

CurePSP connection

ISSUE 36 | SUMMER 2022

I am happy to report that CurePSP has made robust progress over the past six months. Our accomplishments result from a creative and committed team, a deeply engaged board, thousands of generous donors, and hundreds of devoted volunteers. These efforts have brought new hope, resources, and resilience to individuals, families, and carepartners living with PSP, CBD, and MSA.



It is a defining moment for CurePSP as we strengthen our position as the Catalyst for a Cure, partnering with an international alliance of stakeholders from academia and the biopharmaceutical industry. We need to create new pathways where multidisciplinary teams share data and create new ways of understanding neurodegeneration—an infrastructure of knowledge that can accelerate the time to a cure. We can't accomplish these goals alone, and I'm working hard to make sure partners of all sizes and capabilities join the conversation for our path forward.

CurePSP serves on an invitation-only working group with major pharmaceutical organizations and other nonprofits involved in neuroscience research. The objective of this alliance is to advocate for the creation of a federally funded National Center of Excellence in Neuroscience within the Food and Drug Administration (FDA). This establishment would ensure that the right support and subject matter experts assist the FDA in advancing new treatments and therapies for brain diseases including PSP, CBD, and MSA.

Our grassroots efforts are as essential as our global ones. This year, the 19th Annual CurePSP Awareness and Memorial Walk broke new ground in community engagement, awareness, and philanthropy by bringing 200 supporters together and raising close to \$250,000 to support the work of Dr. Sally Temple who leads a great research center. In addition, through CurePSP Patient and Carepartner Advocacy, a new support group called Flying Solo fulfilled the unmet needs of people with neurodegeneration who live independently.

CurePSP Venture Grants will soon evolve into CurePSP Pipeline and Pathway Grants, awarded to investigators whose bench-to-bedside translational research promises the potential for novel drug development and a possible cure.

We continue to invigorate and expand CurePSP's Centers of Care. This network of 28 academic and regional hospitals in the U.S. and Canada give patients access to advanced, integrated diagnostic, therapeutic, and rehabilitative care, including potentially groundbreaking clinical trials.

Our embedded values of Care, Cure, and Consciousness are touchstones that align our ideas and activities with our vision. We are ever curious and aspire to seek the edge of discovery, the tipping point where a cure is found. There's been real and tremendous progress in the past ten years. Technology has rapidly advanced and allows us to see molecules and proteins in ways we could not before. These developments help us understand what causes neurodegeneration in PSP, CBD, and MSA and help us advance new paths to a cure.

As CurePSP starts a new chapter, we invite you along to share the challenges and triumphs of putting PSP, CBD, and MSA in the rearview mirror. Visit our website, write to our team, and witness the careful but assertive new direction so that we can make a difference for you, your families, and the community living with neurodegeneration.

Our name communicates our greatest hope: Cure PSP. Once and for all it touches.

With gratitude,

Kristophe Diaz, PhD

Executive Director and Chief Science Officer
CurePSP, Inc.



Centers of Care & Con

Jessica Shurer, MSW, LCSW, director, clinical affairs and advocacy at CurePSP, talks about her inspiration, dedication, and grand hope for the future.

Q: What inspires your work as the CurePSP director of clinical affairs and advocacy?

My roots as a social worker are at the heart of everything I do—a passion for social justice, advocacy, and the value of each individual’s experiences and strengths. Every person and family living with PSP, CBD, and MSA has unique needs. Ensuring they have the tools, education, and support to get the right care and to make the right decisions for themselves along their journey drives and fulfills me. I want to create an environment where people feel empowered to self-advocate and know how to define and manage the quality of their lives.

Q. What role do the CurePSP Centers of Care play?

Our Centers of Care are a network of specialized medical institutions that act as hubs of expert therapeutic and treatment options, comprehensive support services, and clinical research for PSP, CBD, and MSA. Currently, there are 26 CurePSP Centers of Care in the U.S. and two in Canada. When I first joined the staff at CurePSP in October 2021, I spent the first few months meeting one on one with the directors from all 28 Centers to learn more about their challenges, teams, interests, and goals, as a step in strengthening CurePSP’s connection with the Centers and invigorating the growth of programs and advanced care offered through this network.

Recently, all the Centers agreed to a shared set of bylaws outlining CurePSP’s expectations for excellence in care and outreach as a Center of Care, as we work to further formalize this foundational program. In April, the Centers completed an annual report to capture more information on who they serve and the work they do, and we hosted a virtual gathering of the Centers, focusing on patient-centered care practices and next steps for collaboration within the network. The goal is to expand the CurePSP Centers of Care program and use it to both enhance the standard of care required to meet the complex needs of the PSP, CBD, and MSA community and to foster opportunities for multi-center research efforts.

Q. Describe a “grand hope” you have for patients.

At the top of my “hope list” is helping patients get a timely and accurate diagnosis of PSP, CBD, or MSA. Right now, it takes an average of about two years to obtain a correct clinical diagnosis of PSP, CBD, or MSA, and it’s an emotionally and logistically taxing journey to arrive there. Earlier diagnoses enable patients and families to access therapeutic interventions, opportunities to participate in clinical trials, and the necessary resources earlier in their disease. The collaborative efforts of the Centers of Care, including the data, connection, and insights shared between the top minds in this field, play a big role in that. But ultimately, my hope is for people living with PSP, CBD, and MSA to have the best possible quality of life and to feel supported and cared for, from the time of diagnosis and across all stages of the disease.

Connections of Hope

Q. How do you empower patients at the grassroots level?

Nothing is more powerful than a community of patients, families, and carepartners sharing their experiences and ideas—something as practical as a patient suggesting a cool new type of cup to help someone drink more independently, as heartfelt as a family carepartner’s excitement when learning about CurePSP’s respite grant program, or as encouraging as a grandchild reaching out to us in an effort to meet other young people impacted by these diagnoses. Hope is alive when someone says to you, “I get where you are. I’m there, too. And here’s something that has been a source of support for me in my journey, that may also be helpful for you.” I want CurePSP to be a touchstone of this hope for our community and to create the opportunities for these connections and empowerment.



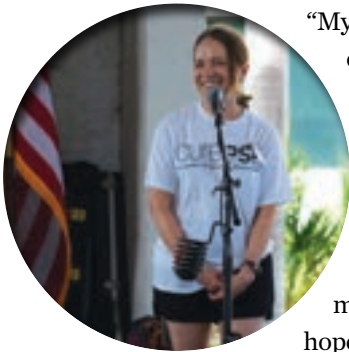
CurePSP has extensive resources, including support groups, education programs, and a vast library of print, online, and video content. One online resource we offer is the recently relaunched quarterly Ask the Expert webinar series, showcasing a multidisciplinary approach of neurologists, social workers, rehabilitation therapists, neuro-ophthalmologists, and other clinicians specialized in these diseases. Our Family Conference brings together hundreds of families from across the country two times a year. We are currently updating and expanding our printed educational materials so that people living with PSP, CBD, and MSA can have accessible and understandable information about their diagnosis and Centers of Care can share these resources in their clinics. And our new Flying Solo online support group addresses a previously unmet need so that now, people with PSP, CBD, and MSA living alone or without a clearly defined carepartner can connect with one another and build their support system.

Q. Any final thoughts about your vision for CurePSP?

I believe in a boots-on-the-ground approach, starting with listening to people living with the diagnoses and healthcare providers caring for them, about what is needed to improve care in the home, the hospital, and the community. It’s an organic but intentional process that evolves into new and stronger collaborative programs and approaches based on the perspectives and experiences of individuals and families navigating life with these diseases, who are the true experts in their care and needs. My vision is to imbue new hope into every aspect of daily life through everything we do under CurePSP’s mission—to raise awareness, build community, improve care, and find a cure for PSP, CBD, and MSA.

Marco Island Returns—Bigger Than Ever.

After two years of virtual walks, Cindy MacDonald and the CurePSP Southwest Florida Support Group returned to Marco Island for their 19th Annual CurePSP Awareness and Memorial Walk, raising more than \$250,000 to support the work of **Dr. Sally Temple**. It was their largest-ever fundraiser, with people coming from across the country and the globe to raise hope and funds.



“My drive is the people,” MacDonald said. “A lot of them are going through this alone. You can get on a computer and log onto different things, but it’s not the physical connection. I’m a hugger, always have been.”

Attendees gathered on Friday evening for their first-ever meet and greet at the Bonita Bay Club, spearheaded by Frank Semcer, a group member since 2018 and a caregiver to his wife, Mary Jane.

“It’s from the heart,” Semcer said. “It’s not about raising money. It’s about once a year doing a wonderful thing and hopefully raising some money for PSP.”



A signature mark of the Walk since its inception is the large square signs placed around the lake at Mackle Park dedicated to those who are still living with or have passed away from these diseases. Each sign tells a story: countless hours devoted to fighting the uncompromising symptoms and preserving the resilient spirits of loved ones. Christina Dean, a member of the support group since 2010 after her uncle had PSP, says that the signs remain the most touching part of the day.

“We don’t know everyone on these signs,” Dean said. “But regardless, we know what they and their loved ones have been through.”

Guest speakers during the event included **Dr. Kristophe Diaz**, executive director and chief science officer at CurePSP, and Dr. Sally Temple, scientific director and co-founder of the Neural Stem Cell Institute and the recipient of the Walk’s fundraiser for the second consecutive year.



Dr. Temple has made pioneering contributions to the neurosciences in stem cell research, using stem cells to grow three-dimensional cultures called neural organoids. These “mini brains” allow Dr. Temple and her colleagues to examine, in real-time, how diseases such as PSP, CBD, and MSA develop in the brain—a fundamental step in creating therapies and interventions to stop the disease process.



Dr. Temple is grateful for the opportunity to learn what people directly affected by PSP need and to further her groundbreaking work.

“I always want to meet the people who are affected by my research,” Temple said. “These are the people we care about. Grassroots means talking to the people who matter.”

Everyone from the CurePSP Southwest Florida Support Group, along with everyone at CurePSP, looks forward to the upcoming year, with hope and determination for finding a cure.

Can Efavirenz Stop Tau in Its Tracks? Dr. Rik van der Kant Leads the Charge.

“For the most part, neurons are built to last a lifetime,” explains CurePSP Venture Grant awardee Rik van der Kant, PhD. “Not true for the rest of the body where billions of new cells are generated every few days. When something goes wrong in the brain, there are fewer ways to correct the mistake.”

The Case of Brain Cholesterol

Although not commonly associated with the brain, 20% of the body’s cholesterol resides in this three-pound organ. Cholesterol is critical for healthy brain structure and function, but when it comes to cholesterol, the brain is finicky, and even a 1-2% “weight gain” can cause neurons to malfunction.

To better understand these issues, Dr. van der Kant went to work under Lawrence S.B. Goldstein, PhD, distinguished professor in the Department of Cellular and Molecular Medicine at the University of California, San Diego, and a collaborative team from Sanford Burnham Prebys Institute in San Diego. The researchers, using “brain cells in a dish,” learned that excess brain cholesterol is linked to the production of excess tau, the protein that accumulates and destroys neural function in Alzheimer’s disease, PSP, and CBD.

Damage Control

Could medication lower brain cholesterol and the ensuing excess tau? The San Diego team tested more than 1,600 FDA-approved drugs, including everyday cholesterol-busting statins—drugs brilliant at reducing blood cholesterol, but terrible at doing the same job in the brain.

Finally, the drug that demonstrated power to lower both brain cholesterol and tau was efavirenz, an antiviral drug with a good safety record. The breakthrough spurred Dr. van der Kant to apply for a CurePSP Venture Grant and target the tau in PSP.

The CurePSP Exploration

Dr. van der Kant and colleagues will investigate whether efavirenz can significantly reduce levels of toxic tau in PSP-like mouse models—enough to halt or prevent disease progression. If efavirenz proves itself an effective PSP disease-modifier, human clinical trials can soon follow for patients with PSP, CBD, and other tau-related diseases. The next best step in the quest to cure PSP.



PRINCIPAL INVESTIGATOR:

RIK VAN DER KANT, PHD,

*Functional Genomics Department,
Vrije Universiteit Amsterdam*

**The CurePSP
Venture Grant:**

Low-dose efavirenz as a
disease-modifying
intervention for primary
tauopathies

Reflections from a Teenage Carepartner on Embracing Family.



My name is Sanjay Geevarghese. I am a second-generation Indian American teenager. I consider myself incredibly privileged, but the ultimate blessing that has shaped my life more than anything else has been family.

My paternal grandparents have slightly different stories. For most of my childhood, they lived in Tennessee. What I remember most is a feeling of sadness that partnered the joy of seeing them. My entire life, my grandfather had Alzheimer's disease. This devastating disease took away everything that characterized him and his personality to my family.

He was highly accomplished and, more importantly, he achieved his life goal: all three of his children went on to find success and make great contributions to the country as well as earn the respect that he was often denied.

After my grandfather died in 2018, the family wasn't the same. At random moments, all of us would start crying while remembering him. His loss was toughest for my grandmother. The loss of my grandfather significantly impacted her after 53 years of marriage. She was starting to engage in this next stage of her life with health and vigor. We all made sure to check in on her constantly. She came to stay with my family and me in Maryland in 2020. We were at the peak of COVID-19 and were bound to the safety of our home. At the time, she was having issues using her right hand. She had trouble gripping objects in her hand, but she still had command over her fingers.

That difficulty has been the hardest aspect for my grandmother to accept. In contrast to my grandfather's cognitive decline and relative physical health, my grandmother has the opposite. She sees her physical decline, which significantly impacts her emotionally. "Why me? What could I have done to deserve this? Why doesn't God take me away?" As a teenager, when I first heard her say things like this, it scared me. It really did, but I didn't show her because my fear would sadden her.

My primary concern is her happiness. I respond to see how she is doing in the midst of these struggles, to remind her that she is loved beyond measure while saying everything is okay even though the illness persists. Through faith, the love of family, and laughter, we are trying to be the treatment for the incurable.

For those who read these reflections, I ask that you encourage youth you know to be a part of their parents' and grandparents' lives. Far too often, young people are shielded from the issues of their elders. However, it is the elders who need the community of support around them now more than ever. In my childhood, my grandparents were that source of light, and I see it as my great blessing to be that light for them now.



Gratitude and PSP

Progressive Supranuclear Palsy

The doctor said to me
It's a rare disease; it's also known
By its nickname PSP.

You may have trouble walking
You may sometimes even fall
If you do, you may fall backward
You may bump against a wall.

You may suffer some confusion
By forgetting many things
You may feel you're disappearing
By the sadness that it brings.

It may affect your vision
Changing how well you can see
Your hands may feel real shaky
When you hold a cup of tea.

You may find it hard to swallow
When your tongue gets in the way
You may feel some deep frustration
With your symptoms every day.

But life can still be meaningful
Life can still be sweet

Feel joy where you can find it
Embrace life now, don't retreat.

Diane Deaver, The PSP Poet
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Life After Loss: A Journal for Navigating the Bereavement Journey

This signature publication features 30 pages on understanding grief, mourning, and bereavement along with shared journeys in grief from our community.

To get your copy of the ***Life After Loss*** journal, please contact Kelsey Woods at woods@curepsp.org or 443-578-5667.

After the Loss: A Bereavement Support Group for Carepartners

3rd Tuesday of each month at 2:00 p.m. ET
To register, please visit www.psp.org/ineedsupport/online-support-groups/





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NEWS AND ANNOUNCEMENTS

NEW SUPPORT GROUP: Flying Solo: A group for PSP/CBD/MSA patients living alone or without a carepartner

Third Wednesday of each month from 2:00–3:30 p.m. ET

To register, please visit www.psp.org/ineedsupport/online-support-groups/

SAVE THE DATE: CUREPSP FAMILY CONFERENCE

November 14, Philadelphia, PA

SAVE THE DATE: HOPE AS BIG AS TEXAS

September 15 at 5:30 p.m. CT

To view all upcoming events, please visit www.psp.org/calendar