From the President

As this newsletter was in its final stages of production, the coronavirus crisis broke. My original letter was one of hope and optimism—and this letter will be that as well. The selfless dedication of healthcare workers, first responders, workers providing essential services, and average citizens banding together to help others (making face masks, bringing food to people restricted to their homes, celebrating milestones with appropriate “social distancing”—we’ve all seen the stories) is inspirational and shows the true potential of humanity.

Here at CurePSP, we quickly assessed the situation and directed our team to work from home. We are providing essential services and are always available by phone and email. There may be some understandable delays in the distribution of print materials and mail. Most of the information available in print is also available on our website.

As you would expect, foundation and volunteer events have been canceled or postponed. Understandably, our 66 (and growing) volunteer support groups are not meeting in person, but our more than 100 peer supporters remain available to provide assistance online or by telephone. This crisis is giving us an opportunity to look at using technology to provide virtual access for support groups and even creating national groups that address specific interests, disease stages, or diseases.

Meanwhile, CurePSP maintains a strong commitment to what we call our “culture of caring.” This is our mission of helping patients, families, and caregivers get through what is a difficult journey even in the best of times and an even greater challenge these days. At the same time, we are supporting research through our Venture Grants program and educating healthcare professionals and creating broad awareness of prime of life neurodegeneration through print, broadcast, and social media channels.

We have put together a tremendously strong team who are using this time to generate new ideas and plan for the future. We will emerge from this crisis more prepared than ever to carry forward our work.

I want to take this opportunity to thank you for your support and send best wishes to you and your family. Together, we will get through this crisis and emerge better and stronger.

With gratitude.

David Kemp | 802-734-1185 | kemp@curepsp.org
It is my pleasure to report, on behalf of the Board, that CurePSP has made significant progress over the past six months. We are strategically and financially positioned for ongoing success in 2020 and beyond. Our mission is laser-focused: To fight, cure, and eradicate the devastation of PSP while we support patients, families, and carepartners through the most challenging circumstances imaginable. Our progress is the result of an extraordinary team effort under the excellent leadership of David Kemp—and the passionate commitment of our staff, volunteers, donors, and Board.

A critical aspect of strengthening CurePSP is the ongoing development of a top-tier Board. To that end, the Board has elected three new members who add a wealth of knowledge and know-how in fulfilling our purpose-driven mission. Joining us is Brent Bluett, DO, clinical assistant professor of neurology and neurological sciences at the Stanford Medical School. Dr. Bluett is a practicing neurologist with expertise in PSP and a heartfelt passion for patient care. Andy Maus, a senior human resources executive with a Fortune 500 company primarily serving the healthcare industry, has been elected to our Board. Like so many of our Board members, Andy has family members with PSP. Jessica Shurer, MSW, LCSW, is a practicing licensed clinical social worker who serves at the Movement Disorders Center at the University of North Carolina, Chapel Hill, CurePSP Center of Care. Jessica’s passion for patients and families has led her to facilitate multiple community support groups for Parkinson’s and atypical Parkinsonism diagnoses. Jessica coordinates specialty interdisciplinary clinics, organizes educational programs and focus groups, and provides training for allied health clinicians such as physical therapists, occupational therapists, and speech language therapists.

Bringing on the best and brightest talent is foundational in moving our mission forward. In addition to our three new Board members, we have recently added two new staff members. Gregg Felice, LCSW-R, a practicing licensed clinical social worker, was appointed as Director-Patient & Carepartner Advocacy. Gregg’s knowledge and ability will strengthen, train, and expand the foundation’s support network leaders, patients, and health professionals. Mr. Felice will work with CurePSP’s Centers of Care and develop and cultivate partnerships with industry, academia, foundations, and other nonprofits in the neuroscience space.

I am thrilled to announce that CurePSP has appointed Kristophe J. Diaz, PhD, as Vice President-Scientific Affairs. Dr. Diaz will direct the foundation’s Venture Grants program, which provides research grants for frontotemporal disorders, including PSP. Dr. Diaz will also assist in identifying new and promising research funding opportunities, expand our growing international partnerships with pharmaceutical and biotech leaders at the frontiers of neurological research, and help to coordinate our activities with government agencies and foundations.

Many heartfelt thanks go to Dr. Larry Golbe, who served as our interim Vice President-Scientific Affairs and whose world-class PSP expertise provided a strong bridge until the role was filled.

As always, efficiency and financial stability are hallmarks of all our endeavors. We are very proud to report that our financial statements have just been audited (as happens every year), and we received a clean, unmodified opinion from our audit firm—a first-class rating. Our program spending ratio is a superior 75%, meaning that for every dollar spent, 75 cents went toward programs and services. Our liquidity is very strong, with adequate financial reserves to continue funding our all-important Venture Grants and genomic research. We will continue to take steps to maximize efficiency, act frugally, and streamline operations.

The Board’s vision is crystal clear: To win the battle against all prime of life diseases, bringing hope and support to all those who suffer with them.
Every dollar counts toward a cure!

Make a big difference in the fight against prime of life diseases like PSP. Here are some ways you can do it.

Host an event to remember!
Want to get involved with CurePSP but are not sure what to do? Hosting an event is a great way to raise awareness and funds to fight prime of life neurodegenerative diseases. And, you won’t have to do it alone. The CurePSP staff are event pros who help plan, coordinate, and stage fundraisers that bring people together to fight diseases like PSP and CBD.

You might hold a mini or full walkathon, golf tournament, wine tasting, or silent auction. If you can dream it, you can do it, and we will help. Email our VP of Events, Jaclyn Zendrian, at zendrian@curepsp.org to get your party started.

Special thanks to CurePSP supporter, Kim Orendor, for creating a birthday fundraiser to honor her dad who is battling PSP. Her family and friends helped to raise over $550!

Michelle’s Mixer rocked! In honor of Michelle Heacock, family and friends celebrated, connected, and danced the night away—raising $11,000 in its inaugural year.

In 2019, our volunteer events raised CurePSP’s profile, and the funds to move research and community programs, ahead.

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www.shopcurepsp.com
Peer Supporter Niti Vaidya

*Why I do it: It gives my life a real purpose*

**Pradeep Vaidya was an independent and successful man,** accomplished in business, a devoted husband, and a father who adored his daughters—his two princesses. “My father was someone who faced everything in life with hope and determination,” says daughter Niti.

When symptoms first appeared, Mr. Vaidya was diagnosed, like so many others, with Parkinson’s. For a decade, he suffered from “Parkinson’s.” After that, it was “MSA,” and finally, the real culprit—PSP. Throughout his heartbreaking journey, Niti managed her father’s complex medical care.

“I had so many questions right out of the gate, and in Mumbai, our home, few resources exist for a rare disease like PSP. My mother, sister, and I were desperate for anything that would stop the downward spiral. We fought for his well-being every step along the way—even in the ICU,” says Niti.

It was a long and courageous battle, one Pradeep Vaidya lost in July 2017, surrounded by his loving family—including his siblings, nieces, and nephews. It was a tragedy that propelled Niti into a new chapter of her life.

**Why did you become a peer supporter?**

“Throughout my father’s illness, I was grieving but was so immersed in caring for him that I didn’t have time to think. After he died, and the flurry of activity halted, I was adrift and needed a purpose.”

“I found CurePSP online, contacted them, and connected to other PSP families in India. Over the past few years, I have worked with at least 20 to 25 families. Recently, Ashok Adusumilli, whose father lives in India, is one of the individuals with whom I am in constant contact.”

“My father’s illness was the saddest experience of my life, but one that has taught me to be even stronger, more empathetic, and resourceful in the face of overwhelming odds. It continues to be a transformative experience,” says Niti.

**Ashok Adusumilli reached out. Niti was there.**

Ashok Adusumilli and his wife, an internist, live in Kansas City, USA. But his father, Sambasiva Rao Adusumilli, who has PSP, lives worlds away in Hyderabad, India. Ashok is actively involved in his father’s care and regularly travels to his parents’ home—a very long haul.
“My father’s problems started in 2013 when my wife, mother, and sisters noticed that something was wrong with his gait,” says Ashok. Initially, Mr. Adusumilli was diagnosed with Parkinson’s, but by 2014, he was diagnosed with PSP and told not to drive—a crushing blow.

“Throughout his life, my father was one you could go to for help. It seemed unimaginable that this was the same person, who at age 14 lost his father and started supporting his mother and younger brother. My father was the success story who built businesses and took care of everyone, including taking excellent care of himself with a healthy diet, yoga, and brisk walking,” explains Ashok.

**Why did you contact CurePSP?**

“By 2016, Dad had developed double vision, his short-term memory was failing, and he was using a walker—barely. I was going back and forth to India, staying for weeks at a time. But the disease was relentless. Intellectually, I understood this is what happens. But in the day-to-day, I still needed some semblance of control and some hope. I contacted CurePSP, and soon after, Niti responded,” says Ashok.

“Niti is supportive, kind, and always present. Because she lives in India, Niti can point us to the right care and support services. She provides insight from her father’s experience: Coping with issues around eating and swallowing, weakness and movement, and of course, the deeply emotional side of PSP. There is something about talking with another ‘traveler’ that adds nuance to what one is experiencing, especially as my father is in such an advanced stage of the disease.”

Ashok notes that at the right time, he will step into the role of a peer supporter to provide solace and support. But for right now, his heart and mind are somewhere else.

**Peer Supporter Paul Strandquist**

**Why I do it: I need to give back**

*Five years ago, Paul Strandquist’s beloved wife, Jojo, lost her battle with PSP.*

“No training prepares you to care for someone with PSP,” says Paul. “You’re living in a tornado zone. Symptoms come out of left field just when you think you’ve reached a plateau.”

About a year after Jojo passed away, Paul knew it was time to reach out and help someone else weather this storm. He contacted CurePSP and was put in touch with an individual whose partner had PSP, the first of several people Paul has supported.

“My motto is to follow someone’s lead and respect their boundaries. Some people prefer to communicate regularly, others not. My job is provide a safe space where a PSP patient or caregiver finds insight and comfort,” says Paul.
Peer Supporter Al Nixon

Why I do it: To honor Eileen’s memory and courage

“Dad, something’s up with Mom—she’s not acting right.”
In the fall of 2011, Al Nixon’s daughters approached him with the unsettling observation that Eileen Nixon’s mannerisms were off in an unnamable but frightening way.

Sadly, the girls were right. In 2013, Eileen Nixon received a diagnosis of PSP. Eileen: Al’s beloved wife. Mother to four accomplished daughters. Operating room nurse. Faithful friend. Good skier. Downward dog expert. And brave beyond belief.

Despite the bad news, Eileen was determined to make a difference. She enrolled in clinical trials that required arduous travel, lumbar punctures, MRIs, CAT scans, and extensive questionnaires. She planned to donate her brain for research—and did.

The whole family joined in the fight. As Eileen’s symptoms exacerbated, Al was up most nights helping her. “I was burning out as a caregiver,” says Al. His daughters insisted that he get help—for himself. Eileen’s neurologist directed Al to CurePSP.

There, Al met a peer supporter who had lost a spouse to PSP. “At the beginning, we all met in person, including Eileen,” says Al. Our peer supporter kept us ahead of the curve—explaining symptoms that might manifest and practical advice for controlling them.”

In November of 2016, just three years after Eileen’s diagnosis, PSP took its final toll. At age 72, Al’s wife of 52 years succumbed to it.

Al was devastated. Despite his anguish, he knew he had to do something. “I wanted to honor Eileen’s memory and the courageous way she confronted this terrible illness. There is a saying in life, ‘You learn, you earn, and then you return.’ Because of the help and kindness I received from my peer supporter, I wanted to do this for others.”

“My role is to act as a sounding board for someone’s questions and concerns. I let people know that they are not alone on this very lonely and difficult journey—and I am grateful to do it.”
CurePSP unites a global community of peer support for PSP patients, families, and carepartners. CurePSP is the world’s leading source of information on prime of life neurodegenerative diseases such as PSP, CBD, and MSA. Here, families, caregivers, and carepartners find the guidance, emotional support, tools, and resources to deal with these debilitating conditions, all under one roof.

Our robust support network includes in-person support groups, online support groups, and one-on-one conversations by phone or email.

Peer Supporters: More than 100 people throughout the world
Throughout the US, Canada, and India, CurePSP has more than 100 peer supporters ready to help by phone, in person, or by email. CurePSP support programs are facilitated by dedicated and trained volunteers, most with first-hand experience of these diseases.

Online Support Groups: Help from anywhere on earth
For those who can’t travel or wish to receive support from home, CurePSP offers 12 online support groups on specific topics. Find details about these groups at www.psp.org/ineedsupport.

Topics include:
- After the Loss: Bereavement Support Group for PSP/MSA/CBD Caregivers
- People with PSP
- Carepartners of People with PSP
- Adult Children of People with PSP
- Carepartners Dealing with Advanced PSP
- People with CBD and Their Carepartners
- People with MSA
- Carepartners of People with MSA

In-person Support Groups: 66 around the US
Meet with people who share your trials and triumphs while gaining disease management techniques. Joy Kirby’s husband, Joey, has multiple system atrophy (MSA). She says of her support group experience, “It’s a healthy way to deal with a tough situation—learning what others are doing and how they cope.”

Smart Patients Forum: A private and safe space online
CurePSP partners with Smart Patients to provide an online community where patients, caregivers, family members, and loved ones can ask questions, give advice, and connect with others. Find the Forum at: www.smartpatients.com/partners/curepsp

“My mother did not die in vain.”

“When my mother, Jacqueline, was diagnosed with corticobasal degeneration (CBD) in 2013, I was terrified for her. What was this disease? How would we care for her?” says Susan Thibeault.

After much searching, Susan finally found a nursing home where the staff had experience with CBD. “Mom had been a nurse and knew the facilities in our region. The disease was so aggressive that by late 2014, Mom lost the ability to speak,” says Susan.

“After my mother died in 2016, I wanted to help others in this situation,” says Susan. She reached out to Joanna Teters at CurePSP and participated in the online Smart Patients Forum. Susan then became a peer supporter by phone and is completing her online training to become a support group leader.

“I explain to my kids that Grandma’s suffering is over,” says Susan. “But her legacy lives on in my work with CurePSP.”
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