

CurePSP Connection

We are witnessing an inflection point in the world of neuroscience. We have entered a new era that will see the acceleration of new treatments and new diagnostics for neurodegenerative diseases. A year ago, I wouldn't have been able to say that but now I can, and this progress is transformational and energizes those that, like CurePSP, are working relentlessly to fund the research and build the partnerships needed to accelerate a cure for neurodegenerative diseases including progressive supranuclear palsy (PSP), corticobasal degeneration (CBD) and multiple system atrophy (MSA).

For the first time in history, a treatment that slows down cognitive decline for those living with Alzheimer's has been approved by the Federal Drug Administration (FDA). In the spring, a similar approach has shown positive results and I'm looking forward to witnessing a likely second FDA approval. These treatments, made possible by Biogen, Eisai, Eli Lilly and the dedication of hundreds of scientists, collaborators and patients across the world, are not cures and do present risks. But they are breakthroughs and these breakthroughs have changed the world and I hope will convince more investors, researchers and leaders to do more.

More progress is to be noted and celebrated: earlier this year, two pharmaceutical companies announced promising results in a therapy aimed at lowering the protein Tau in the brain of those suffering from Alzheimer's. The results published by Ionis and Biogen are the first to demonstrate the successful lowering of this protein that, in PSP, CBD and Alzheimer's, are thought to be responsible for the loss of brain cells and eventually the death of those living with these diseases. Also in the spring, with the support of the Michael J. Fox Foundation, scientists confirmed the development of a new biomarker in Parkinson's disease.

What do these advancements mean for our community?

I realize these breakthroughs are not directly focusing on PSP, CBD or MSA. However, they are validating certain therapeutic and disease monitoring approaches that are applicable to most neurodegenerative diseases. As CurePSP's Executive Director and Chief Science Officer, my role is to make sure these advances also bring new solutions to those living with PSP, CBD and MSA.

In the meantime, we continue working hard towards many activities core to our missions. We're funding promising research via our pathway and pipeline grants; we've grown our network of clinics with our CurePSP Center of Care; we've joined powerful advocacy efforts led by the Michael J. Fox Foundation to make sure the federal government increases its support of research and legislations critical to our patient community; we've added key members to our team so we can raise more funds and drive scientific progress and we've partnered with international groups (foundations, universities and pharma companies) to produce scientific conferences and to help with the design of efficient processes for clinical trials.

The CurePSP team is dedicated to supporting patients and families, our mission and planning for the future — a future that will see new biomarkers and large clinical trials relevant to our community.

Thank you for your support,



Kristophe Diaz, PhD
Executive Director and Chief Science Officer



SUMMER 2023

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CUREPSP CENTERS OF CARE HOPE THAT GROWING COLLABORATION LEADS TO MORE SPECIALIZED TREATMENT OPTIONS



Leading a rare disease clinic can be an isolating experience. Similar to how the general public lacks knowledge on atypical parkinsonisms like PSP, CBD and MSA, the medical community can also be unfamiliar with them, given how little they see such patients. Dr. Antoine Duquette, a neurologist and associate clinical professor at the University of Montreal and director of the CurePSP Center of Care, understands the challenges patients face when seeking an atypical parkinsonism specialist.

“When people hear about strokes, cancer, Alzheimer’s disease or even Parkinson’s disease, physicians have a general idea of how to deal with such patients,” Duquette said. “Whereas they are not comfortable with patients with an atypical parkinsonism diagnosis because they don’t have as much experience with them.”

Awareness has been a part of CurePSP’s mission since its inception, and to make care more accessible for patients, Dr. Duquette and University of Montreal Center of Care Coordinator, Martine Comeau, feel it is crucial to educate their local community, hosting their first Patient & Family Conference at the University of Montreal on November 20, 2022.

“To be able to share with others who were going through the same journey allowed them to calm their anxieties and frustrations, and we hope to host this conference several times throughout the year,” Comeau said.

Comeau has found that oftentimes patients and care partners just need to talk to someone who understands them, which is why they plan on starting a PSP support group in the coming months. The more that Comeau and Dr. Duquette talk to patients, the more it becomes obvious that a holistic and feedback-based approach to care is most effective.

“Palliative care does not mean end of life,” Comeau said. “It means making sure that we are readjusting as the disease progresses so that the patient can feel stable over time.”

It can be hard for patients to get a proper diagnosis of PSP, CBD or MSA and additional information about what to expect for their future. Dr. Marian Dale, assistant professor of neurology and director of the Center of Care at Oregon Health & Science University, says that patients come to the center seeking more information on their disease trajectory.

“A lot of patients want to know how to prepare for what will happen to them in the future,” Dale said. “I think we play a big role in counseling in addition to referrals to proper therapy services.”

Enlisting specialists from multiple departments is an important task for Center of Care directors, and Dale has built collaborations with nursing, physical therapy, social work and other specialists to improve care for their patients and families. Dale says the funding from the Center of Care award has allowed her to put more of a team in place.

Dale has also contributed to the exploration and creation of best practices by leading the CurePSP Access to Care Working Group. The group, which includes Comeau, organizes regular meetings between the respective Centers of Care to tackle issues related to access to care for PSP, CBD and MSA. The group is currently working on a paper that will be submitted to an academic journal on the reasons why patients with PSP, CBD and MSA cannot be triaged the same way as patients with Parkinson’s disease, as their needs are much more urgent.

“It’s been really nice to have that camaraderie,” Dale said. “For most of us, we’re probably the only person at our particular institution whose major clinical and research focus is PSP or atypical parkinsonism.”

The Access to Care Working Group is also developing a survey on barriers to clinical trial participation in PSP, made more efficient by another neurologist on the call, Dr. Michiko Bruno, director of the Center of Care at Queens Medical Center in Hawaii, who had already started a similar survey for a different patient population and provided additional inspiration and insight.

“It’s interesting to see that even though our situation is a little different in Canada, we still have the same struggles as sites in the U.S.,” Comeau said. “Bringing all of our minds together makes our ideas go further.”

As the Centers of Care continue to meet, they look forward to developing models of care that prioritize the patient experience. They hope to maximize the patient’s quality of life while continuing to produce practices that are specialized for atypical parkinsonian syndromes. Every Center of Care brings a personalized level of expertise for treating PSP, CBD and MSA, and as they continue collaborating, they hope to make that approach the standard.



THE SOUTHWEST FLORIDA PSP SUPPORT GROUP AWARENESS AND MEMORIAL WALK TURNS 20 WITH FUTURE LOOKING BRIGHTER THAN EVER



The Southwest Florida PSP Support Group returned to Mackle Park on a clear and sunny Saturday morning to celebrate the 20th anniversary of the Awareness and Memorial Walk. The crowd of over 200 people convened at the shady basketball court-turned event space filled with the color red: red tables, red CurePSP banners and red memorial T-shirts, all symbolizing the love this community has for each other. The space overlooked the serene Mackle Park lake, and even in the shade, attendees felt the warmth of being surrounded by those who had been through similar experiences to them. Members of the Southwest Florida PSP Support Group were dispersed throughout the space, including Cindy MacDonald, support group facilitator and organizer of the walk for more than a decade. She admits that planning the event is a big undertaking but says it always pays off when she sees how far attendees travel to join them.

“My motto of ‘if you build it, they will come’ is proven correct each and every time,” MacDonald said. “It gives families a place to go where they all have something in common, and they feel the ‘heart’ of the event.”

Each sign around the lake tells the story of an individual who never gave up, with their resilient spirits preserved around the placid lake. Dr. Larry Golbe, chief clinical officer, chair of the Scientific Advisory Board and member of the Board of Directors at CurePSP, felt moved by the powerful images surrounding the walk.

“I was touched by families having their pictures taken standing by the memorial signs for their loved ones,” Dr. Golbe said. “Seeing PSP as something affecting whole families rather than just individuals and caregivers gives CurePSP’s work even greater importance and urgency.”

When the crowd finished the walk, they returned to the event space to cool off in the shade, enjoying lunch, live music and a raffle filled with prizes, including the famous “Booze Barrel.” MacDonald emphasizes the lighthearted nature of the support group meetings, and plenty of smiles could be found throughout the space.

Jack Phillips, a member of the support group since 2020 and a board member at CurePSP, credits MacDonald’s contagious enthusiasm for the success of the walk and support group.

“The walk is so uplifting, and it makes the patients and care partners feel important by the participation of family, friends and the community,” Phillips said. “For a disease that is so isolating, the walk is liberating and connecting.”

As the crowd leaves, full of sun and grilled burgers and hot dogs, the walk’s influence continues with the money raised to fund cutting-edge research. The first \$50,000 was matched thanks to the generosity of sponsoring donors, and the event has raised over \$130,000. In attendance were Dr. Sally Temple and Dr. David Butler of the Neural Stem Cell Institute (NSCI), whose research pursuing a unique gene therapy approach using intrabodies is being funded for a second straight year. The walk will also be funding a new project, led by Dr. Chet Mathis at the University of Pittsburgh and Dr. Neil Vasdev at the University of Toronto, who are developing a new brain imaging biomarker that would lead to a faster and more accurate diagnostic of PSP and CBD. Not only does the walk bring hope by allowing members to meet the many faces of their community, but it pushes progress forward with the research that it makes possible. Dr. Golbe says that patients can look forward to increasing clinical trials and imaging techniques.

“There are a few drug trials in progress right now, and a lot more are scheduled to start in the next year or two,” Dr. Golbe said. “Diagnostic testing, especially using MRI and PET imaging, is also advancing rapidly, which for people already diagnosed means that treatment trials will proceed more quickly.”



CUREPSP VOLUNTEER SPOTLIGHT: NITI VAIDYA PROVIDES INDIA WITH THE RESOURCES SHE WISHES SHE HAD

Niti Vaidya knows that good care begins with a plan. When her father, Pradeep Vaidya, was diagnosed with Parkinson's disease in 2004, their family knew his symptoms seemed unusual. He was then correctly diagnosed with PSP in 2012, with Niti, her mother and sister making up for the support network that was lacking in Mumbai, India. They worked together to divide the care responsibilities to maintain her father's quality of life before his passing in 2017, but Niti felt a growing void from the years devoted to around-the-clock care.

"I had nothing to do or look forward to because I didn't have a career and was in my 30s," Niti said.

She discovered CurePSP after her father's passing. She began sharing resources in PSP Facebook groups and connected with others affected by the disease in India.

"What started as a coping mechanism turned into a passion," Niti said. "I started to like helping people and sharing my journey with them, and the group continues to grow."

Niti says India lacks PSP awareness. By sharing her information and experience, she is providing vital support to her community. Her family provided a blueprint for navigating the disease journey, and Niti hopes to share that while improving its shortcomings.

"I always tell people that I wish I had known CurePSP existed then," Niti said.

Since getting in touch with CurePSP, she has become a primary resource for PSP families in India. She has started a support group, hosted Q&A sessions with experts, created an active WhatsApp group and is listed as a CurePSP peer supporter.

"I am glad to have been associated with CurePSP for the last five years," Niti said. "Now I am able to do much more with this group as I have people supporting me with Zoom links and flyers because I am doing this singlehandedly and I don't know how."

Niti is particularly proud of the WhatsApp group, which she says picked up during the pandemic and now includes 141 members. She understands their appetite for new information and says that questions, ideas, emotional support and tips are constantly being shared between members, a community dedicated to making each other's lives easier.

Niti is also a qualified psychologist who received her master's degree during the pandemic, offering counseling to families in need of emotional support. She downplays these sessions, emphasizing the need for more accessible healthcare in India from physiotherapists and other specialists, but those who have talked to her have found it to be an invaluable experience.

"People would always come and tell me they found it very therapeutic to speak to me, so I thought I had this knack in me and wanted to do it with the right training," Niti said.

A PSP diagnosis becomes a massive undertaking for the entire family, and Niti's ability to repurpose her struggle into crucial care is an example of why hope matters. Her progress has given her confidence in other aspects of life; in addition to supporting families, she now works as a screenwriter, writing screenplays for daily soaps and over-the-top shows in India.

"Everyone in my family lost our personal lives because of this 14-year journey with this disease," Niti said. "It just made sense to have a career in writing because of my keen interest in fiction and the ability to work from home, with flexible hours making it easier to help my mom and sister with family responsibilities."

Niti continues to turn her loss into a gain and looks forward to a future with more accessible PSP care that goes beyond her. She has plans in the coming months for the first in-person support group meeting in Mumbai and maintains her selfless passion that has made hope possible for so many in India.



LOVE, LOSS AND LIVING: NAVIGATING HOSPICE

By Julia Freifeld

I received a phone call from hospice, asking whether Mark and I would like to arrange a meeting at our home or at their facility. I was surprised by the call. Mark had not told me about his recent appointment with his internist, where they had discussed hospice care. My immediate reaction was: Oh crap, we're nearing the hospice zone.

After hanging up, I decided I'd go by myself and not tell Mark where I was going.

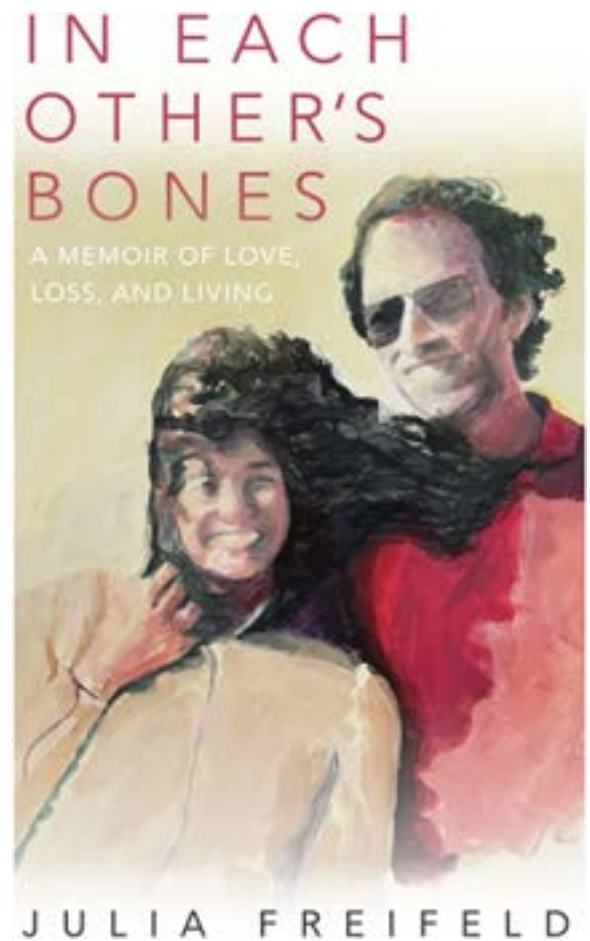
My plan was to get all the information during that first appointment and explain it all to Mark. I felt slightly nauseated driving to hospice. It was surreal going there.

Hospice of Wake County (now called Transitions LifeCare) is a lovely and inviting campus set on a hill in southwest Raleigh. There are several brick buildings surrounded by manicured gardens with benches. Situated in the center of the circular driveway is a pleasing metal sculpture of soaring ribbon-like shapes. I waited a few minutes in a foyer. I noticed how spotless and cheery everything was around me. The colorful wall art was set against warm neutral furnishings.

Joining hospice is a process of acceptance. We weren't ready to accept that Mark was close to dying. So we waited. A few months later, I visited again with Emily. I needed her support and opinion. When Emily got teary during our meeting, I felt a pang of worry; perhaps I shouldn't have asked her to come with me. When we finished our conversation, we had a tour of the grounds, buildings and in-care facility, the Hospice Home. Emily agreed with me that everything about hospice was cheerful and had a relaxed feeling.

The most coincidental thing happened during our tour. We were being shown a small sitting room with two chairs and a window overlooking a garden. In the room was a striking three-foot-tall V-shaped glass vase with a few handfuls of brightly colored pieces of sea glass resting on the bottom. I asked about the vase and stones. I was told each piece of sea glass represented a patient who had died. When the vase fills to the top, the staff creates a mosaic and places the shimmering handiwork in the garden. Emily and I immediately glanced at each other and recounted my trip to Leni's beach house and how these little iridescent pieces of broken glass symbolized a person's spirit.

The hospice team were down to earth, and their conversations were matter of fact. The discussions they had with us about dying were ordinary conversations. They were teaching me how to talk about living and dying in a natural way. There was no taboo. Nothing was off limits.



An excerpt from *In Each Other's Bones: A Memoir of Love, Loss and Living* on Freifeld's role as a care partner for her husband, Mark, during his journey with multiple system atrophy (MSA). From the book's chapter "Hospice on My Speed Dial."

CUREPSP SUPPORT GROUPS PROVE TO BE A STEADY SHOULDER THROUGH LIFE'S TRANSITIONS

Learning of a rare disease diagnosis can be overwhelming because so little is known about what comes next. It can be hard to find peers who understand the experience, and even the internet seems to lack answers to some of the most basic questions. When Tom Tait learned of his late wife Liz's multiple system atrophy (MSA) diagnosis, all he wanted was to be prepared. Through CurePSP, he found the Care Partners of People with MSA Support Group led by Carol Langer and Vera James, and attended his first meeting in 2014.

"Vera and Carol were a phenomenal source of information," said Tait. "I hardly missed a meeting because they were so beneficial for the realities of what I would be up against."

In 2017, Vera and Carol decided to step away from the group, and Tait volunteered to take over, facilitating hundreds of meetings since. He seeks to create an open space that leaves room for all feelings, understanding that these diseases can be confusing and there is no linear path for one's emotions. He emphasizes the anticipatory grief that accompanies a loved one's diagnosis, in which feelings of denial, anger, bargaining, depression and acceptance occur while the loved one is still alive.



He recognizes that people come to support groups in a time of turmoil, seeking peers who have been through a similar experience.

"I found it scary when I first joined and heard that someone passed away, realizing I'd have to be making decisions about feeding tubes and end-of-life things," said Tait. "But it allowed me to get everything in place and learn from listening."

Tait also started a second virtual CurePSP support group, Men Care Partners of People with PSP/CBD/MSA, which he says can be even more emotional, with topics ranging from disease tips to the latest electric cars. He never puts time limits on his meetings, nor does he pretend to have the answers. He says that oftentimes people will find their own answers when given the space. Nancy Montgomery, facilitator of the Central Ohio Support Group for PSP/CBD/MSA Patients and Caregivers and co-facilitator of CurePSP's virtual Women Care Partners of People with PSP/CBD/MSA Support Group, says that people have come up with some very creative solutions to the constantly changing diseases, sharing makeshift adaptive equipment to make everyone's lives a little easier.

"We laugh a lot," Montgomery said. "We've gotten to know each other pretty well, and it's important to take things in stride and keep a positive attitude."



What Brings You Hope Every Day?

“I enjoy looking at the sun. I love the aroma of the beautiful spring flowers coming up.”

- Joanna Galante Aron

Montgomery says that many group members express a gratitude for coming to a place where they feel safe and can share their full range of emotions. She also notes that many members who join following a diagnosis—herself included—seek a sense of structure that may not be possible because of the disease’s nature. She tries to provide them all the assurance she can through information and emotional support, while stressing the importance of quality of life and living in the moment.

“Don’t put off until tomorrow what you can do today,” Montgomery said. “There are so many ups and downs with these illnesses. When you have a good time, don’t say, ‘Oh, we’ll take another walk tomorrow,’ because you don’t know what tomorrow will bring.”

Tait shares a similar sentiment, using the phrase “no regrets” to face reality and make the most of the time spent with loved ones while they are still here.

“I look at these diseases as a long goodbye,” Tait said. “If there’s something you want to talk about or something you want to do for them, then get that out of the way now so that when you’re on the other side of this, you can look back and say, ‘I have no regrets.’ I have no regrets because I did everything possible to make my wife comfortable.”

The care giving role can be so demanding that it is common for care partners to re-discover their own health and needs after their loved one passes. Tait told his wife he would see her again, and Montgomery says it can be a relief to finally reach the end.

“One of the ladies in the women’s group whose husband recently passed away said the next day she went out for a walk in the morning and that was the first time in months she could go out and not have to worry,” Montgomery said. “There’s grief and there’s sadness, but there’s also that release from the care partner role.”

Both Montgomery and Tait have found facilitating to be a rewarding experience, something that Kristen Weidner, a speech and language pathologist and facilitator of the Washington DC Support Group for PSP/CBD/MSA Patients and Care Partners, also sees in her members. Weidner says that many members use their experiences to help others in similar situations.

“I just think it’s so cool that people are getting support themselves, but they’re also able to serve in this capacity,” Weidner said. “It gives them a conduit to take what’s happened to them and make other people’s lives easier.”

Weidner has also been impressed by the number of guest speakers that the group members have been able to enlist, asking their physicians, lawyers or other people who have been helpful to come speak in the group. A PSP, CBD or MSA diagnosis may be a uniquely isolating experience, but with some help, it can also be filled with moments of love, joy, triumph and ultimately renewal. As life changes, count on the CurePSP support groups to be a continued source of hope.

All of CurePSP’s virtual and regional support groups can be found at www.psp.org/ineedsupport

“Hope that your research will find a cause/cure/treatment so that others don’t know the suffering and loss this dreadful disease causes. Hope that my daddy, Charlie White, is waiting for me in Heaven!”

- Kimberly Cattivera

“I hope one day doctors find a cure.”

- Silvi O’Brien

“Picking out the positives in people or situations.”

- Patti Sellers

“Helping those in need and bringing hope into their lives.”

- Doris Driscoll



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