

CurePSP connection

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**ALEX
KLEIN**

*CurePSP
Vice President-
Scientific Affairs*

Research News

2018 started out with great news. Thanks to your generous donations, we published a request for scientific proposals to our Venture Grant program, asking researchers from across the globe who are working to find a cure for PSP, CBD, and related diseases to submit proposals that are currently being peer reviewed by our Scientific Advisory Board. Stay tuned! We will publish the winners in our next newsletter.

CurePSP has always believed that truly effective clinical interventions will result from good, solid basic scientific research. For this reason, CurePSP promotes research that helps generate an integrated picture of these prime of life brain 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 PSP, CBD, and related diseases.

Currently Funded Research

Developing Treatments for Swallowing and Communication Deficits in PSP

Dr. Michelle S. Troche, *Columbia University*

CurePSP is very excited to fund Dr. Troche's research in an often overlooked area of care for PSP patients: swallowing and communication. Results of this study could have direct implications on how PSP patients are treated to improve their swallowing and communication skills.

Dr. Troche is a licensed speech-language pathologist (SLP) with research training in swallowing, cough, and respiratory physiology and is a specialist in movement disorders at Teachers College, Columbia University, New York. Her co-researcher, Dr. Lisa Edmonds, is also a licensed SLP and aphasiologist with research training in acquired neurogenic communication disorders and rehabilitation research.



SLPs play a key role in the management of people with PSP as the primary clinicians for the treatment of swallowing and communication deficits. These deficits result in marked health decrements, the impact of which can be dramatic: the inability to converse and communicate wants and needs often leads to social isolation and emotional distress. Unfortunately, there is a lack of literature and research regarding these specific deficits in PSP patients, making it difficult to determine the best standard therapies and treatments.

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Research News (continued)

The overall goal of this CurePSP grant is to reduce death and sickness secondary to aspiration pneumonia and improve quality of life in people with PSP. The goal of this study specifically is to better understand and document the unique difficulties that people with PSP have when it comes to swallowing, coughing, and communication. Dr. Troche's team want to test whether people with PSP can participate in the kinds of treatment techniques that have been found to improve swallowing, coughing, and communication in people with Parkinson's disease and stroke. The Troche lab will invite 30 people with PSP to undergo a series of swallowing and communication tests. The results of this study will help us develop better ways of evaluating and managing swallowing, cough, and communication dysfunction in PSP.

Clinical Trials

It is exciting to see that there are a number of promising clinical trials in the PSP/CBD field, and we have recently updated and reorganized our clinical trials webpage to keep track of the efforts in the field for you. For more information please visit www.psp.org/clinical-trials or call us at **347-294-2872**.

We have partnered with drug developers AbbVie and Biogen in the recruitment and promotion of their clinical trials of compounds to treat PSP, and are helping to recruit patients for two other studies led by researchers at the University of California, San Francisco. Also, please consider registering with the FTD Disorders Registry to receive the latest information about clinical trials (www.ftdregistry.org).



Thanks to your donations, PSP research continues to make great progress leading to many clinical trials and potential new therapies. I encourage you to contact me with your thoughts and ideas at klein@curepsp.org or 347-294-2872.

Best regards,

Alex

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We are proud to bring you the 2018 CurePSP Guidebook, dedicated to Pierre Gervais, and made possible thanks to the generous support of the Gervais family and others.

This signature publication features 150 pages of the latest information on PSP, CBD, and MSA and is the perfect reference for patients, family, carepartners, and healthcare professionals. The Guidebook is available for a suggested donation of \$20. Please call Kelly Saunders, CurePSP Gift Processing Officer, at 443-578-5670, or email saunders@curepsp.org to get your copy.



Letter from the President



**DAVID
KEMP**

*CurePSP
President*

I want to take this opportunity to thank the many, many people who work tirelessly in the field to support CurePSP. Volunteers are the strength and underpinning of CurePSP and without them we could not function effectively. The efforts of our small staff of six full-time and three part-time employees are leveraged by scores of people who work without compensation to advance our mission.

Here are some stats for 2017:

56 support groups serving around 500 people nationwide

100 volunteers providing telephone and online support

42 people running fundraising events with 3,200 people attending

Here are only a few examples:

Ed Plowman (featured in this issue), whose wife Rose passed away of PSP, has been an incredible resource in monitoring our patient forum and helping us with technical issues.

Abby Sayre, a high school student in Hilliard, Ohio, is raising money through events and crowd funding to support CurePSP in memory of her grandmother, who was a victim of CBD. She was recently interviewed by the Fox affiliate in Columbus.

Sandy Waibel, whose mother suffered from PSP, has been volunteering on a regular basis in our New York office. Her can-do attitude and willingness to do anything that needs to be done are inspiring.

Cindy MacDonald, Christina Dean, Mitch Kanefsky, and their team are running their 15th annual fundraising walk at Marco Island, Florida, on March 10. This event has raised tens of thousands of dollars for our cause.

Ileen McFarland, whose husband passed away from PSP, serves on CurePSP's board of directors and has been essentially serving as another staff member working on patient and carepartner advocacy.

Roxi Padrid, Rick Wolter, and Randi Haley all showcase exemplary volunteerism with their commitment to facilitating support groups in their local areas, representing and advocating for CurePSP at local health conferences, and launching creative and impactful media campaigns, like Randi Haley's "Pies for PSP."

Space does not permit the recognition of the many others who advance our cause.

This spirit of volunteerism separates CurePSP from many other nonprofit organizations whose missions, however worthy, are carried out primarily by paid full-time staff.

The terrible experience of having gone through PSP or a related disease with a family member or friend unites people around our mission to defeat the scourge of prime of life neurodegeneration. We encourage everyone to get involved in patient and family support, outreach and education, and fundraising events in whatever way suits your interests and abilities.

Please contact us if you would like to help – we are here to support you. Call 247-294-2871 or email info@curepsp.org.

A handwritten signature in black ink that reads "Dave".

A Message From the CurePSP Patient and Carepartner Advocacy Committee (PCAC)

The mission of the PCAC is to create awareness of CurePSP and prime of life neurodegenerative diseases. This includes helping create and update educational literature and multimedia resources targeted to patients,



**ILEEN
MCFARLAND**

*CurePSP
Board Member,
Support
Group Leader,
and PCAC
Committee Chair*

carepartners, and healthcare professionals; enhancing public awareness of all prime of life neurodegenerative diseases; and identifying local resources and volunteers to support regional outreach programs of CurePSP.

The PCAC has accomplished many of the goals we defined in our Roadmap for 2017. Our committee consists primarily of members who have experienced the loss of a loved one to PSP, CBD, or MSA. They have walked the walk of caregiving and recognize the many challenges of caring for someone with a rare and progressive

neurodegenerative disease. Our members have varied professional backgrounds that complement how each can provide support and advocate for our patients and carepartners. Our committee members are:

Diane L. Breslow, MSW, LCSW

John Burhoe, Board Member and Chair Emeritus

Steven Goldman, PhD, Board Member, Support Group Leader, and Advocate

Steve Garcia, Support Group Leader and Advocate

Dan Heins, Support Group Leader and Advocate

Ileen McFarland, Board Member, Support Group Leader, and Advocate

Roxi Padrid, Support Group Leader and Advocate

Joanna Teters, CurePSP Staff Member, Patient and Carepartner Advocacy

Key accomplishments in 2017 include:

1. Updating our volunteer database to better serve our patients and carepartners. Our committee contacted more than 100 volunteers to confirm their continued support and update their contact information.

2. Hiring a consultant, Wendy M. Resnick, RN, MS, CS, to author the Support Group Leader Training Manual and provide in-person and online training for all support group facilitators.

3. Improving communications between CurePSP and our many volunteers. CurePSP now distributes a monthly email to all volunteers that includes updates on important issues so they may better serve you.

4. Establishing the Cherie Levien Quality of Life Fund with the generous support of the Levien family.

5. Designating May as the annual CurePSP Support Group Fundraising & Advocacy Month.

6. Attending and presenting at various conferences and symposiums to advocate for our mission as well as participating in the CurePSP Family Conferences and Research Symposiums.

7. Attending many support groups and helping establish new support groups.

8. Conducting a survey of all Peer Supporters to offer them improved, focused support.

9. Advocating locally to healthcare facilities and professionals, local governments, and other institutions.

10. Improving our online resources for patients and carepartners.

There are times you, as a relative or caregiver, may feel isolated in the care of your loved one, but we are here to provide support and assistance as you navigate through this disease. As a nonprofit organization, we are totally dependent on donations to continue the programs that benefit you and support the research that we hope will one day lead to a cure. All of these resources directly or indirectly support patients and carepartners, and we are dedicated to expanding our network of support groups and peer volunteers.

Support

Please do not hesitate to contact a support group leader or a peer volunteer. You can locate contact information for these volunteers on our website www.psp.org/supportgroups or call **347-294-2871**.

Volunteer

There are many ways you can help CurePSP fulfill its mission. If you are interested in volunteering, please call or email Joanna Teters at **347-294-2871**, or info@curepsp.org.

Feature Volunteer



Ed Plowman

When Rose Plowman, Ed Plowman's wife of 56 years, was diagnosed with PSP in 1999,

Ed became her primary caregiver, supporting her through her battle until she passed away in 2008. Her diagnosis was confirmed by Dr. Dennis Dixon, following her autopsy at the Mayo Clinic brain bank.

While caring for Rose, Ed suffered a stroke and was told by his cardiologist and neurologist that his days as primary caregiver were over. With the support of their family, Ed and Rose moved in to a family member's basement, which they transformed into an apartment where they could retain a temporary live-in caregiver for Rose and Ed could begin his rehabilitation.

In between intensive rehab sessions, during which Ed returned nearly to pre-stroke condition within a year, he discovered what is now the CurePSP forum (www.psp.org/forum).

He read every single post from its origin in 2003 and, because he also read whatever he could find online about PSP, he soon began responding to posts.

"I began replying to forum posts, answering questions, offering advice based on my own experiences and observations," said Ed. "It's something I am still doing at age 86 as partial payback for the help and encouragement I received from earlier fellow and sister caregivers in the PSP community, including CurePSP and the PSPA (CurePSP's sister organization in the U.K.)."

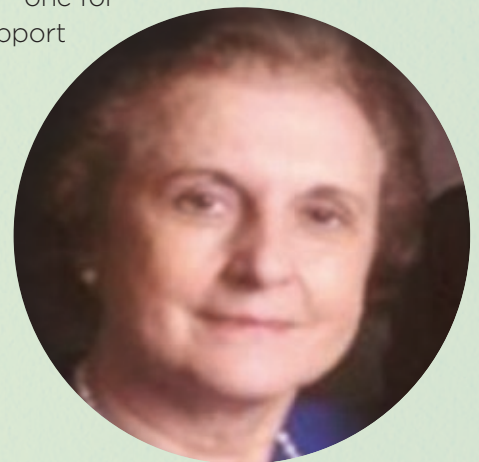
Ed was fortunate enough to be able to recruit and train live-in caregivers — one for weekdays, one for weekends — and he and Rose attended several PSP support groups in their area.

"Probably the most important thing I did was two-fold," Ed said. "Firstly, love, encourage, and spend time with my sweetheart; and secondly, plan and help her with a daily schedule and exercise regimen. These produced amazing results, including near the end, in her quality of life.

"I took her and the caregivers on various trips until she reached late stage, when I often needed to apply the Heimlich maneuver to prevent her from choking," Ed remembered. "By that time, a wonderful hospice nurse was visiting us once a week."

Since his beloved wife passed away, Ed has attended several international medical conferences that convened in the U.S., and became acquainted with some of the most prominent names in neurological research. "On these kinds of out-of-town trips," said Ed, "I would arrange a luncheon meeting with a PSP patient and the caregiver spouse at their home, along with family members or invited guests (often forum members from several states away). These were precious times of deepening friendships, better understanding of the downhill struggles of PSP victims and their families, and renewed hope for treatment and cure for PSP and other fatal brain diseases."

CurePSP would like to thank Ed for his tireless service to our community over many years, and for being a fundamental figure in the management of our forum.



Ed's sweetheart and wife of 56 years, Rose

Raising Awareness

Navigating Veterans' Affairs for PSP Sufferers

From 1967 to 1971, Thyra Burakowski's husband, Anthony (Tony), worked for the United States Navy, and was in Vietnam from 1968 to 1969.

"I cannot tell you much about Vietnam because Tony did not speak about it at all," said Thyra. "I never asked. It seemed to be a part of life he did not want to speak about. From what I understand most of the men don't want to speak about it."

In early 2012, Thyra's husband of 44 years received a diagnosis of PSP and Parkinson's disease.

"Because of Tony's Vietnam War experiences, we asked if Agent Orange could have been the cause of both diseases," said Thyra. "The neurologist confirmed that Agent Orange could quite possibly have caused these neurological disorders, and said that Parkinson's disease was already included on the Agent Orange Presumptive Disease list."

Although the VA approved some assistive home improvements and devices, recognizing Tony's disability was a different story. Thyra filed their first disability claim in late 2013, and things became even more difficult.

"The next four years were filled with large brown envelopes from the VA saying we were denied 'service connection,'" said Thyra. "We filed multiple Notice of Disagreements (NODs) once we received the denials, which involved doctors' letters validating Tony's diagnosis, Agent Orange testing, and contacting our congressman. Yet we were still denied. The VA recognized Tony's Parkinson's disease through coverage of his medicine, therapies, and medical equipment, yet we were denied disability recognition. We were continually told there was no 'service connection' related to his diseases."

"I was exhausted as the caregiver, and the amount of paperwork and forms was overwhelming, but with the help of my family we did not give up," said Thyra.

Over the next few years, Tony experienced weekly falls, excessive choking, double vision, loss of handwriting and, in December 2016, after suffering a choking emergency, they decided it was time for him to enter hospice.

"Once Tony was under hospice care, we contacted our congressman and our case was escalated up the list of hearings," Thyra explained. "Because he was unable to travel and I was with him as his caregiver, my daughter represented him at the hearing and we were awarded a 30 percent disability rating. We were thrilled! Our journey didn't stop there, however. Our representative advised us to file another claim to increase the disability rating to 100 percent because the severe symptoms Tony suffered had made him completely unable to work."



Tony and Thyra, Christmas 2015



*Anthony 'Tony' Burakowski,
summer 2015*

"Sadly, Tony passed on April 4, 2017. Following his death, my family and I felt that it was more important than ever to have him awarded 100 percent disability, not for the money but to help other people in similar situations. We needed to set a precedent for fellow PSP sufferers. We contacted our congressman who said he couldn't help us. We were questioned by a local VA regional office as to why we were pursuing 100 percent, and we were accused of just wanting money.

"I told Tony I would never give up and I didn't," said Thyra. "In August 2017, I contacted the White House via email two times. Within two weeks I received a letter that Tony had been awarded 100 percent service-related disability. The journey with the VA was done, but it was bittersweet. I won for Tony but he wasn't here to celebrate with me.

"I want to help others with emotional support, and hope to set up a foundation in Tony's name to help veterans suffering with PSP and Parkinson's, and their families. For now, my daughter and I are on multiple Facebook pages for Agent Orange victims trying to share wisdom and advice from our experiences."

Have you experienced difficulties receiving service-related PSP disability assistance from the VA? Please contact Thyra Burakowski at thyratony@bellsouth.net, or call CurePSP at 347-294-2873.

Spotlight on Freya Hannan-Mills

In September 2017, 13-year-old Freya Hannan-Mills of London was invited to create a new piece for the esteemed Lyric Theatre, featuring actor Jude Law. The play, which she titled "Mushy Peas and Battered Bits," was inspired by her grandmother Margaret Hannan's battle with PSP. It is about a man with late-stage PSP who takes a final day trip with his caregiver to the beach where he spent his childhood.



Jude Law and Freya Hannan-Mills

"In rehearsals, Jude was extremely interested in PSP," said Freya. "He asked me so many questions about it so he could really understand it, and his performance on the first evening brought many to tears. I thought he absolutely captured and presented how I've witnessed this illness in my Nana."

Until the last few months of her life,

Margaret lived with Freya in their family home, and Freya would spend hours reading to her and painting her nails in different colors while listening to music. "I think PSP is the most horrendous disease. It is a night thief that consumes all as it slowly and insistently steals from you. I have seen how devastating this is for everyone. You feel so powerless," said Freya.



Freya Hannan-Mills

Freya is hoping to further develop her piece into a full-length play and, in the meantime, has been selected as one of London's emerging writers. She is also creating a new piece, to be performed at London's Vaults Festival in March, that explores what it's like to deal with the death of a loved one. Freya is hoping that this will also become part of her longer work featuring PSP.



*Jude Law performing in
Mushy Peas and Battered Bits*



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Upcoming Events

OPPORTUNITIES FOR LEARNING AND SUPPORT

Patient and Caregiver Education Day

Thursday, April 12, 2018

Glen Allen, Virginia

Run For CBD - Team Dosie

Sunday, May 6, 2018

Hilliard, Ohio

CurePSP and Mayo Clinic Family Conference

Friday, June 29 - Saturday, June 30, 2018

Rochester, Minnesota

PSP & CBD International Research Symposium

Thursday, October 25 - Friday, October 26, 2018

London, United Kingdom

