Visiting the Shepherd Center

DAVID KEMP
PRESIDENT, CUREPSP

After a traumatic brain or spinal cord injury, many things become uncertain. Fortunately, there are a number of great rehabilitative care centers in the United States that can help a person rebuild their life. The Shepherd Center in Atlanta, Georgia, is one such center that maintains a great track record for rehabilitation. What the Center is doing today may be helping to shape the future of neurodegenerative disease treatment.

When James Shepherd graduated from the University of Georgia in 1973 at the age of 22, he set off on an international backpacking trip. While bodysurfing in Brazil, he sustained a severe spinal cord injury that left him paralyzed from the neck down. Once James and his parents, Harold and Alana Shepherd, returned to the U.S., they realized how few rehabilitation care options existed in the Southeast, so they decided to do something about it. With the help of friends, family, and supporters, the Shepherd Center was founded in 1975 as a six-bed unit, operating out of leased space in an Atlanta hospital. Since then, the Shepherd Center has grown to its current size with the help of supporters like Bernie Marcus, chairman of The Home Depot, and the Woodruff family, noted Atlanta philanthropists.

Today, the Shepherd Center is one of the leading facilities of its kind in the world, with 152 beds and more than 1,500 staff members. The Center is committed to helping patients reach their therapy goals so they can return to home, work, school, or their community. It is the only rehabilitation center in the nation to have its own intensive care unit onsite, and its return-to-home and work rates are among the best in the country. Patients travel to Shepherd to rehabilitate from every state in the U.S. and also from 62 other countries.

The Shepherd Center utilizes many advanced treatments, including but not limited to:

- The Indigo robotic exoskeleton that allows paraplegics to walk
- “Sip and puff” control for power chairs with a computer game to train patients how to control their 300-pound chairs
- Computers controlled by eye movements and tongue studs
- Functional electric stimulation
- Bicycles and electrodes for upper and lower extremities
- A variety of specific rehabilitation and mobility equipment, much of which is custom made onsite

Besides the technology, Shepherd also uses service dogs to help patients reach their rehabilitation goals. They bring comfort to patients after a hard day and motivate them to participate in exercises. The service dogs, which are primarily yellow Labrador retrievers, are trained to obey more than 90 different commands, including opening the refrigerator and retrieving specific items. They will snuggle with patients and are trained to anticipate when they are having...
nightmares, then move closer to them for comfort. Additionally, they can predict when a patient is going to have an epileptic seizure and warn staff. The service dogs have many rehabilitation duties, but they're also excellent at simply making patients laugh and smile.

Shepherd also treats about 50 soldiers a year under its SHARE Military Initiative. This program focuses on evaluating and treating service men and women who served in the Afghanistan and Iraq conflicts, sustained a mild to moderate traumatic brain injury, and developed post-traumatic stress disorder. The program collects data that can be valuable for legislative change to support unfunded services.

The Shepherd Center conducts up to 50 research projects annually. They maintain clinical data on patients during their time at the facility and also afterward. As a result, they are able to provide cohorts for clinical trials, which is a vital step in furthering brain research.

A former patient and Army veteran, who sustained a head injury in Iraq, recently gave a moving talk about his rehabilitation at Shepherd and his continuing challenges. He still struggles to speak clearly because of his brain trauma, but he has been greatly helped by speech therapists at Shepherd. Patients like this fuel the mission to unlock the linkage between repeated concussions and chronic traumatic encephalopathy (CTE), which isn’t necessarily the underlying cause of this soldier’s diagnosis, but is still important research for many patients at Shepherd. CTE, Alzheimer’s disease, progressive supranuclear palsy, corticobasal degeneration, and multiple system atrophy all fall under the same umbrella of neurodegenerative diseases, known as tauopathies, because they all share the same underlying tau protein misfolding mechanism. As a result of this shared commonality, an Alzheimer’s or CTE-related research breakthrough could potentially unlock the mysteries of PSP, CBD, and MSA.

We are expanding our peer supporter volunteer position. Peer supporters are family members of those who have had PSP, CBD, or MSA, and their role has been to contact other family members by phone to offer individual support. While we continue to recruit more support group leaders, many people don’t have a group nearby or are limited in their ability to travel, which is why peer supporters are so important.

Our plan is to connect new callers to a ‘buddy’ so that a contact with a peer supporter is part of our standard level of care. In connection with this, we will be asking people who are newly diagnosed if they would like to talk with someone who has also just received a diagnosis.

We understand that with PSP, CBD, and MSA, a diagnosis can take a long time and people may have had symptoms for years before the diagnosis is clear. However, there is a need for support once the diagnosis is made, and this is where peer supporters can be of great help. If you have questions or would like to volunteer, please contact Kimberly Anderson at 800-457-4777 ext. 5668 or anderson@curepsp.org.
My husband, Terry Watson, was diagnosed with PSP. After his initial diagnosis, I searched the internet to learn more about the disease, and that is when I was fortunate enough to find CurePSP’s website. The site provided information on local and online support groups, as well as helpful phone webinars. Immediately, I began participating in the online support group meetings. It was convenient and simple to connect with people all over the country who were suffering with the same disease. There were several opportunities to participate during any given week, and when caring for a loved one with PSP, you never know ahead of time when you will have the time and availability to participate.

Through my internet research, I also found a list of face-to-face support groups all over the country and honed in on the contact in my area. I made the call and met the then-facilitator, Kathy Orr, for coffee. As it turned out, she was in the process of meeting people like me to start the support group in our area. Our early meetings were held in a school library room, but as the group grew, we sought out a more accommodating facility. When our group was in between facilities, we met at either Kathy’s house or mine, but this was difficult for many who were in wheelchairs or walkers. One of our participants had a father with PSP who was housed at the Kris Leigh Assisted Living facility in Severna Park, Maryland. She was able to secure a conference room that we are still using today, thanks to the kindness of the Kris Leigh staff.

This experience has been very rewarding on so many levels. First, my husband looked forward to attending the meetings because he could relate to others who shared his journey. The patients were open and candid about their feelings regarding many issues and the interchange of information helped them cope with their eventual decline. Sometimes the meetings became emotional, and other times there was much laughter. To witness this interchange of conversation was so valuable to me.

Occasionally, we would have a guest speaker. For example, Terry had a personal trainer who volunteered her time to attend our meeting and demonstrated ways one could exercise in bed, a wheelchair, with a walker, or sitting in a chair. The group absolutely enjoyed this event because it made them feel unrestricted.

For me, the rewards have come from helping others. If you have been, or are presently, dealing with a loved one who has PSP as a carepartner, spouse, family member, or friend, you know how important it is to feel hope in a very hopeless situation. Facilitating a support group gave me HOPE that, if nothing else, my husband would have a decent quality of life.

If you are considering this volunteer position, be assured you will reap many rewards from the experience. The Foundation offers training that provides guidance and offers recommendations regarding the format of the meeting. It is not difficult; once you bring a group together it just takes on a life of its own.

Healing through Art Therapy

KIMEKO MCCOY
THE ST. AUGUSTINE RECORD

At one time, longtime resident of Crescent Beach Edward Stusnick was a talented craftsman whose specialty was woodworking. Wife Suzanne says he’s multi-talented in the respect that he made and redesigned furniture, created children’s toys, and everything in between. Even the Stusnick home, Suzanne says, is built from scratch.

The eldest of the Stusnick daughters recalls their father as an easy-going wisecrack who was the life of the party. So when the family noticed their father’s health problems becoming increasingly worrisome, no one knew quite where to place the blame. It wasn’t until about two years ago, when Edward’s vision began to fade and he discovered weakness in his eye movements, that the problem became clear. He was diagnosed with progressive supranuclear palsy or PSP.

“In my wildest dreams, I would never have thought anything like this would happen,” Suzanne said.

PSP is a neurodegenerative brain disease, according to the PSP website, that affects the nerve cells that regulate walking, balance, mobility, vision, speech, and swallowing. There is no known cause, treatment or cure.
Meeting Edward

Edward and Suzanne have been married for 58 years. The two were in the education field in New Jersey when they married.

From the beginning, Suzanne noticed Edward’s pronounced interest and talent in woodwork. “He always loved woodwork,” she said. “That was his favorite.”

Throughout their marriage, Suzanne says they made everything including their home. The two even started their own refurbishing company. Between the two, they had the talents of cooking, tennis, woodworking, education, health, and creativity.

“We always worked as a team throughout our marriage,” she said. After New Jersey living, Suzanne and her husband sought after a life in Florida where they’d always wanted to live.

The Stusnicks have two daughters: Cassandra Lietz and Denise Rosetto. The oldest, Lietz, said she remembers coming to St. Augustine with her family on camping trips. Childhood memories like those are what highlight her father in her mind. To Lietz, Edward was a giver who was fun and always around. She said she was close to him and finds a lot of her father in herself. “I think we’re alike in a lot of ways,” she said. While both parents were artistic, Lietz said she really admired her father and through him, she honed her own artistic abilities. “Art seemed like a natural inclination,” she said. For the last 31 years, Lietz has been an art teacher pulling inspiration from both of her parents.

Diagnosed with PSP

When the Stusnick family started to learn about Edward’s health issues, they took him to Mayo Clinic where he was diagnosed. They quickly found out that the disease was not only rare, but devastating. Between little information and no support groups in the area, the family was unsure of what to do.

“I don’t know of anyone who has had it,” Suzanne said. “It’s such a rare neurological disease.” Lietz said she recalls her parents having an overall healthy and active lifestyle. “I didn’t really know what it meant,” she said. “I knew he had health issues.” Instead of falling apart, the already close Stusnick family only banded closer together. “I’m like, bring it on,” Lietz said.

Ed & Co. Clay Artistry

After Edward was unable to continue his woodwork, the Stusnick family relied on what they knew and introduced their father to working with clay. It was a hit with the whole family.

“He enjoyed it because it was a form of creativity,” Suzanne said. The family started at an elementary level but as time went on, they were able to really create some alluring clay art. “It became our family thing for about two and a half years now,” Lietz said.

Lietz and her mother do the painting designs while Edward suggests ideas, rolls out clay and puts on the finishing touches. Initially, the family gave the artwork away, but after considering the amount of work and talent produced, they figured they would sell it and donate the profits to PSP research.

The clay work was well-received, and to date, they have sold more than $1,000 worth of clay art for the CurePSP foundation. “It was fun learning these things and knowing you can produce some very beautiful items,” Suzanne said.

The artwork is not meant to be a business, but the Stusnick family makes it their business to raise funds and awareness for Edward’s disease.

Waiting for a Brighter Day

PSP is listed in the same category as Parkinson’s disease. But PSP is rare because it’s only about one percent as common as Parkinson’s, and when it does occur, it is often misdiagnosed. According to the CurePSP website, no one even realized the disease existed until 1964. It’s a progressive disease, which means early symptoms only get worse and new symptoms tend to develop over time.

Edward’s mobility is declining, and as of December, he’s been in the hospital twice and hasn’t recuperated enough to continue pursuing clay work. During the day, the family has a day nurse to care for Edward. Lietz’ son P.J. is a physical therapist, and, every night, he cares for his grandfather. “He’ll tell you he doesn’t want to die, and that breaks your heart,” Lietz said.

Although some days are better than others, the Stusnick family has held on. Lietz says her father has been to the Gator Bowl, Eric Clapton shows, and other events. It’s a challenge, but to Lietz, health problems shouldn’t be a cause for your life to stop. When the weather warms up, Suzanne hopes to get Edward back into his niche as he’s expressed excitement about it.

This article by Kimeko McCoy appeared in The St. Augustine Record on February 11, 2015.
An Update on Our Family Conferences

TRISH CARUANA, MSW
EXECUTIVE VICE PRESIDENT, EDUCATION AND SUPPORT, CUREPSP

Family Conference, Gainesville, Florida, February 7, 2015

If there is one event that personifies CurePSP’s commitment to those affected by PSP, CBD, and MSA it is our annual family conference. Over the past five years, we’ve traveled to Los Angeles, Boston, Dallas/Fort Worth, Denver, Newark, and, on February 7, 2015, to Gainesville, Florida.

I am pleased to report that we not only exceeded attendance from all past conferences at 150 attendees, but the feedback we received on both the topics we offered and the presenters who spoke was also excellent. This year, we held a support group the Friday evening before the conference that was very well attended. The support group allowed those who came for the conference to connect with one another, discuss the reasons they were attending and what they hoped to get out of the experience. I facilitated the group and it was evident that the 30 people who attended found the experience valuable, indicating it should be a part of every conference. I want to thank all of the professionals who donated their time and expertise to make this event successful, including Doctors McFarland, Golde, and Wicklund, Troche, and physical therapist Joellyn Fox. You can watch the conference on our YouTube channel at: http://www.youtube.com/user/curepsp

Canadian Family Conference, Ottawa, Ontario, June 13, 2015

This year is our first family conference in Canada and we are pleased to host it with our newly formed affiliate, CurePSP Canada. As with all of our conferences, people have attended from many countries outside of the U.S., so this is a great opportunity to participate in our second conference of 2015. The agenda of presenters is being set and topics will cover PSP, CBD, and MSA research updates, Q&As with movement disorder specialists, practical management of symptoms, cognitive and psychological challenges, and ways to maximize support systems. We will have a support group on Friday, June 12, 2015, which will also include the opportunity to meet the members of the Canadian Board of Directors. If you would like to volunteer on the day of the conference, please contact Debbi Giroux at giroux@curepspcanada.ca for more information. The Canadian affiliate is also actively seeking new volunteers from across Canada to contribute their ideas and energy—if you’re interested, please contact Mary Ellen Duncan at duncan@curepspcanada.ca.

Interested in helping the atypical Parkinsonian community in advancing progressive supranuclear palsy (PSP) and corticobasal degeneration (CBD) research?

We are currently conducting new clinical trials on experimental therapeutic drugs with the potential to slow disease progression and research studies to identify gene variations, better diagnostic tools, and clinical rating scales to measure disease progression.

Participation may include:

- Clinical evaluation by a movement disorder specialist
- Cognitive testing
- Biomarker collection such as blood, saliva, urine and/or cerebral spinal fluid
- MRI scans
- PET scans
- Study partner interviews

For more information on current movement disorders research, please call (858)-822-5786, email: MDCresearch@ucsd.edu, or visit our website: http://movementdisorders.ucsd.edu

PSP and CBD Research Studies at NPF’s Newest Center of Excellence Site, UC San Diego’s Movement Disorder Center
Brenda Reams serves as the facilitator for a PSP, CBD, and MSA support group in Fairfield, Ohio, that is open to patients, families, friends, carepartners, and anyone else affected by the diseases.

Who in your life has been affected by PSP, CBD, or MSA and how did you find out about our organization?

Everyone around me is affected by MSA because I’m the one who has it. It was so uplifting to be around other people who had so much in common, specifically information and suggestions from people at different stages of their battle. Discovering the CurePSP Foundation was a true blessing for us! We continued to attend the annual Awareness Walk and began a close relationship with CurePSP.

After mother passed in October 2008, I began to receive phone calls from family members who were dealing with the disease. At first, their questions were hard for me to answer. It had only been a few months since she passed and they brought back memories of problems we had encountered during Mom’s journey. Her softer speech, falls, swallowing issues, and many other symptoms, all common in the progression. The families seemed so desperate to talk with someone who knew and understood PSP. I felt a strong calling that a support group was needed in the area.

Our first meeting was in March 2009. There were eight of us who attended. Experiences, questions, and emotions were shared. I think there is a bonding that occurs and that is why people continue to attend the meetings. I have never regretted my decision to start the support group. Initially, it helped me with the healing of Mother’s death. She had always said, “If it will help others, then let’s do it.” I am carrying out her wishes.

In the past six years, we have had the pleasure of meeting so many afflicted people, their families, and loved ones. They come with many questions, seeking help and support. We work hard to provide that throughout their difficult journey.

The rewards of being a support group leader give you a different outlook on life. Being able to give and help others during a very difficult time in their life makes you a better person. Anyone considering taking on the role of a support group leader will find their life greatly enriched.

If It Will Help Others, then Let’s Do It

CYNTHIA MACDONALD
SUPPORT GROUP FACILITATOR

In 2005, we saw an article in the local paper advertising “CurePSP Awareness Walk.” Our mother had gotten her PSP diagnosis several months earlier. She was living with us at this time. Mother had always been a very outgoing, strong lady. She was very independent. She became even more so after the unexpected death of our father at the age of 60. Her courage and strength during that period of our lives bonded us even more as a very close family.

We all attended the event, thrilled that we had found others with the disease. It was so uplifting to be around other people who had so much in common, specifically information and suggestions from people at different stages of their battle. Discovering the CurePSP Foundation was a true blessing for us! We continued to attend the annual Awareness Walk and began a close relationship with CurePSP.

Brenda Reams serves as the facilitator for a PSP, CBD, and MSA support group in Fairfield, Ohio, that is open to patients, families, friends, carepartners, and anyone else affected by the diseases.

Who in your life has been affected by PSP, CBD, or MSA and how did you find out about our organization?

Everyone around me is affected by MSA because I’m the one who has it. It is my desire to touch those around me in some shape or form. When I was diagnosed, I didn’t know anything about PSP, CBD, or MSA. I googled MSA and CurePSP came up. CurePSP has been the organization there with the most help and knowledge. They are always ready with positive help and suggestions. I recommend CurePSP for help with all PSP, CBD, and MSA questions. They really care!

What made you decide to become a Support Group Leader and what has been the most valuable aspect about being a Support Group Leader?

When I went on the CurePSP website, I found the list of support groups near me. The nearest one listed was two hours away, in Louisville, Kentucky. So my husband and I took a day and drove to a meeting. The support group leader, Dan Heins, and other members met us with open arms. Dan’s wife has PSP. We left with a lot of new knowledge and friends. Dan even gave me an extra rollator he had. Dan and Kim inspired me; if they could help people, I could, too. The most valuable aspect about being a support group leader is the people you come in contact with; everyone from Trish and Kim to the people who attend the meetings. Everyone has something they contribute and I learn so much.

What advice would you give to someone that is unsure about becoming a volunteer?

Everyone has something to contribute, no matter how large or small. My 25-year-old has even sat outside in near-freezing temperatures to help me collect donations for PSP, CBD, and MSA. Every little bit helps and adds up. You are not alone. Hope does matter. CurePSP will send you valuable resources to help with your journey.

How long have you been volunteering?

My first support group meeting was held on September 25, 2014.

Brenda’s Support Group

Information: For patients/families/friends/caregivers affected by PSP, CBD, MSA, and related diseases
Location: Fairfield Lane Library, 1485 Corydale Drive, Fairfield, OH 45014
Meeting Time(s): Last Thursday of every month (excluding holidays) at 6pm, contact facilitator for more info
Facilitator: Brenda Reams, 513-860-2912
I am Richa Kanojia, daughter of Mr. Ramesh R. Kanojia and Mrs. Rena R. Kanojia. I am writing this article on behalf of my younger brother and elder sister.

My mother was just 58 years old when we lost her to progressive supranuclear palsy (PSP). Mother was a kind-hearted, fun-loving woman who got along easily with everyone. She liked to cook and everybody in our family loved her food. My mother even participated in a cooking show once. Even though she was a housewife, it never stopped Mother from taking on social responsibility. She was once the President of the Women’s Association in our community, until she was diagnosed with PSP.

Mother was diagnosed with PSP in June 2011 by our local neurologist, Dr. Dushyant B. Chauhan. Before getting diagnosed with PSP, she used to complain a lot about her back and knee pain, and was taking an orthopedic treatment for the pain. When she stopped getting relief from her physiotherapy and orthopedic treatments, a friend of mine who was working as a physiotherapist, suggested that my mother get an MRI. The scan results confirmed the presence of PSP.

In the beginning of the diagnosis, we didn’t know much about the disease and ignored the importance of physical exercise. My father was the only one aware of what was going to happen to our mother in a few years. Doctors informed him that PSP had no cure and only physiotherapy and the help of loved ones would help slow my mother’s decline. After a year, our family doctor asked us to take better care of Mother and he explained to the rest of our family what exactly PSP was. We were utterly shocked and didn’t know what to do. We consulted with another doctor, Dr. Singhal from Mumbai, and his answer was also the same, that she was suffering from PSP and there was no cure.

Before consulting the doctor in Mumbai, we did a little internet research on our own and found out about CurePSP, an organization in the United States. I contacted them and found out that there was no such organization in India for PSP. Dr. Singhal suggested that I keep looking at CurePSP’s website for any news about upcoming clinical trials. I eventually found a suitable clinical trial, but it was not feasible financially for us to participate because it would have involved traveling to San Francisco. We didn’t lose hope, though, and I looked for other alternative therapies that could help us, but it was all was in vain. We tried acupressure treatment, foot massage treatment, and Ayurvedic medicine, but none of it helped.

PSP patients require specialized care and treatment, which we lacked. During the course of the disease, my mother had one major fall while using her walker in which she broke her lower jaw. After that incident, she lost confidence in her mobility, so we began needing to help her move around the house. My father did an excellent job of taking care of my mother, but soon she started having problems with swallowing food. Even then, she never lost hope and would laugh out loud when silly jokes were told. She also maintained her interest in the outside world and loved to roam around the city.

It was only after my father’s sudden death that my mother lost her hope. She began to get weaker day by day. Eventually, our neurologist suggested that my mother have a PEG tube implanted, but she refused. Just one month after my father’s death, my mother died. My parents loved each other so much that they didn’t want to live without one another.

PSP does not only affect the people suffering from it, but also those around them. It requires a lot of mental and emotional strength. It’s very painful to look at your loved one progressively losing their hope and charm of life. I can’t even imagine the pain my mother went through during that period of her life. PSP turned a fun-loving, enthusiastic person into someone else. I have no words to describe it.

Sharing Your Personal Story

Have you thought about writing about your experience with PSP, CBD or MSA? If you’ve been affected by these diseases, we want to hear your story. We often feature personal stories on our website and in our newsletter. Writing about your experience with PSP, CBD or MSA can be helpful in dealing with the powerful emotions that often surround these diseases and may help to bring some sense of closure for those that who have lost loved ones to the disease.

If you’re finding it to be a difficult task, here are some things that might help. Set aside a few minutes each day to jot down some of the important points you want to cover. Once you’ve gotten more than five or so, write a few short sentences about each point. Then come back again later and write a few more. Put the paragraphs together and start adding in more details and filling in the gaps.

Submit your stories, along with high resolution photographs, via email to Bruce Janele, Director of Communications and Public Awareness, at janele@curepsp.org.
Upcoming Events  OPPORTUNITIES FOR LEARNING AND SUPPORT

SPECIAL EVENTS

1st Annual CurePSP Charity Ride 2015
Saturday, June 20, 2015
Arlington, Washington
http://ride2015.kintera.org/curepsp

10th Annual Putt for PSP
Saturday, July 25, 2015
Syracuse, Indiana

1st Annual Neil Williams Memorial Golf Challenge
Friday, August 7, 2015
Braselton, Georgia

CONFERENCES

CurePSP Canadian Family Conference
Saturday, June 13, 2015
Southway Hotel
Ottawa, Ontario
http://www.curepsp.org/events/family-conferences.html

NEW SUPPORT GROUPS

Manitoba - Winnipeg
Information: Patients, caregivers, and family affected by PSP, CBD, MSA, or other disorders
Location: Bronx Park Centre, The Meeting Room, 720 Henderson Hwy, Winnipeg, MB
Meeting Time(s): Last Tuesday of every month, 6:30pm-8:00pm
Facilitator: Kristyn Luft, 204-541-0211, krisshew@gmail.com

Florida - Tallahassee
Information: For anyone affected by PSP
Location: Westminster Gardens, 10th floor meeting room, 301 E. Carolina St., Tallahassee, FL 32301
Meeting Time(s): First Monday of every month at 2:00pm
Facilitator: Ann Foster, 850-980-6875, afoster75f@juno.com