A FUTURE FREE OF NEURODEGENERATION begins with you.
Highlighting these families’ stories is one way CurePSP continues to advance education, advocacy, treatment, and a cure.
Your contribution today makes a different future possible. Because Hope Matters.

MARÍA DEL CARMEN ACOSTA, MEXICO, AUGUST 1954
“We live in the city of Chihuahua, Mexico. My mother has corticobasal degeneration. It took many years to find her diagnosis since very few cases were diagnosed in our city. There are very few doctors and nurses, and they do not know of the disease. My mother began with symptoms in 2015. After going to many doctors, her disease was finally confirmed in Mexico City at the National Institute of Neurology. Before traveling to Mexico City, I looked up information about the disease and came across CurePSP’s page. This disease has been complicated for my mother since she is a doctor, and she knows everything she is going through. Seeing that nothing can be done to help her has brought impotence and great suffering to our family.”

PRISCILLA EDDY
Daughter of María del Carmen Acosta

JOHN MACDOUGALL, CALIFORNIA, JUNE 1949
“It has been difficult for our whole family to see dad suffer from this disease, but we are managing the best of it we can. We see that when he does have a good day, it can be the best thing for everyone. He has always been a do-it-yourselfer. And despite the fact that he has PSP, I think he could do anything. In the past, we have seen his 110-year-old mother (Dorothea) as well as his 106-year-old father (John).”

EVAN MACDOUGALL
Son of John MacDougall

LUTHER ULRICH, MINNESOTA, OCTOBER 1953
“My father, Luther Ulrich, was diagnosed with PSP in late 2016. Before he was diagnosed, he was active and enjoyed outdoor activities such as golfing, hiking, and fishing. He loved to be out in nature. However, when he was diagnosed, he had to give up these activities. He is currently under the care of hospice at home. We take each day one at a time, but for now, my brother and I have moved back home to help care for our dad.”

EMILY ULRICH
Daughter of Luther Ulrich

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OUR COMMUNITY often feels overlooked. When faced with a diagnosis of neurodegeneration, patients and their loved ones can feel isolated and alone. CurePSP is working to shine a light on those who are often left in the shadows. These are the stories of those working to fight neurodegeneration—the patients, caregivers, children, parents, and friends. With the hope and strength found in this community, we are finding the way forward. Here are their stories.

KAREN KENDALL
CALIFORNIA, OCTOBER 1945
Karen Kendall is known for her enthusiasm and optimism, and she tackles the challenge of PSP with the perfect combination of grit and grace.

DANIEL UPDIKE
MICHIGAN, MAY 1952
“My dad is a brilliant man. He has always been hard-working and out and out did it. He rode his bike to work and back for over 15 years. Even during ice storms! He was on a bike ride for the DELMAC, which is a several days-long event where cyclists ride from west Michigan to the upper peninsula, when he lost balance and crashed going down a hill. He was life flighted to the hospital and spent several days there before being transferred to Mary Free Bed for full-time rehabilitation. He was no longer alone. His kids started to think that something was wrong before the crash. It gets harder and harder to do things with my dad; we just keep researching and adapting to try to give him quality of life. He has truly inspired my siblings and me to always stay active and to have fun doing challenges.”

JENNIFER TOWN
Daughter of Daniel Updike

CHERIE LEVIEI
MASSACHUSETTS, SEPTEMBER 1948
“Her body wearied when PSP attacked, but her mind and her guidance remained until the very end. In those last several years, however, she was no longer unstoppable alone. She engaged with physical therapists week after week after week, determined not to give ground to what she always called ‘that nasty disease.’ And she accepted help from a dear friend and caregiver. Her doctors noted that these physical efforts and her willingness, reluctantly at first, to accept outside care extended her quality of life, not just her time of life, for at least six months. Outside caregiving also was a blessing for the family—it allowed healthy family relationships to continue along with the family’s own caregiving efforts.”

SIMONE LEVIEI HALSEY
Daughter of Cherie Levien

BRUCE ALFRED JESTER
NEW YORK, AUGUST 1941
“Over the last six months of his life, my mother, brother, and I watched him soften into a mere soft shell of the hardworking little league coach, electrician, and the man who built the house my mother still lives in to this day. My mother and I are now in a situation I never would have dreamed of. I am someone who always searches for the goodness in life. I’ve learned to lean on my faith and I’ve developed a deeper bond. But this last six months of his life I could only manage to get through at all because of the support of friends and family. My mom and I have never met a more amazing family of people. It’s not just one of them, it’s the whole family. Over the last six months, Bruce made a difference. I think he gave us all hope. He truly believed hope matters.”

KAREN TELARICO
Daughter of Bruce Alfred Jester

KAREN KENDALL
Diagnosed with PSP

Diagnosed with PSP

Diagnosed with PSP

Diagnosed with PSP

Diagnosed with PSP