News from the Vice President - Scientific Affairs

CurePSP is very proud of its history of funding cutting-edge science projects that will help to find novel therapies for PSP and related disorders. During the last 26 years, we have funded >170 grants with a total volume of more than $13m. In a new series of articles, we would like to introduce you to our grantees and their work. Today, we present the work of Dr. Jori Fleisher and her amazing efforts to improve care for PSP patients by developing a home visit program.

Also, CurePSP has partnered with the FTD Disorders Registry. We invited Dr. Dianna Wheaton, director of the FTD Disorders Registry, to talk about its aim and scope, why a patient registry is important, and how it will help to find better care and therapies.

Best regards,

ALEX KLEIN
CurePSP Vice President - Scientific Affairs

CurePSP’s Participation in Research

We are very excited to announce a new collaboration with the FTD Disorders Registry. This partnership joins CurePSP’s Patient Engagement Program (www.psp.org/ineedsupport/pep/), which works with pharmaceutical companies and research organizations to facilitate human clinical trials.

FTD (Frontotemporal Disorders) is an umbrella term that covers behavioral variant frontotemporal dementia (bvFTD), any of the primary progressive aphasias (PPA), progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), or FTD with motor neuron disease (also called FTD-ALS). The registry is open to people diagnosed with one of these diseases, current and former caregivers, family and friends. As a member of the registry, you can help advance treatments and cures. Please visit www.ftdregistry.org to learn more or, for more information or help with the registration process, contact CurePSP at info@curepsp.org or 347-294-2873.

The FTD Disorders Registry

by Dr. Dianna Wheaton

The FTD Disorders Registry was founded by The Association for Frontotemporal Degeneration (AFTD) and The Bluefield Project to Cure Frontotemporal Dementia. A diagnosis of FTD is isolating, and the FTD Disorders Registry seeks to become a place where patients and families impacted by any of the FTD spectrum of disorders can appreciate their role within the broader FTD community. The FTD Registry is both a contact registry and a research registry. As a contact registry, persons diagnosed with FTD, their caregivers, family members and friends can complete the online JOIN form and receive FTD research updates and the latest registry news. The contact registry is open to U.S. residents and the international community of FTD families.

As a research registry, people diagnosed with one of the FTD disorders, their caregivers, family members and friends can participate in online research surveys and learn about upcoming clinical trials. After creating a

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Research Funding News

CurePSP believes that truly effective clinical interventions will follow good, solid basic scientific research. For this reason, we promote research that helps generate an integrated picture of PSP, CBD and related diseases at preclinical and clinical levels. CurePSP believes that in the long term, research of this nature will prove indispensable in developing a prevention or cure for these and other prime of life diseases.

Care Where It Counts: Interdisciplinary Home Visits for PSP-Related Disorders

Dr. Jori Fleisher, assistant professor, Neurology and Population Health; Amy Lemen, program director; Dr. Alessandro Di Rocco, Founders Professor of Neurology and director of the Division of Movement Disorders, and their team at the Marlene and Paolo Fresco Institute for Parkinson’s and Movement Disorders at NYU Langone Medical Center, New York, NY, received a generous gift from the Nesbitt Charitable Fund, Houston, Texas, in memory of Sarah Boone Nesbitt, who suffered from PSP. Their project is a comprehensive study of the effects on quality of life and healthcare use of in-home visits by an interdisciplinary team consisting of a neurologist, a nurse and a social worker. The new program builds upon the work and research that originated from the Interdisciplinary Home Visit Program for Parkinson’s Disease at the Fresco Institute, which was established in 2014 and supported by the Edmond J. Safra Foundation and the National Parkinson’s Foundation.

Progressive supranuclear palsy (PSP) and related disorders (PRD) are debilitating, costly and understudied conditions that have significant impacts on patients’ and their caregivers’ quality of life. When patients with severe neurodegenerative diseases progress to the point that they can no longer access their usual care, their risk of hospitalization and institutionalization increases. Unfortunately, when these same patients are hospitalized or institutionalized, they suffer from excess morbidity and mortality compared with individuals without movement disorders. There is a tremendous unmet need to foster continuity of care for the sickest patients with neurologic disease. Evidence supports interdisciplinary and home-based models of care in other elderly populations; however, no such models have been studied in people with PRD. Improving access to comprehensive, specialized, in-home patient care and caregiver support offers the potential to minimize the downward spiral of morbidity and preventable healthcare utilization.

Dr. Fleisher’s team wants to test whether, and to what degree, interdisciplinary home visit programs will improve patient- and caregiver-reported outcomes and healthcare utilization when compared with usual care, and to identify unmet needs in this population. To do so, she will recruit at least 20 individuals with PRD living in Manhattan who meet Medicare “homebound” criteria to receive quarterly home visits from a specialized team of a neurologist, social worker and nurse. Visits will include usual clinical assessments, medication and home safety reviews, and discussion of advanced directives and unmet needs. Dr. Fleisher and her team will measure the change in both quality of life and caregiver strain over the course one year. They also plan to compare these subjects to usual care as measured by individuals with PRD living in the community and participating in CurePSP support groups who agree to complete an online survey annually for two years.

This is the first time that CurePSP is engaging in research related to patient care and we are proud to have partnered with NYU Langone in this project. We hope that the results will prove that in-home visits are effective, improve the quality of life of patients and carepartners, and even help to reduce costs that are involved in caring for patients suffering from PSP, CBD and related disorders.

Please visit our Facebook page (www.facebook.com/pg/curepsp.foundation/videos/): Dr. Fleisher was live on our Facebook channel talking about PSP and related disorders.
What is the Patient Engagement Program (PEP)?

CurePSP’s Patient Engagement Program (PEP) was created in 2015 in response to a proposal by Bristol-Myers Squibb (BMS) to partner with them in a study about progressive supranuclear palsy (PSP) from the points-of-view of both a person with the disease and their carepartner. BMS had developed a novel treatment (medication) for PSP with the hope that it would slow the progression of the disease and they were about to launch a clinical trial at multiple sites across the U.S. Partnering with BMS offered a tremendous opportunity for CurePSP to represent the experiences of those who have and are suffering with this devastating prime of life disease. We carefully reviewed eligibility requirements for participants, the study locations and the steps that would be involved at each visit for patients and carepartners.

Following our initial meeting with BMS, I continued to research the challenges of conducting clinical trials and I discovered that:

• The average drop-out rate from clinical trials is 30 percent
• Nearly 80 percent of studies fail to finish on time
• Eighty-five percent of clinical trials fail to retain enough patients

While these statistics are striking, they do not account for PSP patients struggling with symptoms that will worsen over time and make participation in the studies that much more difficult. The goal of PEP is to work in tandem with pharmaceutical companies to address these problems and accelerate clinical trials by providing precise recruitment and personalized retention services. PEP is now collaborating closely with both AbbVie and BMS in their PSP studies.

While PEP cannot assess or enroll people in the clinical trials, we serve as the central point of study information and a voice of advocacy for all people with PSP and their carepartners.

Some of the services PEP provides to pharmaceutical companies include:

• Organizing patients and carepartners who volunteer to share their experiences with PSP study teams
• Reviewing and revising user-friendly materials designed to explain the study to patients and carepartners
• Conducting specialized searches in CurePSP’s database to identify patients in various areas of the country near to study sites
• Identifying medical professionals who treat people with PSP and informing them of the study
• Marketing study information to people affected by PSP via multiple channels including direct mail

Some of the services PEP provides people with PSP and their carepartners:

• Information about studies via the CurePSP website: http://tinyurl.com/PEP-Study-Info
• Study updates as available from the pharmaceutical companies

Trish Caruana, MSW
President, CEO
Patient Engagement Program (PEP)
443-794-4340 OR caruana@pepclinicaltrials.com
Light of Day provides $80K Challenge Grant

Again this year, CurePSP has been chosen by the Light of Day Foundation for an $80,000 matching grant, requiring CurePSP to raise at least an equivalent amount from donors.

The Light of Day is a registered charity that utilizes the power of music to raise money and awareness in its continuing battle to defeat Parkinson’s disease and related illnesses such as PSP and ALS. It started as a birthday party for founder, close friend and band manager Bob Benjamin, who suffers from Parkinson’s. Light of Day’s relationship with CurePSP began in 1998 when co-founder and Executive Director Tony Pallagrosi’s mother Dolores was diagnosed with PSP.

CurePSP is grateful for Light of Day’s support of our cause and we urge our supporters to contribute generously to reach our goal of matching this grant – and beyond. If you would like to take advantage of this matching grant offer, please call our donations office on 443-578-5670.

Your legacy may be a cure

CurePSP relies on the generosity of its individual donors to carry out its mission. We do not receive government funding nor major foundation support. Most of our funding comes through several mailed and emailed appeals during the year and from bequests. Over the last four fiscal years 38% of our income has come from generous bequests.

There are several ways that you can consider to create a personal and family legacy that will recognize your commitment to our cause. These gifts may be current and ongoing, or be willed to the foundation. There are significant tax advantages to these gifts and they can be derived from assets and as a result may not reduce or may even generate current income.

Examples of planned giving would be:

- **Sustaining gift** A pledge from one to five years. This helps CurePSP to project its income and for you to spread out a donation over years.
- **Support gift** Monthly, quarterly, semiannual or annual donations help to give CurePSP predictable cash flow.
- **Tribute gift** To memorialize or honor a loved one. We provide a remembrance page on our web site, and friends, family and business associates can also contribute in memory of your family member who has passed on.
- **Legacy Fund** Family funds with specific philanthropic goals. Friends, family and business associates can contribute and funds will be used in an area of our mission of most interest to your family.
- **A bequest from your will** This does not affect income during your lifetime and is easy to revoke if your situation changes.
- **Gift of stock** in a publicly held company or donation of interest in a closely held business. The gift will be valued at the appreciated value of a traded stock or at the appraised value of a privately held company.
- **Donation of life insurance policy** to CurePSP or name CurePSP as a life insurance policy beneficiary. You can deduct the value of the policy and future premium payments and the value of the policy comes out of your taxable estate. Or you may keep the policy but name CurePSP as a policy beneficiary.
- **Donation of tangible personal property** such as a car, artwork, collectibles, etc. In most cases, you may deduct their fair market value with no capital gains liability.
- **Transfer of real estate interests** or retained life estates wherein you continue to live in your home. In the case of a real estate transfer, you transfer the burden and expense of managing the property, take a tax deduction and remove the property from your taxable estate.
- **Retirement plan distributions** can be done tax-free to CurePSP but will get hit with heavy income and estate taxes if passed to your heirs.
- **Direction of donor-advised funds** to CurePSP rather than charities designated by the fund administrator, which may not be aligned with your interests.
- **Charitable annuities** You make a gift to CurePSP and receive guaranteed fixed payments, often for life.
- **Pooled income funds** A charitable mutual fund, wherein gifts are pooled and invested and investors paid income. When the investor passes on, his or her share is withdrawn and paid to CurePSP.
- **Charitable bargain sale** CurePSP purchases an asset from you at less than fair market value. You deduct the discount and CurePSP realizes the gain upon sale.
- **Charitable lead trust** You may designate some trust income to CurePSP for a period of years, which will reduce possible gift and estate taxes on trust assets passed on to family.

There are many ways to do well while doing good through tax-advantaged donations to CurePSP. Think of leaving a family legacy that will carry through generations by thinking of CurePSP in your financial and estate planning. Please call David Kemp, President, at 802-734-1185 to discuss.
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Brain Autopsy: It Matters.

by Danielle La Porta

The end. The journey is over. Almost 40 years since we met. Where did all the time go?

I miss him and I miss us. Who am I now, without him, without this disease that encompassed the last 40 years of our marriage? This wasn't what we envisioned. Bill looked forward to retiring and getting a part-time job selling peanuts at Citizens Bank Park in Philadelphia watching his Phillies.

Our marriage wasn’t perfect but it was perfect for me. We bickered but we compromised. The reference of marriage of two becoming one, we did. Coming from two very different backgrounds, we forged our own family values. Let me digress and give you an example. In the midst of the disease, I was trying to get him dressed and he was arguing with me. I told him I was tired of arguing. And he smiles (the best he could or maybe I imagined his smile) and says “That’s what we do. If I don’t who will?”

Others have described me as fierce and tough. I simply did what had to be done each day as I was raised that way by a strong Italian mother. Our children were encouraged to live joyful lives while we fought the ravages of this disease. The brain autopsy clearly indicated it was not even the demonic disease we thought he had endured.

Bill had classic PSP symptoms. His first symptom were the dry eyes and very probably the two falls, one from a ladder and one from his bike the year earlier. Yet almost 4 months after his death we found out he did not have PSP. His brain pathology indicated CBD. Now almost a year later, another friend finds out the same.

Quite frankly, the discussion frightened him. But I persisted for the closure it would bring in trying to make sense of a senseless terminal illness. Also, the expectation was to provide much needed health information for my adult children and my husband’s siblings. Finally, I needed to be reassured that I took good care of him: The report did all of that. It didn’t bring him back but I am sure it will help others too. My belief is that leading scholars will keep reviewing these reports. If you have not looked into it, please do. If you need help, don’t hesitate to ask.

I made it through these challenging years with the support of my family, colleagues, church community and dear friends. Where I looked for strength to get through many days and the quietness of nights was the community of PSP online. It was with this support, of my new found friends, that I was able to navigate the chaos of this horrible disease and get through days I never imagined I had the strength to get through. I am so blessed and grateful. Now here is Bill’s story:

“Bill earned his wings and now, hopefully, after a very long hard fought battle, is at peace. In our sorrow, we look for the joy; of the times remembered of the Bill I and so many others loved. Memories of this handsome, stubborn, kind gentleman who loved his family passionately, offered service to others without expecting anything in return, worked endlessly to provide for his family and loved riding his bicycle on the country roads, sharing many of those miles with our daughter. Our children, Jessica and Matthew, were the center of his universe. “I’m so proud of you” and “I love you” were the most important words he could say to them and he never stopped telling them. So as we shed our tears, try to think of all the silly things he did: dancing the night away, body surfing “down the shore”... and now riding his bike into the sunset... with the Lord’s arms wide open.”

Considering brain donation? Please see our web site www.curepsp.org (“I Need Support”) for more information. You may also call the Mayo Clinic Brain Bank Coordinator Jessica Tranovich at 904-953-2439 for more information.

From left to right: Danielle LaPorta, daughter Jessica, son Matthew and Bill LaPorta, at Matthew’s graduation from medical school, May 2010, Stratford, NJ.

Danielle and Bill LaPorta, Turnersville, NJ, on their wedding day, March 8th 1980.
Raising Funds and Awareness: CurePSP Awareness and Memorial Walk

The 14th annual CurePSP Awareness and Memorial Walk took place on Saturday, March 18, in Mackle Park on Marco Island, Florida. The event honors people who are suffering and remembers those who have passed due to PSP, CBD or MSA.

Founded in 2004 by Joan Reifler, in memory of her late husband, Norman, who passed away from PSP in April 1999, the walk was first located at the Naples Bath & Tennis Club. Cynthia MacDonald, Mitch Kanefsky and Christina Dean, along with their team of dedicated volunteers, took it over in 2011, moved it to Mackle Park and re-branded it the CurePSP Awareness and Memorial Walk. The walk is hosted by the Southwest Florida PSP Support Group in Naples, which meets on the second Saturday of every month and which Cynthia chairs and co-facilitates along with Mitch.

“The response of the attendees and the stories they tell of the journeys they take with their loved ones are what motivate us,” Cynthia explained. “Participants come from Florida, out of state and from Canada. We don’t just raise funds; we are trying to extend awareness.”

This year, the event honored the outstanding service and dedication of its founder, Joan Reifler, whose work building attendance, collecting raffle prizes, and, most of all, baking cookies, has been the backbone of the event.

“Every year for the past 14 years, she has baked over 500 cookies for each walk and they are ALWAYS the highlight of the food table,” Cynthia said. “There were a couple of years that she went back to New York before our walk date, but she still baked and froze her cookies to donate. Joan never missed a year! If it wasn’t for her, we would not have our event, and we want to honor her dedication.”

CurePSP would like to thank Joan, Cynthia, Mitch and Christina for their tireless efforts; over 14 years, the walk has raised more than $250,000 in support of CurePSP’s programs of research, awareness and support. At the time of this writing we learned that the day was a tremendous success, and we will offer a full recap with pictures and stories of the day soon. Congratulations Joan Reifler, and thank you Cynthia, Mitch and Christina!
Abigail Sayre  
Hilliard, Ohio 43026

Cure PSP  
30 E. Padonia Road #201  
Lutherville-Timonium, MD 21093

January 9, 2017

Dear Cure PSP,

My name is Abby Sayre and Mary Kay (Dosie) Withrow was my grandmother.

My grandmother had corticobasal degeneration (CBD), a degenerative brain disease that affected nearly every part of her body. She required assistance in every area of her life and was no longer able to understand or communicate. But, as she was throughout her life, she was patient and always kind. She was my inspiration and I loved her dearly.

My grandmother passed away October 30th, 2016, after living with the disease for more than eight years. One of my projects at school was to do something that benefits other people and I chose to raise money to donate to CurePSP. At this time, there is no cure for CBD. My goal was to raise money to help research efforts so that other families don’t have to lose their loved ones to this disease.

In addition to collecting donations through a GoFundMe account, I worked with my grandfather (Mary Kay’s husband) to make 200 cake pops. When someone at my school made a donation, they got a cake pop. My goal was to raise $300 by December 31st, 2016. I made $157 from cake pop donations, plus another $600 through the GoFundMe site. The total amount raised for my project was $757!

The GoFundMe account has already been transferred to CurePSP. Enclosed is a check for the offline and cake pop donations.

I will always miss my grandmother. She was wonderful. I hope that this money helps fund research to find a cure for CBD. I hope that other families don’t have to lose their loved ones to this disease.

Sincerely,

Abby Sayre
Upcoming Events

O P P O R T U N I T I E S F O R L E A R N I N G A N D S U P P O R T

Patient and Medical Professionals Education Day: Focus on PSP
Tuesday, May 9, 2017
Richmond, Virginia

Atypical Parkinsonism Family Education Symposium
Friday, May 19, 2017
Chapel Hill, North Carolina

2017 Midwest Family Conference
Friday, June 23 – Saturday, June 24, 2017
Chicago, Illinois

2017 CurePSP International Research Symposium
Thursday, October 26 - Friday, October 27, 2017
San Francisco, California