841-3260

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

**Peer Supporter:** Raphael Stern **City:** New York, NY Email: rstern@gmail.com Phone: 917-589-8660

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

**Peer Supporter:** Sarah Weingarten **City:** Forest Hills, NY **Email**: <a href="mailto:sarah.weingarten@gmail.com">sarah.weingarten@gmail.com</a> **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:* 3<sup>rd</sup> 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**: <a href="mailto:shannon.heacock@gmail.com">shannon.heacock@gmail.com</a> **Phone:** 215-260-3413

Experience: Cared for a parent with PSP

Peer Supporter: Susan McLaughlin City: Pittsburgh, PA Email: susan.mclaughlin37@icloud.com Phone: 412-352-9369

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

# Philadelphia Support Group for people with PSP/CBD/MSA/LBD and care partners

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, lauren.zelouf@pennmedicine.upenn.edu, 215-829-

3038

### **Vermont**

Peer Supporter: Janis Appel City: St. Albans, VT Email: jappel1130@gmail.com Phone: 802-527-7398

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

**Peer Supporter:** Mary Ford Clarke **City:** Bennington, VT **Email**: mary.clarke322@gmail.com **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:** <a href="https://uso2web.zoom.us/meeting/register/tZYocu-qqjwpHNTKmoFxpKt7LGigfDAry23Q">https://uso2web.zoom.us/meeting/register/tZYocu-qqjwpHNTKmoFxpKt7LGigfDAry23Q</a> **Meeting Time:** 3rd Saturday of each month from 2:00p-4:00pm ET **Facilitator:** Kristen Strader, <a href="mailto:strader.kristen@gmail.com">strader.kristen@gmail.com</a>