As caregivers, we tend to forget about ourselves and focus primarily on the care of our loved ones. Unfortunately, this can cause caregiver stress and may jeopardize our own health or peace of mind.

Identify your concerns: What do I need most, or first?
The categories of concerns that follow are intended to empower you as a caregiver and help you to prioritize your needs. Attempting to respond to all of them at once would be overwhelming. Instead, take your time and determine what is most helpful for you in your present situation.

Disease and/or Caregiver Education
CurePSP has numerous materials and online resources to help educate you about the diseases as well as the challenges and opportunities of caregiving. Contact CurePSP at 347-294-2873 or visit www.psp.org. You can also try AARP (www.aarp.org/caregiving) and Family Caregiver Alliance (www.caregiver.org).

Time Management Skills
Managing the care of a loved one is like running a company. You face a series of daily routines and problems that need solving. Ask yourself: How can I make this as easy as possible on myself? Can I organize, prioritize, or delegate some of the tasks?

Stress Management Skills
Stress management is an essential aspect of caregiving. Recognize when you are stressed and know when to set your limits. There are numerous resources on the web for stress management, and you will be able to find one that is suited to you. Do not overlook this.

Self-Care
While your number one focus is your partner, you can’t take care of them unless you are physically and mentally capable of the challenges. You have to be healthy. Take exercise breaks, rest when possible, eat healthy food, and don’t be afraid to accept help, even if it means simply taking a break and relaxing for an hour.

Emotional Support
You alone can do it, but you don’t have to do it alone. Caregivers need a place to vent their emotions and not feel guilty about sharing their feelings and concerns. Some choose professional counselors, family members, friends, or faith counselors, while others seek out support groups.

Continued on page 3
Your continued support over the years has made it possible to maintain a world-class research program that we are immensely proud of, and I want to share with you some of the amazing work being done with your gifts.

**CurePSP Venture Grants**

In the Spring 2018 issue of this newsletter, I wrote that we were reviewing proposals for our Venture Grants and promised to announce the winners in this issue. I am proud to say that, because of your generous support, we have awarded four new grants.

**Dr. Ed Burton**  
University of Pittsburgh, PA  
Awarded $59,449 for one year

**Functional Evaluation of PSP GWAS Genes in a Tauopathy Model In-Vivo**  
Dr. Burton and his team will investigate certain variations in so-called risk genes that increase or lower the risk of developing PSP. By targeting each of the candidate genes, the Burton lab will clarify their roles in neurodegeneration, providing a basis for future studies to develop effective drugs to treat PSP.

**Dr. Todd L. Cohen**  
The University of North Carolina at Chapel Hill, NC  
Awarded $100,000 for two years

**Uncovering Unique Tau Profiles That Distinguish PSP From Other Tauopathies**  
Central to PSP are aggregates of abnormal clumps of the tau protein that lead to impaired neuron function, behavioral abnormalities, and cognitive deficits. Dr. Cohen’s research will focus on the prevention of abnormal clumping of tau proteins and, potentially, the onset or progression of PSP.

**Dr. Thomas Koeglsperger**  
Ludwig-Maximilians-University of Munich, Germany  
Awarded $75,182 for two years

**Investigating the Role of Syntaxin 6 (STX6) for Tau Protein Cell-To-Cell Transmission**  
One of the risk genes associated with PSP is named Syntaxin-6 (STX6). In this study, Dr. Koeglsperger aims to manipulate the expression of STX6 and study the uptake of tau protein in cultured human neurons, providing further insight into the cause of PSP, and supporting the investigation of new drugs to halt the progression of the disease.

**Dr. Xiaobo Mao**  
Johns Hopkins University School of Medicine, Baltimore, MD  
Awarded $75,000 for one year

**The Role of TTR1 in Mediating Tau Spread In Vitro and In Vivo**  
The underlying mechanisms of abnormal tau spreading in the brain are not well known. Dr. Mao’s experiments will provide new insight into these mechanisms and potentially reveal a novel therapeutic approach to treat PSP or CBD.

Thanks to the support of our donors, these four studies will improve our understanding of PSP and lead to future development of treatments. Please visit [www.psp.org/research](http://www.psp.org/research) to read more about the amazing research CurePSP is involved in to treat and cure PSP and related prime of life brain diseases.

*Continued on page 5*
Tips for Caregivers (continued from front cover)

CurePSP has approximately 100 volunteers who are available to take your calls and approximately 50 support groups nationwide. The majority of our volunteers were once caregivers and understand your journey. Do not hesitate to contact them. The support groups and peer supporters are listed on our website at www.psp.org/supportgroups.

Community Services and Resources
Knowing the local services and resources available to you is very important. You may also need to identify and obtain products to assist your loved one with daily activities or mobility. Our online SmartPatients Forum (www.psp.org/ineedsupport/forum/) provides information about helpful adaptive equipment. CurePSP and the Alzheimer’s Association (www.alz.org) are good resources for this purpose.

Finances, Home Care, Long-Term Care Planning, Healthcare Powers of Attorney
You may have thought these concerns were still years away and may not have had anything in place when PSP struck. A social worker or personal attorney would be able to assist you with sorting out these very important details. You can otherwise seek out a geriatric care manager or eldercare attorney in your area.

SOME QUICK TIPS
This is simply a list of tips that may help you over the course of your caregiving. Cut it out and place it somewhere in your home where it will be a gentle reminder to also take care of yourself.

- Prioritize your concerns or needs
- Think about and jot down “action steps” that you can take to deal with those concerns
- Develop a support network of professionals and nonprofessionals
- Discuss your ideas and needs with people in your support network
- Implement your ideas with help from others
- Build in quality time for yourself—an hour or more a day, if possible
- Keep up with your own hobbies
- Exercise means better sleep, more energy, and decreased tension and depression
- Try to practice some relaxation or meditation techniques
- Eat balanced and nutritious meals
- Drink water
- Get enough rest
- Take time to relax and have fun
- Maintain a sense of humor
- Get regular check-ups and keep your own medical appointments
- Use positive self-talk (“I am doing a good job.”)
- Know that it is okay to cry
- Seek comfort from your faith and/or spiritual practices
- Find meaning, insight, and an acknowledgment of your strengths
- Beating A Carepartner
This signature book, an excerpt from our 2018 CurePSP Guidebook, covers all things carepartners should know about caring for a loved one with a prime of life brain disease.

From caring for your partner to caring for yourself, this book includes chapters such as: “Making Meaning to Stay Positive”, “Caregiver Stress and Burnout”, “Keeping Families Strong”, “The Seven Deadly Emotions of Caregiving”, and more.

Read and download the book from our website at www.psp.org/carepartner-resources or call Carol Henry, CurePSP Gift Processing/Data Quality Coordinator, at 443-578-5670 to have a copy sent to you. This brochure is made possible by our caring supporters and dedicated contributors.
The Hope Tour

The Hope Tour is a collaboration between CurePSP and the Light of Day Foundation to raise money for families affected by prime of life neurodegeneration, including progressive supranuclear palsy (PSP) and related diseases. The Hope Tour combines Light of Day’s blockbuster fundraising concerts with CurePSP’s programs and services to directly support families dealing with the devastating effects of prime of life neurodegeneration.

Recognizing the enormous financial and emotional toll these diseases can take on the sufferers and their families, and the need for research into cause and cure, CurePSP will identify which programs to support with money raised from fundraising appeals, concerts, and other events. CurePSP is grateful to Light of Day for its continuing support through generous matching grants. Stay tuned for future Hope Tour Events!

The Stavros Niarchos Foundation Grant

CurePSP has received a two-year, $50,000 grant from the Stavros Niarchos Foundation (SNF) to support the Cherie Levien Quality of Life Fund. This fund was established in 2017 in memory of Mrs. Levien by her husband, Lawrence Levien, and family.

The Stavros Niarchos Foundation (SNF) is one of the world’s leading private, international philanthropic organizations, making grants in the areas of arts and culture, education, health, sports, and social welfare. Since 1996, the Foundation has committed more than $2.5 billion through more than 4,000 grants to nonprofit organizations in 124 nations around the world.

The SNF funds organizations and projects that exhibit strong leadership, sound management, and aim to achieve a broad, lasting, and positive impact on society at large. The Foundation also supports projects that facilitate the formation of public-private partnerships as an effective means of serving public welfare.

How Research in PSP and CBD Helps in the Fight

[Diagram showing comparisons between Alzheimer’s Disease, Parkinson’s Disease, Progressive Supranuclear Palsy, and Corticobasal Degeneration]

ALZHEIMER’S DISEASE
- 5.7 million patients in the U.S.

COMMONALITIES
- MAPT/TREM2 risk genes
- Tau protein misfolding, templating, spread, and aggregation
- Associated with less education

PARKINSON’S DISEASE
- 1 million patients in the U.S.

COMMONALITIES
- Protein misfolding, templating, spread, and aggregation
- Major mitochondrial defect
- Dopaminergic loss
- Associated with well water use

PROGRESSIVE SUPRANUCLEAR PALSY & CORTICOBASAL DEGENERATION
- 23,000 patients in the U.S.
Brain Bank at the Mayo Clinic
Jacksonville, FL
Your contributions have allowed us to support the work of eminent pathologist Dr. Dennis Dickson at the Mayo Clinic for brain donation and storage. This aids countless lines of scientific inquiry worldwide with essential tissue samples, and also informs the patient’s family, through autopsy, of a final, accurate diagnosis. Your gifts also allow CurePSP to reimburse families for some of the expenses of brain donation. Further information can be found at www.psp.org/brainedonation.

PSP Genetics Consortium
CurePSP and our partners from the Tau Consortium are leading this unprecedented effort to map the genomes of 2,000 people who have suffered from PSP. This study will help us to develop the best possible treatments for PSP and find new drug targets, and wouldn’t be possible without your support. Please visit www.psp.org/genetics to meet the team behind this world-class initiative.

Research News (continued from page 2)

Clinical Trials
You have made it possible for us to partner with leading pharmaceutical companies that run clinical trials on drugs to treat PSP. As the preeminent advocacy organization for PSP, we are publicizing the trials, helping to recruit patients to participate in them, and advising the companies on best practices to keep patients in the trials. Participating in a clinical trial helps bring us closer to a cure. To learn more about enrolling, please visit: www.psp.org/clinical-trials

Thank you for your generous support of this vital mission. You have made it possible to raise awareness of PSP, CBD, and related prime of life brain diseases, fund the best research searching for treatments and cure, and provide a caring, supportive network around the United States and abroad.

Because of you, we have hope.

Alex Klein

Against Related Brain Disorders

OTHER TAU DISORDERS

- Amyotrophic lateral sclerosis (ALS) / Parkinson-dementia complex
- ALS-Frontotemporal spectrum disorder
- Argyrophilic grain disease
- Behavioral-variant frontotemporal degeneration (bvFTD)
- Chronic traumatic encephalopathy (CTE)
- Creutzfeldt-Jakob disease (CJD)
- Dementia pugilistica
- FTD with parkinsonism-17 (FTDP-17)
- Globular glial tauopathy
- Inclusion-body myositis
- Lytico-bodig disease (ALS/Parkinson dementia complex of Guam)
- Niemann-Pick disease type C (NPC)
- Frontotemporal dementia (FTD, Pick’s disease)
- Primary progressive aphasia (PPA)
- Progressive subcortical gliosis
- Subacute sclerosing panencephalitis (SSPE, Dawson’s Disease)

COMMONALITIES
- Tau protein misfolding and aggregation
- Spectrum of pathologic and clinical features
Neurodegeneration does not just impact the elderly; it can strike when a person is in their 40s, 50s, or 60s, when they have family responsibilities, careers, and active lives. While we frequently hear heartbreaking stories about the ravages of PSP from husbands, wives, siblings, relatives, and caregivers, this article acknowledges the sons, daughters, grandchildren, and great-grandchildren who have had to come to terms with the devastation caused by PSP. We present four stories from kids about the effect that the disease has had on them and their lives, how they have dealt with PSP, and how they plan to make a difference and spread awareness.

“I was in fourth grade when my father first went blind for unknown reasons, as he had an odd case of PSP. When he was blind, he lost no motivation and remained very positive and was eager to conquer his new affliction. We would remind ourselves that the disease was affecting his mind and certain things he would say were the disease taking control and not things that he truly meant. I tell my friends about it and really look forward to the release of the documentary on my father called Train Keeps A Rolling, showing his impossible struggle against PSP, and capturing how hard it is to deal with this disease. When this documentary releases, I plan on telling my friends and people I meet about it.”

- Chris Golub

“When I was eight, my Dad went blind and got PSP, but at the time we didn’t know what it was. I would help my Dad by guiding him and mainly helping him with his blindness. My whole family went through a lot, but my Dad always stayed positive, which really helped me deal with it. I think the best way anyone can help at the moment is by raising awareness. If I could tell my eight-year-old self one thing, it would be to spend as much time with my Dad as possible because he was such a great guy and an even better Dad.”

- Matthew Golub

“When I was six years old, my Great-Grandma was diagnosed with PSP. PSP is a really hard thing to watch someone go through. I felt like I couldn’t do anything to help the disease. And not only could I not do anything, I knew that the doctors couldn’t really do a lot either because there’s no cure yet. Watching my Gramms in the final stages of PSP was the saddest thing I’ve ever experienced. I hope that other kids my age whose family members have PSP will be open to learning everything there is to know about it, and not be shy about talking about the disease to other people. I want everyone to know that PSP is a disease that exists. It’s often misdiagnosed, sometimes misunderstood, and it’s an awful thing to watch someone you love to go through. It’s really important to remember that even when your loved one who suffers from PSP can’t communicate with you any longer, they know that you’re there, and they are comforted by the time that you spend with them. They are more aware of what’s happening than you might think, so don’t take those opportunities to spend time with them for granted. I want to make a difference, moving forward, by continuing to stay updated on all things PSP. I feel confident that someday there will be a treatment and hopefully even a cure, so that nobody has to go through what I went through with my Gramms.”

- Cammie Allen
The holiday season is often a time of heightened activity—planning vacations or trips away, visiting friends and relatives, planning and preparing extravagant meals. But for people with PSP and their carepartners and caregivers, it can be a time of heightened anxiety. Dealing with the sufferer’s physical, mood, and emotional changes during this traditionally social time can be overwhelming and lead to withdrawal rather than participation.

In order to help carepartners and caregivers overcome these anxieties, here are some possible anxiety triggers and suggestions of ways to work around them.

**Trigger #1:** You find yourself thinking, “Before my (spouse/partner/family member/loved one) had PSP, holidays were easy/perfect/happy. In the current circumstances, I don’t know how we can possibly celebrate.”

**Adaptive responses:** Don’t glorify the past. In all likelihood, past celebrations also contained some stress, difficulties, and challenges. Try to modify your plans to make them realistic, easier to carry out, and more in line with the needs and schedule of the person with PSP.

**Trigger #2:** You’re reluctant to see certain friends or family members over the holidays because these very people have disappointed you by their lack of concern, help, or visits.

**Adaptive responses:** Prepare yourself for being with these people by thinking about possible ways of dealing with your feelings. How will you feel if you choose not to invite such people or if you decline their invitations? Are you able to consciously put any hurt aside in the presence of these people and focus on enjoying the positive aspects of the holiday events?

**Trigger #3:** How will guests react to noticeable changes in the person with PSP?

**Adaptive responses:** It is not your job to make other people feel comfortable, but if it will help you to feel more comfortable, let friends and family know a bit more about the person’s condition. You might do this ahead of time, in a phone call or a note. Also, you and the person you care for could discuss mutually agreeable responses to questions that may come up from others.

**Trigger #4:** “I’ve done so much giving all year long. I hope someone will ‘give’ to me.”

**Adaptive responses:** Give yourself the gift of respite. This is important on a regular basis, but even more so during the holidays. In fact, the holiday season is a perfect time for you to make a resolution for respite. Consider asking a family member or friend to give you the gift of respite, a period of three or four hours during which you can do something special for yourself.

**Trigger #5:** “I’m afraid of feeling tired and stressed during the holidays.”

**Adaptive responses:** In your holiday to-do list, self-care needs to be one of the top priorities. Make a promise that you will take care of yourself. Eat well, get adequate sleep, drink water, walk, or exercise. Avoid worrying about all the little things. Focus on the most important tasks. Ask for help (see #4 above).

**Trigger #6:** “The holidays are too busy.”

**Adaptive responses:** Slow down. Accept fewer invitations. Stay a shorter amount of time at different festivities. Spend quiet, meaningful time with your loved one who has PSP. Share together how you have each grown and changed on this PSP journey. Share your gratitude for your lives and one another.
Upcoming Events

Opportunities for Learning and Support

Bowling for Pop Pop
December 8, 2018
Sterling Bowl, Sugar Creek, MO 61216

The 16th Annual CurePSP Awareness and Memorial Walk
March 9, 2019
Mackle Park, 1361 Andalusia Terrace, Marco Island, FL 34145

Dallas Caregiver Retreat
May 4, 2019
Texas Presbyterian Hospital
8200 Walnut Hill Lane
Dallas, TX 75231

Family Conference with UNC
June 7, 2019
North Carolina
Location to be announced