From the President

In this issue of CurePSP Connection, we celebrate the dedicated volunteers who make up the foundation of our organization. These are the energetic and capable people who head support groups, provide online and telephone support, distribute our literature, put on fundraising events, and generally support our cause. Most of our volunteers have had a direct connection with PSP or a related disease, so they are especially valuable in empathizing with the newly diagnosed or with those who have recently lost a loved one.

CurePSP has a small staff (nine people, full- and part-time), so we depend on volunteers to make the impact that we do. In this issue, we recognize our support group leaders and peer supporters, who help people who are unable to attend in-person support groups. These dedicated folks provide a vital lifeline for those struggling with the devastation of prime of life neurodegeneration. If you are interested in becoming a volunteer supporter, I urge you to contact Joanna Teters at teters@curepsp.org.

But our volunteer support doesn’t stop there. In this issue, we also recognize volunteer events that play a vital role in helping us raise funds to support our programs, education, and research. Sundaes to Stop PSP, Ken’s Ride, and the Szczerba golf event are three of the many created each year to recognize loved ones and support CurePSP. Events are gratifying in several ways: they raise money for the cause; they recognize the wonderful life of a loved one; they connect you with old friends and new people; and they’re just darned fun! If you would like to create an event, please contact Jaclyn Zendrian at zendrian@curepsp.org. She and our team can help you every step of the way.

Finally, we have expanded our library of informational literature. Working with CurePSP consultant Diane Breslow, LCSW, we have added brochures on several important topics, including palliative hospice care and advance healthcare planning. And we are proud to have just published our disease summaries and our allied health services brochure in Spanish, recognizing the widespread use of that language in the Americas. This was accomplished thanks to the support of Henry Cisneros, former mayor of San Antonio and Housing and Urban Development (HUD) Secretary under President Clinton. The project is in memory of his sister, Pauline Cisneros Polette, who passed away from PSP.

To you, our supporters, and all of our volunteers, I offer my profound thanks for your efforts.

Because of you, we have hope!

With gratitude,

Dave

David Kemp | 802-734-1185 | kemp@curepsp.org
From the CurePSP Patient and Carepartner Advocacy Committee (PCAC)

Each season brings a new beginning, new possibilities, and new reasons to hope, and those of us at CurePSP look forward to the many challenges and goals that lie ahead. Our mission remains the same: to provide education and support for patients, families, and carepartners who are affected by devastating prime of life neurodegenerative diseases. Our many constituents depend on us to keep them updated on the advances in care, caregiving, and family education, and to work with healthcare professionals to enhance public awareness of these diseases.

Our Patient and Carepartner Advocacy Committee (PCAC) is comprised of ten volunteers and two CurePSP staff members. These volunteers, who are lifelines to the many constituents that we serve, are highly trained in various professions and possess both the experience and credentials to serve. Caregivers who have volunteered their time and experience also share their input and help spearhead projects relating to the caregiver journey.

Over the past six months, the PCAC has been creating new and updated resources and programs, described below. Working with the CurePSP staff and consultant Diane Breslow, LCSW, the PCAC has revised the CurePSP Guidebook, which will be published soon. We are also currently working with Dr. Lawrence Golbe to create a new pamphlet, “Understanding the Use of Psychotropic Medications with Neurodegenerative Diseases Such as PSP, MSA, and CBD,” as well as a directory of psychiatrists versed in PSP and neurodegeneration.

In addition, we have created new informational pamphlets for both caregivers and patient education that cover such topics as “Understanding Levels of Home and Community-Based Services and Residential Care,” “Understanding Palliative and Hospice Care,” “Advanced Healthcare Planning,” and for those who have suffered loss, “Facing Loss and the End of Your Caregiver Role.” These pamphlets are available now and accessible online at CurePSP.org and in print, on request.

Over the next several months we expect to complete several caregiver tools that will assist you in navigating your loved one’s care. One of these is the CurePSP Caregiver Binder, which will help simplify logging and storing pertinent information relating to the patient’s diagnosis, symptoms, insurance, financials, and agreed directives. The forms can be organized either electronically or printed for those who may need them, such as EMTs, emergency rooms, physician offices, caregivers, nursing homes, rehab centers, home health aides, and hospice.

Many caregivers who have suffered a loss have asked for guidance, tools, and resources to help them through their grieving process. In response to this need, CurePSP now has an online Bereavement Support Group led by two volunteer professionals, Elaine Book, BSW, MSW, and Lissa Kapust, LICSW. If you are interested in participating in this group, please access more information on our website.

This month, our newsletter also recognizes and honors the following volunteers who serve our organization as Support Group Facilitators (SGF). They dedicate their time to embrace patients who have been diagnosed with PSP, CBD, MSA, or other rare neurodegenerative diseases, and their caregivers. Presently, we have 66 support groups nationwide and four internationally. This year alone, we have established six more support groups in response to our families in need. Most of our SGFs were once caregivers themselves and know how difficult the journey is for the patients, caregivers, and their families. We cannot thank them enough for their unrelenting dedication and compassionate support.
Support Group Leaders

**In-Person Support Group Leaders**

Ann Ludwig - Tempe, AZ  
Randi Haley - Little Rock, AR  
Don Perdue - Irvine, CA  
Arik Johnson - Los Angeles, CA  
Robin Riddle - San Mateo, CA  
Ed Fargusson - Sacramento, CA  
Darlene Gerow - San Diego, CA  
Helenn Franzgrote - Englewood, CO  
Ruth Fletcher-Carter - Johnstown, CO  
Kenneth Knutson - Johnstown, CO  
Bill Johnson - Oakville, CT  
Cindy MacDonald - Naples, FL  
Paul Freeman - Fort Lauderdale, FL  
Christabelle August - Atlanta, GA  
Jackie Green - Woodstock, GA  
Rick Wolter - Woodstock, GA  
David Takehara - Glenview, IL  
Pamela Palmentera - Chicago, IL  
Carol Gebert - Marion, IL  
Tam Smith - Kansas City, KS  
Dan Heins - Louisville, KY  
Janet Edmundson - Falmouth, ME  
Chelsea Ganc - Towson, MD  
Melissa Diggin - Boston, MA  
Mary Meagher - Delton, MI  
Joan Hlas - Minneapolis, MN  
Anita Barni - St. Louis, MO  
Ruth Almen - Las Vegas, NV  
Cyndi Roemer - Summit, NJ  
Myra Hirschhorn - Willingboro, NJ  
Lisa Hughey - Cherry Hill, NJ  
Corlynn Hullfish - Cherry Hill, NJ  
Roxi Padrid - Albuquerque, NM  
Jane Jensen - New York, NY  
Janet Charleston - New York, NY  
Brittany Buza - Albany, NY  
Desmond Bhimull - Melville, NY  
Veronica Cea - Chappaqua, NY  
Caryn Utberg - Chapel Hill, NC  
Jessica Shurer - Chapel Hill, NC  
Jessica Thomas - Greensboro, NC  
Dave Potter - Berea, OH  
Pat Beekman - Berea, OH  
Nancy Montgomery - Columbus, OH  
Vicki Werden - Mason, OH  
Lois Elsbrock - Mason, OH  
Kyle & Cayla Kilby - Tulsa, OK  
Vicki Blacken - Portland, OR  
Josue Etienne - Philadelphia, PA  
Rose Buric - Youngwood, PA  
Dan Palmer - Knoxville, TN  
Judi Nudelman - Austin, TX  
Karen Kennemer - Houston, TX  
Catrina Neiser - Dallas, TX  
Ileen & Bill McFarland - Dallas, TX  
Rosa Gutierrez - El Paso, TX  
Matt McKeon - Fairfax, VA  
Suzanna Eller - Seattle, WA  
Safia Al Sadoon - Washington, DC  
Stephen Goldman - Washington, DC  
Kelly Clapham - Calgary, AB, Canada  
Kimberley Adrovez - Burlington, ON, Canada  
Sandie Jones - Toronto, ON, Canada  
Bob Brett - Surrey, BC, Canada

**Online Support Group Leaders**

Martha Kenney - People with PSP  
Janet Edmundson - Carepartners of People with PSP  
Laurie Huffman - Adult Children of People with PSP  
Karry Forsythe - People with CBD and their Carepartners  
Cathy Chapman & Vera James - People with MSA  
Tom Tait - Carepartners of People with MSA  
Steve Garcia - Carepartners of People with Advanced PSP  
Lissa Kapust & Elaine Book - Bereavement for Carepartners of PSP/MSA/CBD
SUNDAES TO STOP PSP
The amazing members of CurePSP’s Glenview, Illinois, support group came together last June 23 to host their second annual event, Sundaes to Stop PSP. It was an incredible day filled with music, raffles, and endless ice cream. They were able to raise awareness about progressive supranuclear palsy (PSP) and its related prime of life neurodegenerative diseases while having a great time together. With the support of our community, carepartners, family members, and friends, their generous donation to CurePSP is nearly triple from last year! Huge congratulations to this group on its amazing event. We look forward to seeing what next year has in store!
SZCZERBA GOLF EVENT
Andy Szczerba was a husband, father, grandfather, friend, and an avid golfer who loved to make people laugh. In his honor, on September 9, 2019, his family hosted their fourth annual golf tournament following his passing. With over 66 golfers out on the course honoring Andy, it was their biggest group yet. Family and friends enjoyed an amazing day of golf, a putting contest, an auction, raffles, and dinner—making memories together and raising funds for CurePSP.

KEN’S RIDE
In honor of her husband, Ken Appel, Jan Appel hosted the first annual Ken’s Ride along the Missisquoi Valley Rail Trail in Vermont on May 11, 2019. Ken was a passionate cyclist who passed away from progressive supranuclear palsy (PSP) and frontotemporal dementia (FTD). This ride of hope brought families, friends, and carepartners together in celebration of Ken and his fruitful life. His family hopes that this event will continue to raise awareness and begin a community dialogue regarding the impact of these diseases on individuals and their families.
New Resources and Materials Available for You!

New Suite of Educational Brochures by Diane Breslow

Educator, support group leader, consultant, and program development specialist Diane Breslow, MSW, LCSW, has created a suite of educational brochures that are now available for you. Diane Breslow (Illinois Licensed Clinical Social Worker), works with individuals and families. She has a long-standing knowledge of movement disorders as well as expertise in systems theory and has taught psychology and social work at many Chicago-area colleges and universities.

Ms. Breslow received her BA with Honors in psychology from the University of Missouri in Columbia and holds a Master’s degree in social work, with a specialty in family therapy, from the University of Maryland School of Social Work.

Email info@curepsp.org to request your brochures now.

Our Brochures Are Now Available in Spanish!

We are excited to announce the Spanish language version of our brochures, Some Answers: PSP, CBD, MSA and Allied Health. Their production was substantially funded by Henry Cisneros in memory of his sister, Pauline Cisneros Polette. They are available online or in print by request.
We’re on Flickr!

We are excited to announce the new CurePSP Image Library on Flickr! On Flickr, all photography from past events is easily accessible for you to view and share with friends, families, volunteers, and professionals. Images from future events will be added as we receive them. You can also download these images to keep. If you don’t see your event in our library, we would love to hear from you so that we can add them.

www.flickr.com/curepsp

CurePSPTV

CurePSPTV launches this month, highlighting vital information about the CurePSP organization. We want to keep you up-to-date with footage from our yearly family conferences, research updates, family stories, and practical resources that you can use on a daily basis.

Don’t miss out! Subscribe to our YouTube Channel to get notified when new videos are published.

www.psp.org/tv
Upcoming Events

opportunities for learning and support

Parkinson’s IQ + You – Southern California
December 14, 2019
Hilton Anaheim
777 W Convention Way, Anaheim, CA 92802

Parkinson’s IQ + You – Phoenix
January 11, 2020
Arizona Biltmore
2400 E Missouri Ave., Phoenix, AZ 85016

Tau 2020
February 12-13, 2020
Marriott Marquis Washington, DC
901 Massachusetts Ave., NW, Washington, DC 20001

The 17th Annual CurePSP Awareness and Memorial Walk
March 21, 2020 @ 10:30 am – 1:30 pm
Mackle Park
1361 Andalusia Terrace, Marco Island, FL 34145