

CurePSP connection

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From the President

With spring comes hope. The remarkable achievement of scientists in quickly developing vaccines against this deadly disease means that we may be able to return to a life approximating what we knew before COVID-19 by the end of the year. This triumph of science also gives us hope that we will find treatment and cure for the scourge of neurodegeneration. Research into progressive supranuclear palsy (PSP) has become a focus for investigators and pharmaceutical companies. CurePSP is aiding this effort in important ways through direct support of research with its Venture Grants program as well as by helping pharmaceutical companies with clinical trials of drugs.



I am pleased to be able to say that your foundation has succeeded over the past challenging year thanks to your ongoing support. We have strong cash reserves that allow us to implement robust initiatives in patient and family programs, communication and awareness, and research. I am particularly proud of our team, who pivoted quickly more than a year ago to remote work and have maintained their sense of purpose and positive, collaborative spirit throughout. We have learned quickly to use the latest technologies to run events like our recent Neuro2021 International Research Symposium, our gala 30th Anniversary Celebration, and several volunteer fundraising events like the Bonelli Music Bash and the 18th Annual CurePSP Awareness & Memorial Walk at Marco Island, Florida, which is on its way this year to being a record fundraiser thanks to a \$25,000 match from two generous donors.

Our volunteers as well have adapted to this situation by continuing their support groups online. I'd point particularly to our South Florida group run by Cindy MacDonald and her team and our Austin, Texas, group headed by Judi Nudelman. "Supervolunteers" like John Snyder, Al Nixon, James Bernard, Nancy Frehill, Tom Tait, Nancy Montgomery, Jan Appel, Margo Silk, Bill Furlow, and so many more have been essential to our success. Our board of directors have been steadfast in their support; in addition, many are generous in commitment of their time: Bill McFarland as chair, Vice Chair Amy Branch in legal affairs and development, Ileen McFarland as head of our Patient & Carepartner Advocacy Committee, Justin Shea in finance, Everett Cook guiding investments, Maggie Orseth heading strategy, and Andy Maus consulting in HR. And I'd be remiss if I didn't recognize Lawrence I. Golbe, MD, who serves on the board of directors, as head of the foundation's Scientific Advisory Board, and as director of clinical affairs for the foundation. "Dr. Larry's" commitment is amazing as he evaluates research proposals, answers questions from our patients and families, heads our Centers of Care program, conducts Ask the Doctor sessions, and performs other services too numerous to mention.

Certainly, we all have been challenged over the past year, and none more so than our patients and families who already faced the unremitting pain and suffering caused by neurological disease. Our slogan, "Because Hope Matters," has never been more relevant or poignant. We are not through the pandemic yet, but better times lie ahead. Thanks to you, CurePSP is well positioned not just to survive but to thrive.

With gratitude,

David Kemp | 802-734-1185 | kemp@curepsp.org

Quality of life. Quality of care. All in your home.



You've made the decision: You'll care for your loved one with PSP or CBD in the comfort and familiarity of home.

Gregg Felice, LCSW-R, CurePSP volunteer liaison, applauds this decision and suggests that planning start upon diagnosis: "I encourage the patient and family to discuss the various aspects of home care early on, including finances and caregiving responsibilities. These are difficult conversations, but they help manage expectations and get everyone on the same page before a crisis occurs."

Plan early. Take control.

Key players in the planning process include the patient, primary caregiver, family, neurologist, and family physician. An eldercare lawyer can develop a financial strategy to pay for care as a disease progresses and to ensure that the patient receives all eligible benefits and services. Regardless of someone's finances or estate value, a plan protects assets and resources, especially when dealing with the cost of long-term, in-home care.

Build a care team from day one.

Develop a network of trusted experts to help you navigate the complicated clinical and emotional journey of PSP and CBD. Include your neurologist, office social worker, internist, and staff from a local movement disorder clinic. Remember to add family and friends into your plans for errands, meals, and making visits to the ailing person.

Stay safe every day.

Is your home safe enough to provide excellent care for your loved one? And, safe enough for you to deliver the care? Schedule an in-home consultation by an occupational therapist (OT) to find out. The OT will evaluate the eating, sleeping, toileting, and showering areas, and may make recommendations, such as moving a second-floor bedroom to the first floor, bringing in a hospital bed, or installing a walk-in shower. Suggesting innovative assistive devices and gadgets is another area where an OT can help.

Get skilled services at home.

Reach out to your neurologist or visiting nursing association for a clinical assessment of a patient's needs for skilled in-home physical therapy, occupational therapy, and speech therapy. These may be essential services to keep the patient independent and active for as long as possible.

Home care for a spouse or parent with PSP, CBD, or MSA is an optimal choice. These rare diseases require specialized knowledge and clinical care, so plan early and make adjustments as needs dictate.



How three families did it:

Nothing stopped Dan and Kim. Not even PSP.

"I always knew I would care for Kim at home," says Dan Heins. "Kim's comfort was the only thing that mattered. I was lucky enough to work from home and have a caring support network from our church. What I didn't know how to do, I learned."



Kim's constellation of symptoms was complex and included swallowing difficulties, aspiration, and weight loss among others. The couple decided on a PEG feeding tube to provide nourishment and comfort for two years before Kim's passing.

"Even with a feeding tube, Kim and I went on our 18th cruise. PSP was not going to stop us."

What Dan did:

- Brought a hospital bed upstairs next to his bed
- Bought a lift chair recliner to ease movement into and out of the chair
- Trained to insert and care for a Foley catheter
- Learned to use a suction machine for aspiration
- Relied on hospice for seven months to provide palliative services

Never, ever tell Ileen something is impossible.

After her husband Terry's PSP diagnosis and the fog of grief lifted, Ileen McFarland got her ducks in a row. "A care home was never an option," explains Ileen. But the layout of their Annapolis home made it difficult for Ileen to care for Terry. "He was a big guy, maybe 200 pounds, and he could no longer support his body weight," Ileen explains. The clock was ticking.

And then, a solution: After a family discussion, Ileen's brother and sister-in-law encouraged Ileen and Terry to move in with them. Ileen renovated the space they'd be living in and planned for Terry's escalating needs.

"Every day, PSP was stealing a little bit of him. I needed a place where we could still enjoy our life together, and Terry would get the best care—from me."



What Ileen did:

- Created the new space with wider doorways, an open shower, lower sinks
- Installed a swing lift to elevate Terry's power chair into their SUV
- Used mobility discs for wheelchair transfer
- Relied on an Invacare Get-U-Up Hydraulic Stand-Up Lift
- Found a psychologist specializing in end-of-life issues



Julie and Jim power through CBD with strength.

"I'm a big believer in planning," says Julie Pridgen, the primary caregiver for her husband, Jim, who has CBD. "I wanted a motorized wheelchair to give Jim more independence. I also knew that a motorized wheelchair took months to arrive. We filled out the paperwork for it early on in Jim's illness—which made all the difference."

Jim is a big believer in doing everything to fight CBD. He has enrolled in two clinical trials at Johns Hopkins and has planned for a brain donation. Jim and Julie are regular support group attendees. Jim asks, "What Zooms do we have today?" The couple attends CurePSP Patients and Partners together, among others.

Every night, Jim says to Julie, "Thank you for everything you did for me today." Julie responds, "You make it easy."

What Julie and Jim do:

- Installed a stairlift
- Obtained a motorized wheelchair
- Plan to turn the first-floor office into a private space for Jim
- Request all the home OT, PT, and speech therapy for which Jim is eligible
- Download a disease-specific brochure from CurePSP.org to bring to Jim's doctor visits

Digital brilliance. Social media savvy.

“CurePSP has always been on the digital forefront,” says **Sabrina Da Rocha**, director of marketing and communications. “When COVID-19 hit and in-person communication stopped, digital and social media became the only way CurePSP could communicate directly with patients, family, carepartners, scientists, and volunteers—and they could reach out to us.” It was a heavy lift for Sabrina and **Denise Forero**, marketing and social media manager—with all communications resting on their shoulders.

Sleepless nights. Game-changing results.

Sabrina and Denise focused on building new audiences and innovating ways to disseminate information. The team expanded CurePSP’s social media presence on Facebook, Instagram, Flickr, and Twitter; created connectivity between platforms; enhanced the CurePSPTV YouTube channel; and strategically engaged the millennial audience—83 million new potential donors who represent the future of giving. This strategic move paid off on Giving Tuesday, raising a record \$74,000 that went directly to strengthen CurePSP’s mission.



• **Sabrina Da Rocha**
• *Director of Marketing*
• *and Communications*

• **Denise Forero**
• *Marketing and Social*
• *Media Manager*

Heal at home with Wellness Wednesday.

Denise is acutely aware of the importance of both physical and emotional health for patients, carepartners, and families dealing with neurodegeneration. She created Wellness Wednesday: a 30-minute video episode led by professionals to inspire people at home, featuring mind and body awareness and exercises.

*Tune into CurePSPTV at
youtube.com/curepsp*



A test for PSP and CBD?

Amanda Woerman, PhD, will ace it.

Ask Amanda Woerman, PhD, what gets her out of bed each morning,

and almost instantly, she responds, “The hunt for a diagnostic tool to accurately diagnose PSP from CBD—the basis for all drug development and potential cures. Early on, patients with either PSP or CBD have physical and behavioral symptoms that are quite similar and are often misdiagnosed—for years. Though both are tau-based neurodegenerative conditions, at the molecular level they are unique and separate diseases.

“We must know which disease we’re dealing with to develop drugs to fix specific biochemical or biological errors,” explains Woerman. An all or nothing proposition.



The CurePSP Venture Grant: Disease-Specific Diagnostics

Woerman’s research builds on the work of Sjors Scheres and Michel Goedert, who demonstrated that in CBD, Alzheimer’s disease, and Pick’s disease, the tau protein misfolds into a different shape for each. It is likely that in PSP, tau also misfolds into a unique structure, and as in all proteins, its structure dictates biochemical and biological activity. Dr. Woerman can use this knowledge to develop disease-specific diagnostics and isolate tau protein characteristics in PSP and CBD disease samples—laying the groundwork for diagnostics to support a personalized approach to treating the two diseases.

Science tells us that neurodegenerative diseases such as PSP and CBD begin to develop 20 years before symptoms appear. Early accurate testing and drugs to stop the damage when the condition is in a nascent stage is the great hope for people at risk.

“I catch my breath when a patient suffering from a neurodegenerative disorder can’t get a diagnosis,” says Dr. Woerman. “Without one, they may miss out on certain healthcare benefits and, as an added burden, must live with the uncertainty of not knowing what they have.”

“Although we don’t yet know the original trigger that causes tau to misfold and malevolently inhabit the brain, we’re making great strides toward developing a diagnostic test, which neurologists can use to provide a consistent and accurate diagnosis of PSP or CBD.”

Amanda Woerman, PhD

Woerman Lab,
University of Massachusetts,
Amherst, MA

CurePSP Venture Grant:
Investigating PSP and CBD
Tau Strain Biology to Support
Novel Diagnostic Development

A crisis with a silver lining

For thousands of families suffering from neurodegeneration, in-person support groups are an anchor and a safe space. In March 2020, this support system crashed as COVID-19 left patients, families, and caregivers stranded. Something had to be done and fast.

Joanna Teters, CurePSP community outreach and resource manager; **Gregg Felice**, CurePSP volunteer liaison; and **Ileen McFarland**, CurePSP board member, support group leader, and PCA committee chair, pounced on the challenge.

A monumental regrouping

With organization and speed, the team transitioned many of CurePSP's more than 60 in-person support groups to virtual platforms—a Zoom-driven powerhouse. They created six new national online groups, adding to the eight already operational, retrained peer support group leaders, recruited new leaders, and educated patients and families about the Zoom platform.



Joanna Teters
Community Outreach
and Resource Manager

A crisis with a silver lining

“CurePSP's new online support group network connects patients, families, and caregivers who never might have met—forging bonds and friendships across the country—a blessing—in the disguise of a crisis,” says Joanna.

Nancy Montgomery jumping in to help

Nancy, an experienced support group leader whose husband, Jerry, has PSP, teamed up with Jan Appel, a seasoned group leader who lost her husband, Ken, to PSP. Together they formed an online group for women whose loved ones have PSP, CBD, or MSA. The group quickly expanded to twice-monthly meetings where new friends and new ideas flourish.

More silver linings

The work of CurePSP goes on, no matter what. To reinforce relationships with peer support leaders and volunteers, Gregg and Joanna created Office Hours, a once-a-month Zoom get-together where peer support leaders, volunteers, board members, and staff discuss ideas to empower the passionate CurePSP volunteer network.

Those who have lost a loved one to neurodegeneration need a private, compassionate place to grieve. Gregg created and facilitates an online group called **After the Loss: A Bereavement Support Group for Carepartners**.

Joanna says, “I'm proud of our ability to bring patients and families vital resources for each step of the journey: from pre-diagnosis through bereavement and brain donation. The voice of the patient must be heard and their needs met.”



A standing ovation for everyone

CurePSP's 30th Anniversary Celebration raised \$50,000.

On December 7, 2020, we made CurePSP history, bringing together a virtual global audience of more than 572 people to celebrate CurePSP's 30-year legacy of changing lives. Along the way, our donors, leaders, supporters, patients, families, and volunteers raised close to \$50,000.

Congratulations to **Jaclyn Zendrian**, vice president – events, and **Kelsey Woods**, events and community outreach coordinator, who transformed our 30th Anniversary Celebration from an in-person gala to a dazzling interactive digital experience that brought together a global community of PSP, CBD, and MSA families. Double the sentiment for **Rich Spain**, **Amy Branch**, **Ileen McFarland**, and **Larry Levien**.



• **Jaclyn Zendrian**
• Vice President – Events



Lots of compliments for **Sabrina Da Rocha**, director of marketing and communications; **Denise Forero**, marketing and social media manager; and **Christine Cassimatis**, events coordinator. Their teamwork and digital brilliance made the evening's events run seamlessly.

Many special thanks to **Tony Dokoupil**, our master of ceremonies and co-host of *CBS This Morning*, who flawlessly hosted this dynamic virtual celebration.

Applause, applause for **Acute Inflections**, a sophisticated duo who brought the evening together musically and magically.

Heartfelt appreciation goes to our wonderful patients, families, and caregivers whose pictures and stories brought our mission to life.

Kudos to our Silent Auction participants. Your support raised \$5,479 to fight PSP and related disorders.

Honors, awards, and recognition for the leaders, clinicians, and scientists whose 30 years of scientific achievements have moved us that much closer to a cure—the great hope of everyone at CurePSP and the neurodegeneration community.

CurePSP®
UNLOCKING THE SECRETS OF BRAIN DISEASE™

30th
Anniversary



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CurePSP Resources for COVID-19 Crisis

Throughout this coronavirus crisis, CurePSP continues to remain committed to offering as many opportunities to connect with others in your community who are facing similar hardships, as well as ways to speak with peer supporters, connect on our Smart Patients Forum, and attend an online teleconference support group or one of our new Zoom webinars.

Please find our full network of resources for you and your loved ones during the coronavirus crisis here:

www.psp.org/covidresources

