CurePSP Research Funding and Grants Program

For more than 25 years, CurePSP has been active in not only supporting patients, their care partners and families, but also in funding cutting-edge research and the development of novel therapies. With pride we can look back and report that CurePSP has funded more than 160 studies, with an accumulated budget of just under $13 million! These are staggering numbers considering how the foundation started: as a small group of people who were affected by the disease in some way and believed that through patient and family support, intensive research and hard work, a cure could be found one day.

During this journey as a relatively unknown organization, CurePSP has transformed into one of the leading nonprofits in the area of prime of life diseases. CurePSP has become a reliable partner in brain science, establishing a trusted relationship with the research community that includes world-renowned scientists from around the globe. Our grant awardees range from a Nobel-Prize winning researcher and the leading scientists in the fields of neurodegeneration to the young and outside-the-box thinking, early-career scientists.

The National Institute of Neurological Disorders and Stroke (NINDS), part of the National Institutes of Health (NIH) in Bethesda, Maryland, recently confirmed during the NINDS 9th Nonprofit Forum that the work of foundations like ours is of highest importance – not only in terms of offering patient support, but also in allowing researchers to experiment and search for novel therapies outside government-funded projects. The NIH calls this seed funding, which permits scientists to prove new ideas and concepts using this data as a basis for larger national projects.

by
ALEX KLEIN
CurePSP Vice President Scientific Affairs

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Speaking of larger projects, CurePSP has undertaken enormous multimillion dollar efforts to study the genetic causes behind PSP. The past projects have led to revolutionary results and have most importantly identified new risk factors that are now new targets in drug and therapy development. Hence, we are extremely excited about our next large undertaking. The PSP Genetics Consortium was recently formed under the umbrella of CurePSP and the Tau Consortium, which was founded by the prominent investor and philanthropist Richard Rainwater. The consortium will identify DNA sequence variants that cause, increase the risk of onset or protect against PSP.

The study will use DNA samples provided anonymously by 2,400 PSP patients and another 600 control subjects. Once these gene variants are identified, there is the potential to prevent or treat the disease through the identification of new targets for drug development. The study is expected to begin immediately and the consortium will continue to work together for at least five years after its initial publication of results. Consortium investigators are affiliated with leading U.S. and European universities including the University of Pennsylvania, Mayo Clinic, UCLA, University College London (UK), Technical University of Munich (Germany) and Justus-Liebig University Giessen (Germany).

Dr. Jeffrey Friedman, the consortium’s managing director for CurePSP, said, “Patients, families, physicians and researchers need a better understanding of the genetic factors that play a role in the development of PSP and more common neurodegenerative diseases. Identifying new genes is like putting handholds and footholds onto a blank climbing wall, providing the critical information we can use to advance ourselves up the steep pitch and arrive at meaningful treatments for these devastating diseases.”

Patrick Brannelly, Program Director of the Tau Consortium, added, “Richard Rainwater became an icon of American business by thinking big and forging creative partnerships with the most talented people on the planet. His legacy lives on as we apply his approach to the conquest of a terrible neurodegenerative disease. The PSP Genetics Consortium will bring new hope to the patients and families who are struggling with PSP and related disorders.”
Meet Jaclyn Zendrian, CurePSP Director of Events. Jaclyn has a Bachelor of Arts in Business and a Master of Arts in Management from Notre Dame of Maryland University. Most of her career has revolved around medical organizations, including the Johns Hopkins University Neurology Development Office. Before joining CurePSP, Jaclyn worked as a Project Manager for Med-IQ, a full service, accredited medical education and quality improvement organization.

While at Hopkins, Jaclyn had the opportunity to shape her position into a role that she felt best suited her skills. It was during this time that she discovered an affinity and ability for event planning. Jaclyn was drawn to the new position of Director of Events at CurePSP because of her familiarity with nonprofits and neurology specifically. Plus, she is able to travel across the country, connecting with patients and families affected by neurodegenerative diseases.

At CurePSP, Jaclyn manages the educational programs and events, handling everything from concepts to venue and speaker selection. Having overseen two Family Conferences since joining CurePSP, Jaclyn has great satisfaction knowing that patients, caregivers and families have a new sense of hope because of the information, resources and connections afforded through the events. “The most exciting part of the events are the conversations and many email exchanges afterwards with people who are finding ways to make their lives more manageable,” says Jaclyn.

Jaclyn grew up on Long Island, but has lived in the Baltimore area for several years but will relocate to the New York office. She volunteers with her alumni networking committee and also handles the mailings for a local animal shelter. Jaclyn loves to travel, and her trips have taken her to Spain and several U.S. states to visit family. She is looking forward to the possible expansion of the CurePSP conference program, making events more accessible to those looking for both support and the newest developments in finding treatment and cure.

**CurePSP Grants Program**

The backbone of CurePSP’s research activities is still the investigator-initiated Grants Program. Most of the over 160 funded projects were awarded through this program, which is open to researchers worldwide. CurePSP accepts applications three times a year (March, July and November). All research proposals must investigate the disease mechanism or develop new therapeutic strategies for PSP or any of the prime of life diseases. To select the best applications, CurePSP follows international standards in the peer-review process. All applications are reviewed by several independent experts from around the world, who form the Scientific Advisory Board (SAB). The process is led by Dr. Lawrence Golbe, Director of the Division of Movement Disorders and Program Director of Neurology Residency of Rutgers Robert Wood Johnson Medical School. Dr. Golbe, a CurePSP Board member and head of its SAB, is one of the leading figures in PSP research and has extensive expertise in treating PSP patients.

Once the best applications are selected, the SAB makes funding recommendations that are discussed by a subcommittee of the Board of Directors, the Research Committee, which is chaired by Dr. Jeff Friedman. The final approval and the funding decisions are made during a Board of Directors meeting. The awardees receive a check for a maximum of $100,000 for a time frame of 1-3 years. During this time, the research groups have to conduct their proposed experiments. CurePSP closely follows the progress of each experiment. After the termination of the grant, the awarded researchers are expected to attend the CurePSP International Research Symposium to present their results.

The investigator-initiated Grants Program has been very successful and has played a pivotal role in developing new therapeutic approaches, some of which are currently being tested in the clinics.

**Best regards,**

Alex
The 2016 West Coast Family Conference was held in San Mateo, California, February 19-20, 2016, and proved to be a big success. With approximately 73 registrants, attendees included patients with PSP, CBD and MSA, their care partners and family members, as well as families who had lost loved ones to the diseases. On the evening of Friday, February 19, a networking session took place, providing an opportunity for everyone to meet one another before the conference began on Saturday. Actress and CurePSP National Spokesperson, Patricia Richardson, members of the CurePSP Board of Directors and actress and author Kathryn Leigh Scott also joined the networking event. Ms. Scott lost her husband to PSP and has written a book about their journey. It was quite an experience to witness so many people, who may have felt alone in dealing with the diseases, talking, laughing and exchanging their personal stories with each another.

Following the networking session, a roundtable discussion was hosted by Bill McFarland, Chair of the CurePSP Board, Board Member Ileen McFarland and Patricia Richardson. Each spoke about their personal journey with PSP, how it affected them and why they are involved with CurePSP. Afterwards the audience had an opportunity to ask questions and express their concerns about what the future holds for research and support. It was difficult to end the discussion because there was so much meaningful dialogue and information to share about what to expect from the conference the following day.

Later that evening, attendees were invited to return to participate in two support group meetings, one for patients and one for care partners. It was an emotional evening in which everyone shared their stories and expressed how these diseases have affected their lives. Although each patient’s story differed, they all had the same message: life has changed and the struggle is difficult. In your prime of life you expect to retire and enjoy time with your children and grandchildren, not struggle with a disease that has no cure. Care partners had much the same message, but with an added concern – how not to get burned out. We discussed the importance of caring for yourself and ways to maintain a healthy and peaceful mind, body and spirit.

Saturday began with a wonderful breakfast and some time to reconnect. There was a multitude of speakers covering a wide variety of subjects, ranging from research and clinical trials to diagnosis and living with the disease. The morning began with a welcome and patient profile by David Kemp, CurePSP President, followed by Brent Bluett, DO, a movement disorder specialist at the Cleveland Clinic Nevada, who addressed the milestone timelines for PSP. Adam Boxer, MD, PhD, Associate Professor of Neurology at UCSF, spoke about clinical trials. Trish Caruana, MSW, CurePSP

by
ILEEN MCFARLAND

CurePSP
Board Member

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Executive Vice President and Patient Engagement Program (PEP) President & CEO, explained the mission of PEP and discussed enrolling patients in clinical trials. Aimee Kao, MD, PhD, Department of Neurology at UCSF, described the research she is conducting using stem cells, which is funded by a grant from CurePSP.

At noon, a delicious lunch was served and the break provided additional time for the participants to mingle and discuss the morning events. During lunch, Kathryn Leigh Scott shared her experience as a caregiver to her late husband, which she describes in her recent book, *Last Dance at the Savoy: Life, Love and Caring for Someone with Progressive Supranuclear Palsy*.

The afternoon began with a presentation by Joey Laus, MS, CCC-SLP, a speech language pathologist. She discussed the role of a speech language pathologist in a patient's care and the importance of early communication intervention and swallowing techniques. Robin Ketelle, MS, RN, UCSF Memory and Aging Center, who is involved with a large NIH-funded study of PSP and CBS, works closely with both caregivers and patients. Ms. Ketelle's presentation focused on individualized care plans according to the setting, either at home, in a residential care facility or short-term acute care. She addressed how families can advocate to become part of the care process. Pravin Khemani, MD, Assistant Professor in Neurology and Neurotherapeutics, UT Southwestern Medical Center, addressed the problem with diagnosing atypical Parkinsonism; how long it takes to get a correct diagnosis; the role of a movement disorder specialist; and how a PT, OT and SLP are important in patient care.

The message during the 2016 West Coast Family Conference focused on hope. Hope because the research is aggressive and progressive. Hope because there are programs available to assist those struggling with caregiving and the issues involved with daily living. Hope because patients can become participants in clinical trials and feel they will make a difference. Everyone at the conference was moved because attendees were vocal about their needs, passionate about how to cope with their journey and receptive to understanding more about the research and advocacy programs.

CurePSP schedules several family conferences each year.

If you have never attended one, please consider how valuable it would be for you and your loved one. The experience benefits patient and families in so many ways, including a positive outlook for the future.
Our dad, Tommy Harris, was misdiagnosed for three years with having strokes. Although his condition was getting worse and more symptoms were appearing, he was told to keep taking baby aspirin and come back for follow-ups in a couple months. When Daddy finally went to the University of Arkansas for Medical Sciences (UAMS), there were no signs of a stroke and he was initially diagnosed with ALS. The family was distraught because we knew the outcome of this diagnosis. The correct diagnosis of PSP was made not long afterwards, and our family was excited that Daddy did not have ALS. However, as we researched the disease, we soon found out that both ALS and PSP are very hard and difficult journeys.

The neurologist told us about CurePSP and that the organization was a great resource to learn more about the disease. When Daddy had a terrible fall in spring 2014, which resulted in an ER visit, none of the medical staff knew of the disease. After calling the social worker at the neurologist’s office looking for support, we learned there were only Parkinson’s or Alzheimer’s groups that we could attend. While these groups were a blessing, they lacked some understanding of the unique battle of PSP patients and caregivers. As many others sharing this journey know, explaining the symptoms and behaviors resulting from these diseases is difficult. My family decided that things needed to change in our state, and we started planning the first support group for PSP, CBD and MSA in Arkansas.

CurePSP gave us a step-by-step guide to starting the group. We had never organized anything like this before or been a part of a support group. With the help of CurePSP, things seemed less scary and overwhelming. The first step was to find somewhere to meet. This task should have been easy, but it took a few months and became a little discouraging. I stumbled onto a phone number that was listed on a Parkinson’s support group site and called just to get insight on finding a meeting place in Arkansas. I spoke with Priscilla Pittman, who works for Alzheimer’s Arkansas, and she said we could meet there. Alzheimer’s Arkansas has been a great local resource for our group from the beginning.

The first meeting was August 2014, and there were only five attendees: my parents, my sister Carrie Dalrymple (who has helped a ton to make this possible) and John and Donna Anderson. More than a year and a half later, our support group averages about 18 people and we are constantly welcoming new members. Attendance at the December 2015 meeting, including special guests, was 48. There is such a special closeness within our group, and even though we have shed some tears, there are smiles and laughs even in the midst of these hard times.

A major aggravation to support group members is the lack of knowledge about neurodegenerative diseases by many doctors and the public. Many went through years of misdiagnosis and several doctors, causing unnecessary emotional stress, added financial expenses and the loss of valuable time to seek helpful resources and clinical studies. Members have often taken materials from CurePSP to their doctors to inform them of PSP, CBD and MSA. While awareness is very important, our focus will always be to support each other.
Jerry Taylor, a support group member, PSP patient, Arkansas Senator and Pine Bluff Mayor, and his wife Linda have done much to make others aware of these diseases, including reaching out to their legislative connections. Through these connections, Senator Cecile Bledsoe and her husband heard about the special meeting planned for December. Our December meeting was going to be the typical monthly meeting until a member decided it was time for us to take more action. Carolyn Lay was instrumental in making this meeting a very special event. She spent many hours on the phone and email to make everything happen. With Carolyn’s hard work, our December meeting was such a big success. It was a huge honor to have such an amazing group of people in the same room. Our group may be small, but with great ideas, big hearts and a passion to help others, we hope to bring support to those battling these diseases and make a dark time as bright as it can be.

Arkansas Support Group Special Event

On December 17, 2015, the Little Rock Arkansas PSP Support Group held an “awareness” event at the Pleasant Valley Country Club in lieu of their regularly scheduled support group meeting. The facilitator, Randi Haley, along with major support from Carolyn Lay, orchestrated a day that will be remembered by all who attended. People from all facets of the community joined together to discuss ways to raise awareness of PSP, CBD, MSA and Lewy Body Dementia. In attendance were patients, family members and caregivers, a neurologist and neurosurgeon from UAMS, state senators, news media, CurePSP Board Members and support group volunteers. In all there were 48 participants, which included 17 new attendees and 11 speakers and special guests.

The special guests and speakers included:

Mark Pippenger, MD, neurologist, UAMS
Erika Petersen, MD, neurosurgeon, UAMS
Laurie Ann Ross, Senior Director of Development, UAMS
Cecile Bledsoe, Arkansas Senator, and her husband Dr. James Bledsoe
Kevin Anderson, Assistant Director for Fiscal Services of the Arkansas Legislature
Bob Clausen, KARK Channel 4 News anchor
Chris Wren, Arkansas ICAN
Eric Godwin, personal trainer
William McFarland, Chair, CurePSP Board of Directors
Ileen McFarland, CurePSP Board Member

The energy in the room was powerful. Through presentations, discussions and a questions and answers session many new ideas for promoting the diseases evolved, including:

- On February 4, 2016, Bob Clausen from KARK Channel 4 to air a feature on the diseases.
- On April 10, 2016, UAMS is holding “The Second Annual Parkinson’s Forum” at which Parkinson’s Plus Syndromes will be included.
- CurePSP will be providing a step by step process for brain donation.
- An “awareness day” in Arkansas will be scheduled in 2016, and will receive news media coverage.

The meeting was a major success and most attendees walked away with a better understanding of these diseases, how important it is to educate the medical community, the importance of bringing awareness to their community through benefits, special events and news media coverage and most important, ways to support patients and their caregivers.
Upcoming Events

OPPORTUNITIES FOR LEARNING AND SUPPORT

2016 Canadian Family Conference
Friday, May 13 - Saturday, May 14, 2016
Hamilton, Ontario, Canada

Medical Professionals Education Day:
Focus on Atypical Parkinsonism
Monday, May 16, 2016
Baltimore, Maryland

Patient and Medical Professionals Education Day:
Focus on PSP
Thursday, June 2, 2016
Philadelphia, Pennsylvania

Jennings-Kroemer Putt for PSP Golf Tournament
July 30, 2016
Syracuse, Indiana

2016 International Research Symposium
Friday, October 27 - Saturday, October 28, 2016
Jersey City, New Jersey