

# **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="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

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, aleinixon@comcast.net, 860-307-6862

#### 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 PSP/CBD/MSA patients & care partners

Location: <a href="https://uso2web.zoom.us/meeting/register/tZMvcOytqDIsGNUZ6I2SaynOuWfc26UqdwS">https://uso2web.zoom.us/meeting/register/tZMvcOytqDIsGNUZ6I2SaynOuWfc26UqdwS</a>

**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:* 4<sup>th</sup> Monday of the month from 12:30-1:30pm ET

Facilitator: Sarah Phelan, MS, sphelan2@jhmi.edu

#### Massachusetts

**Peer Supporter:** Kathryn Buckley **City:** Northbridge, MA **Email**: katbuckley31@aol.com **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**: thomas.loewald@gmail.com **Phone:** 508-446-1920

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

Peer Supporter: Rev. Lee Riggs City: Natick, MA Email: <a href="mailto:rev.riggs@gmail.com">rev.riggs@gmail.com</a> 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: rev.riggs@gmail.com Phone: 618-365-4984

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

Massachusetts Support Group for PSP/CBD/MSA care partners *Location:* 

*Meeting Time:* 3<sup>rd</sup> Wednesday of every month from 7:00-8:00pm ET *Facilitator:* Tom Loewald, <a href="mailto:thomas.loewald@gmail.com">thomas.loewald@gmail.com</a>, 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: Steve Garcia City: Ringwood, NJ

Email: 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 **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**: <a href="mailto:amybranch6@gmail.com">amybranch6@gmail.com</a> **Phone:** 919-614-3285

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

**Peer Supporter:** Kara Holisher **City:** Plainview, NY **Email**: kbhx2@optonline.net **Phone:** 516-884-2601

**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:** <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**: 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

# Albany Support Group for PSP/CBD/MSA patients & care partners Location/Meeting Time: Contact facilitator for location and meeting time

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

### **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 PSP/CBD/MSA/LBD patients & care

partners

**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@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

 $\textbf{\textit{Location:}} \ \underline{\text{https://uso2web.zoom.us/meeting/register/tZYocu-qqjwpHNTKmoFxpKt7LGigfDAry23Q}}$ 

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

Facilitator: Kristen Weidner, weidner.kristen@gmail.com