

News from the Vice President – Scientific Affairs

A world free of PSP, CBD and related brain diseases—this is the vision for our work at CurePSP. To achieve this vision, we are working very closely with researchers in academia and industry worldwide to find a cure.



**ALEX
KLEIN**

*CurePSP
Vice President—
Scientific Affairs*

Research Funding

CurePSP's research funding program has recently received a major facelift: our newly named Venture Grants now offer a unique funding opportunity for donors who want to be actively involved in research that could lead to a cure for PSP. It is our belief that a cure for PSP could mean a cure for all neurodegenerative diseases, including Alzheimer's and Parkinson's diseases; the respected journal *Scientific American* recently published an article that makes this very case.



Dr. James Wark and his wife Soryl Angel. Dr. Wark recently passed away from MSA.

Applications for our Venture Grants are available to researchers three times a year. CurePSP's international Scientific Advisory Board, chaired by board member and world-renowned PSP expert **Dr. Lawrence Golbe** from Rutgers University, conducts a vigorous peer review of all applications, recommending only the best for funding. The final funding decision is made by our Research Committee and the board of directors.

Our latest Venture Grants were awarded to **Dr. Monica Sanchez-Contreras** from the Mayo Clinic in Jacksonville, FL, and **Dr. Tsuneya Ikezu** from Boston University, Boston, MA.

Please contact our President, **David Kemp**, if you are interested in supporting these researchers. (kemp@curepsp.org, +1 802-734-1185).



Dr. Sanchez-Contreras



Dr. Ikezu

Other Research Funding News:

We are very proud to announce our continued collaboration with **Dr. Natura Myeku** from Columbia University, supported through the very generous donation from the Fred and Mabel R. Parks Foundation, through Jim McClellan, a CurePSP board member. Dr. Myeku is an assistant professor working with **Dr. Karen Duff**, a world-renowned scientist in the field of protein misfolding with a focus on tau. Dr. Myeku will focus on repurposing drugs that have already been approved by the U.S. Food and Drug Administration (FDA) for other diseases, potentially accelerating the development of therapies for PSP and related diseases.

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Equally exciting is our new scientific collaboration with **Dr. Sally Temple's** lab at the Neural Stem Cell Institute (NSCI) in Rensselaer, NY. Thanks to the fantastic and generous efforts of the **Gervais family**, and CurePSP board member **Amy Branch**, who were able to raise the funds for a postdoctoral fellowship for **Dr. Mo Liu** at the NSCI, we hope to see results in stem cell-related research. Dr. Liu will develop a model brain in a laboratory dish made of reprogrammed skin cells from patients with PSP. This “brain in a dish” will, in turn, facilitate efficient testing for new drugs under laboratory conditions. The fellowship recognizes **Pierre Gervais**, who recently passed away from PSP.



*Pierre Gervais
and his wife, Jocelyne.*

None of this work would be possible without the support of all of our generous and loyal donors.

For more information on clinical trials please contact **Ms. Trish Caruana**, MSW, Vice President – Patient and Carepartner Advocacy, at caruana@pepclinicaltrials.com. You can find more information on this program on our web site, www.curepsp.org.

I encourage you to contact me with your thoughts and ideas at klein@curepsp.org or +1 347-294-2872.

Best regards,

A handwritten signature in blue ink that reads "Alex".

JASPERSON FAMILY GENEROUSLY FUND NEW VENTURE GRANT

Newell Jasperson of Wisconsin Rapids, WI, has generously and fully funded a CurePSP Venture Grant in progressive supranuclear palsy (PSP) research.

CurePSP's Venture Grants are designed to support investigators in their initial studies to provide “proof of concept” of innovative ideas and lead to further funding. CurePSP is one of the few sources of this seed funding for research into PSP and related prime of life brain diseases. CurePSP Venture Grants are carefully selected from many applications by the foundation's Scientific Advisory Board (SAB) working with CurePSP's Vice President – Scientific Affairs, Dr. Alex Klein.

The Stephen N. Jasperson Study: Small Molecule Activators of Phospholipase D and Tau Clearance via Autophagic Flux is funded by Newell Jasperson in honor of his son, Dr. Stephen N. Jasperson, Professor Emeritus of Physics at Worcester (MA) Polytechnic Institute. Dr. Jasperson suffers from PSP.

Principal Investigator W. Haung (Ho) Yu, PhD of Columbia University, will study ways to stimulate autophagy, the brain's “garbage disposal,” to accelerate the elimination of toxic tau protein buildup. The build-up of the tau protein as a toxic aggregate is a hallmark of PSP and the related disease corticobasal degeneration (CBD) and is likely a primary event in the onset and development of these devastating diseases. While it is not known why these proteins accumulate, it is possible to reverse the buildup by stimulating a cellular pathway called autophagy, a mechanism within every cell to get rid of unwanted protein or other material. This recycling process is critical for cellular health and we understand that it may become dysfunctional with aging and disease. In an effort to combat the accumulation of proteins like tau in brain cells, the Columbian investigators have developed a series of drugs that can promote the clearance of tau through autophagy. In this study, investigators will test these drugs in a brain slice model of PSP/CBD to identify if they facilitate the removal of abnormal tau and would have utility in slowing or ultimately reversing disease progression.

A NEW PARTNERSHIP EXPANDS CLINICAL TRIAL RESEARCH

CurePSP has signed on as a strategic partner in the Michael J. Fox Foundation's **Fox Trial Finder**, a tool that matches patients with clinical trials. This relationship is expected to expand the reach of our Patient Engagement Program and provide a broader network of partners for clinical trials.

"Facilitating clinical research on this spectrum of fatal diseases, which strike most often in the prime of life, is crucial to developing new therapies," says Alex Klein, PhD, CurePSP Vice President - Scientific Affairs. "Research into progressive supranuclear palsy, in particular, is accelerating because it is seen as possibly holding the key to unlocking the secrets of all neurodegeneration, including Parkinson's disease."

Clinical trials are a final and crucial step on the path to developing better treatments for patients. Currently, between 40 and 70 percent of trials worldwide face delays because of a lack of volunteers.

Fox Trial Finder was created by the **Michael J. Fox Foundation** to help increase the flow of willing participants—both people with Parkinson's and those who do not have the disease—into the clinical trials, accelerating the drug development process.



TO LEARN MORE

Call 1-800-457-4777, or go to <https://foxtrialfinder.michaeljfox.org/>

Spotlight on Staff

Welcoming Our New Staff

CurePSP has made some additions to its dedicated team, we would like to introduce them;



Lucas Metherall

Marketing Manager

Lucas joined CurePSP as Marketing Manager late last spring to build the organization's online presence via various social and digital media platforms and ensure that the new website serves as a valuable and easy-to-navigate resource. In addition, Lucas will also oversee the organization's media relations, manage its merchandise program and promote its many volunteer events. Lucas comes to CurePSP from Sydney, Australia, where he developed his passion for digital and social media and received a Bachelor of Communications from the University of Technology. "I am very excited to be here at CurePSP and to serve the PSP community by spreading the word and raising awareness," says Lucas.



Joanna Teters

Office Manager

Joanna stepped into the role of Office Manager at CurePSP in April of 2016. Operating out of the New York City office, Joanna provides direct support to the president and staff, works closely with board and committee members on various projects, helps to maintain an organized and effective office space, and connects CurePSP volunteers and supporters with the resources and information they need to help fight for a cure. When the phone rings, she lends an empathetic ear and provides professional referrals to caregivers, patients and family members who seek support when they or loved ones are stricken by PSP. Raised in New Paltz, NY, Joanna graduated from Berklee College of Music in Boston, MA, in 2014 with a degree in Professional Music and Business. She performs with her eponymous band at venues around the country.



Sabrina Da Rocha

Events Coordinator

Sabrina works with Cure PSP Director of Events Jaclyn Zendrian to support volunteer networking, fundraising and foundation events. She joined CurePSP in 2016 from Robert Half International in New York City, where she was Senior Account Manager. Prior to that, she worked for Town Sports International, the largest owner and operator of fitness clubs in the Northeast and Mid-Atlantic regions and the third largest fitness club operator in the U.S., as Promotions and Marketing Coordinator. She also worked as Promotions and Special Events coordinator at the *New York Daily News*. Sabrina received her Bachelor of Business Administration degree with a marketing major from Iona College, New Rochelle, NY, where she rowed NCAA Division I crew. Her family is from Brazil and she is fluent in Portuguese and Spanish.

Riding for a Cure

Ann Arbor to Mackinac Island Ride Raises \$43,000 for a CurePSP-administered Dickie Howson PSP Research Fund

Richard (“Dickie”) Howson passed away in Montreal, Quebec, Canada, in February 2015, six years after he was diagnosed with PSP at the Mayo Clinic.



Dickie Howson (center) and his sons, Jono (left), and Nico (right).

A former Royal Navy officer who served across the globe, Dickie emigrated from Britain to Canada in the mid-1950s, where he raised a family and pursued a career in shipping. He was a uniquely charming and witty individual who enlivened the experience of the many people he met during his long life.

After Dickie Howson’s death, his son Nico wanted to honor his father by raising awareness of PSP and supporting CurePSP-sponsored research into the disease—and so Dickie’s Ride for PSP was born. A Professor of Law at the Michigan Law School, Nico and four friends resolved to bicycle over 350 miles from Zingerman’s Delicatessen in Ann Arbor, MI, to Mackinac Island at the northern tip of Michigan’s Lower Peninsula, where Lakes Huron and Michigan meet.

They completed Dickie’s Ride for PSP last June 2-5, spending almost 22 hours in the saddle to bike over 350 miles. The ride raised more than \$43,000 for a Dickie Howson PSP Research Fund, with more than 200 donors from over 13 countries. This happy result was a tribute to Dickie Howson, his remarkable life and his final struggle with PSP, but also an expression of the desire of so many people around the world to contribute in a meaningful way to solving the disease which so affected Dickie Howson’s final years.



Nico Howson and his two children, Theo and Cal, before departure in Ann Arbor, Michigan.



Nico's departure from Zingerman's Delicatessen in Ann Arbor, Michigan.

In consultation with CurePSP, Nico Howson and his family elected to direct the funds raised by Dickie's Ride for PSP to the PSP Genetics Consortium, a collaboration with the Tau Consortium that works with the latest gene sequencing and data analysis technologies to identify mutations that predispose people to developing PSP and related neurodegenerative tauopathies (diseases involving the tau protein).

Below is an excerpt of what Nico wrote to the many donors who supported the effort:

“At the end of our ride, my fellow riders kindly urged me to the front of our group to lead us into Mackinaw City. I duly sprinted ahead and took that moment to face the heavens and have a shouted conversation with my father. I told him that we had finally “done something” for him, something that we simply could not do when he was in the pitiless grip of PSP at the end of his long life. This thought-conversation enabled me to feel some level of joy mixed with relief— I had finally helped him. The truth is, of course, that YOU helped me aid him (and future victims of PSP) via your donation to the Dickie Howson PSP Research Fund. I will forever be grateful for your support of Dickie's Ride for PSP and how you directly enabled the unaccustomed feeling of joy and release I can now associate with his illness and passing.”



Jill Hugessen, Marc Brillon, Ken Duck and Sami Barmada, the four riders who accompanied Nico.

David's Story

Dear CurePSP, I would like to share with you a story of unconditional love and hope for the future.

My son, David, was only seven years old in 2015 when he asked if he could “fundraise to help Grandma.” David was always extremely close with my mother, his Grandma Beverly, from the moment she held him at the hospital on the day of his birth.

When David was four, my mother was diagnosed with PSP. She initially responded to medication and, although she had a tilt and moved much more slowly, she was still determined to be the best Grandma to all of her grandchildren. About a year and a half after her diagnosis, she fell and hit her head and my son, as young as he was, began to see that Grandma was quite ill.

David began fundraising the summer of 2015, I believe as a way to help his young mind cope with his grandmother's illness. I kept telling him that his idea was not only going to help his Grandma but others with PSP as well.

His first efforts at his summer art camp were so contagious they held an art show so that he could sell his prints, with all proceeds going to CurePSP. The art show was dedicated in honor of his Grandma.

He went on to collect cans and water bottles from neighbors, camp counselors and from home, which he would deposit every week at the supermarket. When the school year began, David raised more money for his cause at his martial arts school. He also raised money at our neighborhood bank and at his barber's by leaving a can he designed with his personal written message on it.



A proud David with his fundraising jar.



David and his Grandma, Beverly Sheren, the day of his birth.

His father helped him create a PowerPoint to present at school to the first and second grade classes in order to raise awareness for PSP. His teacher was so impressed that he took a video of David's presentation and showed it to all of his colleagues. I believe that people donated to David's cause because of the deeply personal way in which my son was able to touch their hearts. When David spoke about his Grandma, his face lit up like a Christmas tree.



David hoped to donate to CurePSP in honor of his Grandma. Unfortunately, as I write this letter, my son's fundraising efforts will now be donated in her memory. My mother passed away on April 25, 2016 after suffering for almost four years from this devastating disease.

Even towards the end, my mother was always aware and she communicated with her eyes and eyebrows. My son called every night and would Facetime with her to tell her that he loved her. She would wait all day for David's call and her face would light up when he did. My son's final words to her were, "I love you Grandma with all of my heart. You are the best Grandma ever! Good night, sleep tight and don't let the tickle bugs bite." David turned eight the month his Grandma died.

My son, David Rosenbaum, would like to proudly donate \$300 to CurePSP in memory of his beloved Grandmother, Beverly Sheren. He sent the donation on July 12, 2016, what would have been my mother's 74th birthday, as a wonderful way to honor her memory.



Sincerely yours,

Jodi Rosenbaum



David was always close to his grandma, right up to her passing.



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Upcoming Events

OPPORTUNITIES FOR LEARNING AND SUPPORT

The 2016 International Research Symposium

Thursday, October 27 - Friday, October 28, 2016
Jersey City, New Jersey

The 14th Annual Marco Island Walk

Saturday, March 18, 2017
Mackle Park, Florida

2017 Southwest Family Conference

Friday, March 17 - Saturday, March 18, 2017
Phoenix, Arizona

2017 Care Partner Retreat

Saturday, April 29, 2017
Portland, Oregon

2017 Midwest Family Conference

Friday, June 23 - Saturday, June 24, 2017
Chicago, Illinois

