

CurePSP connection

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I am honored to have the opportunity to build on CurePSP's prominent and unique position in global neurodegeneration as its executive director and chief scientific officer. For 30 years, CurePSP's vision has driven pivotal achievements in research and programming in the fight against neurodegeneration, especially over the past six years under Dave Kemp's transformational leadership.

Solving neurodegeneration is the medical moonshot of the 21st century.

CurePSP is well-positioned to launch this endeavor: by exploring novel treatments and cures while supporting hundreds of thousands of families worldwide devastated by these diseases.

Our pillars of Care, Consciousness, and Cure guide all aspects of our mission: focusing our responsibility to patients and caregivers and uniting their voices with the work of researchers and industry as they pursue a cure for PSP, CBD, MSA, and related neurodegenerative disorders.

Shortening the time to a cure means extending our scientific understanding of neurodegeneration by creating new pathways through which advanced knowledge is shared: multidisciplinary partnerships and collaborations between patient groups, academic researchers, private and public funders, technology and computational innovators, and the biotechnology and pharmaceutical sectors—synergy to accelerate the road to a cure.

The CurePSP-sponsored conference Neuro 2021 is a prime example of this fusion: 250 professionals from 15 countries attended the virtual two-day event—the best minds in science and industry exploring questions to help unravel the mysteries of neurodegeneration.

As we move forward together, I will ensure that the voice of our patients and partners is heard. CurePSP will advance partnerships, such as our work with the Rainwater Charitable Foundation, to fund more impactful drug discovery programs and core capabilities. In addition, our organization will aspire to help the pharmaceutical industry understand patient needs and deliver better clinical trials and real-world studies so that researchers can effectively assess and develop new therapies and treatments.

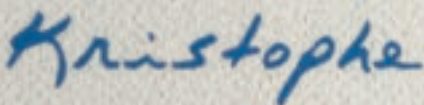
It is an honor to increase our direct support to patients, caregivers, and families through initiatives such as the Cherie Levien Quality of Life Fund, which enables immediate assistance for families needing respite.

In addition, CurePSP Centers of Care (CoC) connect patients and their families to the best possible care at dedicated medical hubs around the country. Our goals also include increasing regional and national support groups and reaching out to underserved and more diverse communities. To this end, CurePSP has translated our support materials into Spanish, French, Portuguese, and Hindi.

Success for CurePSP's role depends on input and support from our benefactors, sponsors, and financial advocates. I need to hear from you: to listen, to learn, and to collaborate on fostering new ways to bring hope to the ultimate quest of the 21st century.

Thank you for your continued support and drive toward Care, Consciousness, a Cure, and a world free of PSP.

With gratitude and respect,



Kristophe Diaz, PhD



Landmark Clinical Care Education

Advice on symptom management from 37 top clinicians

How many times have people suffering from PSP or CBD heard their neurologist deliver the terrifying news, “I’m sorry, but there’s nothing I can do for you.” **Lawrence I. Golbe, MD**, emeritus professor of neurology at Rutgers University and CurePSP’s chief clinical officer, explains, “As rare and complex diseases with no cures as yet, PSP and CBD have become ‘orphaned’ in the minds of many clinicians.”



“While no specific treatment or way to slow the underlying disease process exists, there are treatments that ease most of the symptoms, which is called palliative or symptomatic management. These measures can not only improve quality of life but can also help avoid or delay life-threatening complications of the diseases. It’s up to the neurologist and other clinicians to understand and offer them.”

A groundbreaking guide to relieve symptoms

Under the auspices of the CurePSP Centers of Care, Dr. Golbe along with **Irene Litvan, MD**, of the University of California, San Diego; **Alexander Y. Pantelyat, MD**, of The Johns Hopkins Hospital; and **Brent Bluett, MD**, of Stanford supervised the writing of a landmark publication: *Best Practices in the Clinical Management of Progressive Supranuclear Palsy and Corticobasal Syndrome*.

Evidence-based and peer-reviewed, the best practices guide incorporates the vast knowledge and experience of 37 top neurodegenerative clinicians throughout the US and Canada: a must-read and refer-to guide for all physicians and clinicians managing the symptoms of individuals with PSP or CBD.

In August 2021, the guide was published in the esteemed online clinical publication *Frontiers in Neurology*. It is available to anyone, free of charge, who wishes to download or use it. www.frontiersin.org/articles/10.3389/fneur.2021.694872/full

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Send the link. Print a hard copy.

Download to your phone.

Patients and caregivers should consider offering this guide to their neurologists, movement disorder specialists, primary care physicians, nurse practitioners, ophthalmologists, optometrists, rehabilitation medicine specialists, neuropsychologists, physical therapists, and speech/swallowing therapists.

Bring it to the hospital, emergency room, and nursing care facilities. It could make a huge difference in how someone with PSP or another neurodegenerative disease has their symptoms managed, with the hope of enhancing their quality of life.



A new genetic crime scene for PSP? Dr. John Ringman gathers evidence.

For one large Southern California family, the phrase ‘it runs in the family’ is not a playful reference but an ominous statement. It describes the shared toll that PSP has taken on multiple generations: six relatives currently diagnosed with PSP, 19 members at risk of developing it, and at least four already having succumbed to PSP, a diagnosis confirmed through brain donation and autopsy.



John M. Ringman, MD, the Helene and Lou Galen endowed professor of clinical neurology at USC, explains the situation: “For two decades, this family has courageously worked with the University of Southern California (USC), exploring the biological, behavioral, clinical, and now, genetic mechanisms underlying PSP.”

PRINCIPAL INVESTIGATOR:

JOHN M. RINGMAN, MD

Helene and Lou Galen
Endowed Professor of
Clinical Neurology, Keck
School of Medicine,
University of Southern
California, Los Angeles

**The CurePSP
Venture Grant:**

Genotyping Familial
Progressive Supranuclear
Palsy

Most cases of PSP are sporadic—with no known heritable link to anyone in a family. However, researchers have discovered that there are rare families in which many cases of PSP or related disorders occur, in which mutations in the MAPT gene, which codes the protein tau, have been identified. It is a genetic error that dooms tau to misfold, malfunction, and aggregate in the brain’s pathways, thereby destroying movement, behavior, and cognition.

A further mystery

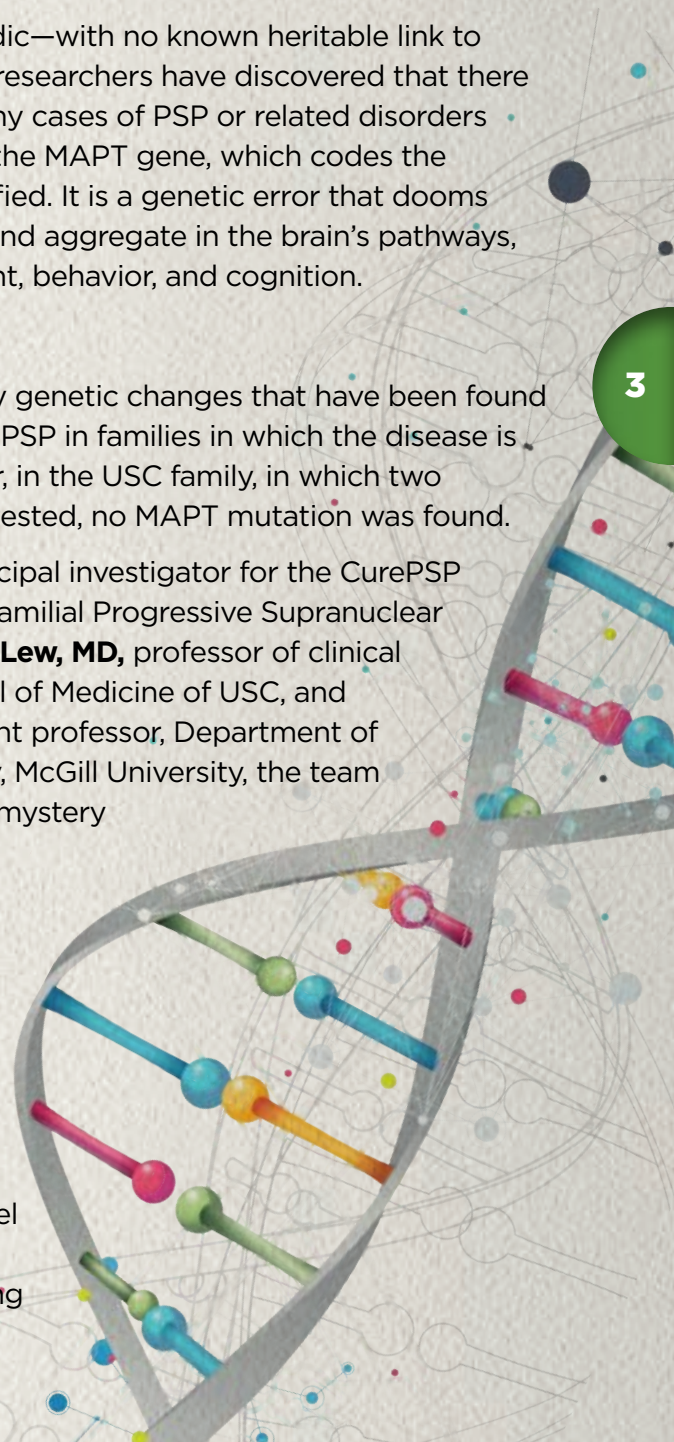
Variants in MAPT are the only genetic changes that have been found to be clearly associated with PSP in families in which the disease is so clearly inherited. However, in the USC family, in which two affected persons have been tested, no MAPT mutation was found.

Enter Dr. John Ringman, principal investigator for the CurePSP Venture Grant, Genotyping Familial Progressive Supranuclear Palsy. Together with **Mark F. Lew, MD**, professor of clinical neurology at the Keck School of Medicine of USC, and **Ziv Gan-Or, MD, PhD**, assistant professor, Department of Neurology and Neurosurgery, McGill University, the team is ready to solve the genetic mystery of PSP in this family.

Hunting a new genetic suspect

“Through the CurePSP-funded research, my colleagues and I plan to examine the DNA of this family: testing members who have PSP and those who do not. Our goal is to locate their genetic similarities and differences and identify what appears to be one or more distinct, disease-causing genes in PSP,” explains Dr. Ringman.

“This new knowledge might provide the basis for creating novel therapies to repair or reverse the genetic ‘mistakes’ in other forms of PSP and in life-destroying neurodegeneration involving tau in generations to come,” says Dr. Ringman.



Hike, Bike, Walk. Unite to

Not even COVID-19 could stop our devoted CurePSP volunteers, supporters, donors, and idea-makers from raising the bar on fundraising events—big ideas that yielded big results—bringing help, hope, and funds where they're needed most.

2,650 miles closer to a cure: \$26,506 raised

This April, former CurePSP board member **Jeff Friedman** and his daughter, Rachel, embarked on a life-changing 2,650-mile hike from the Mexican border to Canada along the Pacific Crest Trail. The mission: to raise funds to stop PSP. Through the generosity of an extraordinary donor, CurePSP received a matching grant of \$15,000 toward the Hike for CurePSP fundraiser, and every dollar raised was doubled!

Father and daughter started the hike together and trekked past streams, forests, and rattlesnakes. Jeff later left the trail to focus on helping Rachel with resupply. He joined back up with Rachel on a few sections, but for a majority of the trail, Rachel was a solo traveler.

Rachel's favorite part of the journey was the breathtaking wildflowers in the Sierra Mountains—hiking above 10,000 feet for approximately 130 miles. That is grit and training.

On September 21, an exultant Rachel crossed the border into Canada, ending a journey to end PSP. Follow Rachel and Jeff's amazing journey on Twitter [@HikeForCurePSP!](#)



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The \$100,000 Wow Walk

The 18th Annual CurePSP SW Florida Support Group Awareness

& Memorial Walk fundraiser was a huge success. Even as a virtual event, they exceeded their goal of raising \$100,000. CurePSP is grateful to all our friends of the SW Florida Support Group who work year round to raise awareness of those affected by PSP, CBD, and MSA. Through the generosity of two donors in the Naples Support Group, CurePSP received a matching grant of \$25,000, doubling every dollar given.

This year's walk supports a research initiative to advance novel therapeutics, led and supported by our longtime partners the Rainwater Charitable Foundation—research that will be conducted by **Dr. Sally Temple** and **Dr. David Butler** from the Neural Stem Cell Institute located in Rensselaer, NY.

Thank you for joining us on this walk down memory lane and for your contributions!



Stop PSP in Its Tracks.

Hope as Big as Texas fundraiser: \$43,436 raised

A big mission with a big heart! The goal of the **Hope as Big as Texas** event was to raise funds, awareness, and support for families impacted by PSP, CBD, and MSA who need in-home respite care. In the form of grants, the funds come through **The Cherie Levien Quality of Life Fund**, launched in 2017 through Larry Levien's generous donation in honor of his wife, Cherie, who was diagnosed with PSP.



Ileen McFarland, leader of the Dallas Support Group, orchestrated the Hope as Big as Texas event and brought together all the support groups in the state of Texas to participate in an art-themed extravaganza. Exciting segments from the virtual celebration included a museum visit, a Rice University Mariachi Luna Llena performance, a cocktail-making class, and a silent auction!

Through the generosity of several extraordinary donors, CurePSP received a matching gift of \$25,000. Thus, every dollar our donors and supporters gave was doubled!

Our gratitude and a big-as-Texas thank you to our extraordinary CurePSP staff, board, and community:

Christine Cassimatis, *Event Coordinator*

Kelsey Woods, *Community Outreach and Resource Manager*

Ileen McFarland, *Board Member*

Amy Branch, *Board Member*

Carol Loughlin, Rosa Guitierrez, Christine Cisneros Corser,

Karen Kennemer, Nancy Harvey, Courtney Garvey, and Judi Nudelman



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Ken's Ride: A Ride for Hope that wheeled in \$10,640

Throughout the month of May, CurePSP and Jan Appel hosted a virtual fundraiser to honor Ken Appel—husband, father, and avid bike rider who bravely fought PSP. This year's virtual ride of 26.3 miles was the length of the Missisquoi Valley Rail Trail in Vermont where Ken used to ride his bike. Funds raised will benefit those experiencing the hardships of neurodegenerative diseases such as PSP, CBD, and MSA.

Thank you, Jan, for such a great idea and your perseverance!



Caring for your mind, body, and spirit.

At CurePSP, we support the individuals, families, and caregivers dealing with PSP, CBD, and MSA in a holistic way—taking into consideration their physical, clinical, psychological, and spiritual needs. Below is a sample of the programs CurePSP offers.

Watch CurePSP's Ask the Doctor webinar for clinical updates.

Have a virtual visit with leading world experts in PSP and related disorders. During every webinar, the doctors—such as **Lawrence I. Golbe, MD**, and **Alexander Pantelyat, MD**—will review the latest clinical and research findings and answer questions from the audience.



Improve physical and mental well-being with Wellness Wednesday.

Each 30-minute episode of web-based Wellness Wednesday brings together patients and caregivers with top-name professionals from the worlds of physical therapy, tai chi, yoga,



- meditation, and exercise. In each session,
- participants—in the comfort of their home—learn
- new ways to achieve motivation, flexibility, and a
- sense of accomplishment and calm—at their own
- ability level. Watch prior episodes of Wellness
- Wednesday on the CurePSP YouTube channel.

Find solace, information, and community with CurePSP online support groups.

You are not alone. CurePSP and our many communities are here to listen, help, and comfort you at every step along this difficult journey—starting with PSP/CBD/MSA 101: An Educational Support Group for Early-Stage Patients.

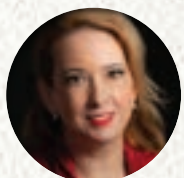
- People with PSP/MSA/CBD and Their Carepartners
- Carepartners of People with PSP/MSA/CBD
- (Women Only) Support Group for Caregivers
- (Men Only) Support Group for Caregivers
- People with PSP
- Carepartners of People with PSP
- Carepartners Dealing with Advanced PSP
- People with CBD and Their Carepartners
- People with MSA
- Carepartners of People with MSA
- Gen Z Support Group for Those Dealing with PSP, CBD, and MSA
- Adult Children of People with PSP
- After the Loss: A Bereavement Support Group for Carepartners

To sign up for an online support group, visit www.psp.org/ineedsupport/online-support-groups

Meet the team who brought the CurePSP 2021 Family Conference to life.

In May, more than 200 patients, caregivers, families, scientists, and CurePSP staff gathered virtually for the CurePSP 2021 Spring Family Conference. Kristophe Diaz, PhD, CurePSP executive director and chief scientific officer, welcomed the attendees and shared CurePSP's vision of a world free of PSP, CBD, MSA, and other neurodegenerative diseases. On day two of the conference, Dr. Diaz outlined an in-depth overview of CurePSP's leadership role and impact in neurodegenerative research.

Creating a virtual conference to rival an in-person event took imagination, teamwork, and hard work. Here is the CurePSP team that made it happen.



Jaclyn Zendrian, Vice-President, Events

I oversaw the CurePSP Family Conference planning, from concept through speaker selection and execution to ensure the conference unfolded seamlessly. As always, our goal was to exceed expectations and bring an educational and meaningful experience to patients, families, caregivers, donors, speakers, and sponsors.



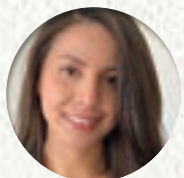
Joanna Teters, Support and Education Manager

As part of the conference planning committee, I worked with Jaclyn, Christine, and Kelsey to discuss and finalize presentation topics, speakers, and the schedule. On day one of the conference, I led an immersive tour of CurePSP's educational materials and resources—a lifeline for people with rare diseases such as PSP, CBD, and MSA along with their families and caregivers.



Sabrina Da Rocha, Director, Marketing and Communications

Denise Forero and I worked closely with the planning committee to create the marketing plan and messaging for the conference. Our goal was to attract a wide and diverse audience, reaching out early and often, so that anyone who might benefit from the conference would save the date and attend.



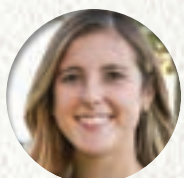
Denise Forero, Marketing and Social Media Manager

Social media channels like Facebook, Instagram, and Twitter—with their cross-channel marketing that built awareness and attendance—were invaluable for promoting the conference, which attracted 200 individuals. Quite a turnout!



Kelsey Woods, Community Outreach and Resource Manager

Naturally, we wanted to create the best guest experience for attendees, so the team utilized a new media platform that allowed viewers to watch real-time video presentations, access schedule information and PSP resources, and engage in interactive chat functions all on the same page.



Christine Cassimatis, Events Coordinator

I supported Jaclyn's efforts, tracked registration, and formatted the event platform page. This was the first time CurePSP worked with the new platform, and although minor glitches arose, the team quickly ironed them out and provided a great experience for registrants.

Many, many thanks to our speakers and patients who graciously agreed to participate in the conference. Watch the entire 2021 CurePSP Family Conference online on the CurePSP YouTube channel at www.youtube.com/curepsp



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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

