I am excited to report that 2016 was a year in which CurePSP’s commitment to these core values was expanded and strengthened. CurePSP’s outreach to patients and caregivers is broader, deeper and more professional than at any other time in our history. Our unflagging commitment to research into the science of neurodegenerative diseases was shown in 2016 by our sponsored Research Symposium and the commitment of more than $900,000 to a variety of targeted research projects. We have continued to build on initiatives begun back in 2013 and 2014, when Dave Kemp and Alex Klein were brought aboard, and this year CurePSP’s headquarters were relocated to New York City—the epicenter of fundraising activities. Our ability to better tell our powerful story has been strengthened through improved branding and communication enhancements. We are well placed to advance our mission in 2017, but let no one be fooled by our progress: we still have a long way to go.

The prime of life neurodegenerative disorders on which we focus, invariably fatal, are highly complex. Their causes are only now being revealed, and there remain no effective treatments or cures. We hope you will continue to accompany us in 2017. Because Hope Matters™, your Board of Directors, predominantly former family members and caregivers with firsthand knowledge of these dreadful prime of life diseases, are passionately committed to ensuring that patients and caregivers receive support while funding research that is underway world-wide to unravel neurodegenerative disease. Under the leadership of your board of directors, our President, Dave Kemp, and our Vice President – Scientific Affairs, Dr. Alex Klein, CurePSP’s 2016’s strategic focus was on four areas critical to patients, caregivers, partners and researchers.

1. PATIENT/CAREGIVER OUTREACH AND SUPPORT
Outreach to patients and caregivers is broader, deeper and more professional. The new, professionally developed website provides easier, clearer navigation. CurePSP staff continually update content to meet the needs of users, reducing implementation time and cost. These changes to the design include rapid updating when scientific breakthroughs occur or editorial errors are discovered (a capacity which has already been put to good use as the new website was rolled out). Our Facebook page has become a true forum for patients, families, caregivers and others, and Twitter and Snapchat have
been energized to promote foundation developments and events in order to take full advantage of social media. Our Patient and Caregiver Assistance roadmap has received board approval and new support groups have opened, including the first ever in New York City. In 2017, we plan to release a nationwide directory of partner care centers for PSP and related prime of life diseases.

Immediate telephone response to newly diagnosed patients and families is a renewed focus, with information packages sent after each call. “Customer Service” is at the core of all staff responsibilities, regardless of specialty. Even our President is available 24/7/365 via his mobile phone, which has been widely circulated in direct mail campaigns. Volunteers are an essential component of our initiatives. Each support group leader is personally contacted, with foundation developments and new materials provided regularly. Trish Caruana, our Vice President – Patient & Carepartner Advocacy, has initiated regular communication to volunteers, providing the capacity for discussion among patients and caregivers or updates on developments in the research community or at CurePSP. We are providing more training for support group leaders; a formal training manual and tools for online learning are in development. Family conferences continue to be conducted at historically high levels. Plans include increasing conferences in FY 2017 and beyond, contingent upon funding to support the growth.

One particularly generous donor has committed significant resources to greatly expand our Respite Fund, supported under a “preferred provider” relationship with a national in-home aide company. Thanks to the contributions of another philanthropic donor, we are funding new, first-ever (for CurePSP) formal scientific research into caregiving. Physician/clinician outreach has been expanded to include training videos for neurologists-in-training, developed earlier this year and distributed at a cost of some $20,000. To raise awareness within this community, an outreach initiative was launched to 15,000 neurologists and movement disorder clinics worldwide, raising awareness about CurePSP’s resources and capabilities. An easy process for physician referrals to local support groups has also been implemented.

CurePSP is building strong connection with like minded organizations. Typical of our new focus includes relationships with the Association for Frontal Temporal Degeneration (AFTD), the Michael J. Fox Foundation for Parkinson’s Research, Parkinson’s Alliance, the Light of Day Foundation, the Alzheimer’s Drug Discovery Foundation (ADDF), BrightFocus Foundation, the MSA Coalition, the National Organization for Rare Diseases (NORD), the Neural Stem Cell Institute, the Tau Consortium and others.

We will continue to work with these organizations, as well as others, regarding advocacy programs that involve Federal agencies such as the Centers for Medicare & Medicaid Services (CMS) and the Social Security Administration—particularly important to patients and caregivers for whom government financial support is critical to their quality of life.

2. LEADERSHIP IN THE RESEARCH COMMUNITY

Scientists and researchers now believe that certain “building block” components of healthy brain cells become abnormal. These irregular proteins proliferate, causing neighboring healthy cells to die. One common brain protein, the tau protein, appears critical in understanding many neurodegenerative diseases, perhaps even Alzheimer’s. CurePSP’s priority for many years to better understand tau function has placed us in the vanguard of efforts to obtain definitive answers about these abnormal processes.

In October 2016 we held the largest and best received Research Symposium in our history, in greater New York City, with more than 140 world-class registrants. We are raising funds for the PSP Genetics Consortium, managed by CurePSP’s board member Dr. Jeffrey Friedman in collaboration with the Tau Consortium. This global team of prominent investigators has the goal of identifying all gene variants associated with PSP.

We have visibly moved to the center in the fight against neurodegeneration, able to partner with other nonprofits as well as healthcare institutions and pharmaceutical companies such as the Mayo Clinic, NYU Langone, the Cleveland Clinic, Bristol-Myers Squibb and AbbVie. Joint funding of research and co-branding of projects create new and exciting opportunities for the foundation, with endorsements and “brand awareness” of CurePSP as a leader in the fight against neurodegeneration. In particular, our Patient Engagement Program is poised to generate notable income through partnership with pharmaceutical companies in clinical trials.
3. ENHANCED FUNDRAISING CAPACITY

CurePSP is proud to have maintained our four-star Charity Navigator rating, and our top ratings with other rating services such as GuideStar. We have done this even when faced with so many new initiatives and the move to NYC. Events fundraising significantly increased, with support for volunteers and a number of new events such as October’s “Wine in the Hill Country,” which raised more than $40,000.

We have instituted direct mail approaches to reacquire lapsed donors and maximize the productivity of our existing list of about 76,000 live donors. We continue to strengthen our capacity for targeted fundraising. Facebook advertising aimed at our donors, our Facebook fans and those who have expressed interest in prime of life neurodegeneration through their online activity, is in testing and is showing strong returns. Larger donors within our current list are recognized through face-to-face meetings, and new targets have been identified outside of our existing donor base for development by staff and board. Our plan is to develop a broader donor base as CurePSP moves from being a small “rare disease” foundation to being at the center of the fight against neurodegeneration.

Our focus on Legacy Funds, which facilitate ongoing fundraising around the interests of families who have been impacted by prime of life neurodegeneration and who choose to honor their loved one in perpetuity, has been revitalized by providing prominent online recognition of family members along with a donation link. In addition to broad-based support from local fundraisers and smaller contributors, we are now strategically positioned to partner with foundations and philanthropists who can further support our cause.

4. EFFICIENCY AND BUSINESS DISCIPLINE

Our headquarters was relocated to Manhattan in 2016, using entrepreneurial incubator space that provides maximum economy and flexibility – no fancy offices or long-term lease commitments. Accounting and transaction processing remains in Maryland to optimize talent and occupancy expense while our NYC presence has fostered growth and talent in staff available to CurePSP: we now have a smaller but more-effective staff, and the one-time expenditures associated with the move are behind us. Importantly, we are positioned to scale upward in all areas without a significant increase in overhead. Our new brand identity, first rolled out in 2015, is now fully implemented. Materials have been reformatted, reprinted and are up to date. Branding and web site design and development expenses are now largely behind us.

In summary, CurePSP is a 501(c)(3) not-for-profit enterprise with the same passion for our key stakeholders—patients, families, researchers and staff—as any for-profit business. This is an exciting time for progress in the arena of neurodegenerative disease, and your CurePSP is passionately dedicated to continuing that progress!

Bill
I have had the privilege of heading the organization for two years and am proudest of developing a team that is delivering services and managing projects more efficiently and effectively than ever. I would like to take this opportunity to recognize the people who make CurePSP successful.

**Alex Klein, PhD**  
Vice President – Scientific Affairs  
Alex came to CurePSP from the European Union, where he had the challenging job of navigating the politics and complexities of distributing funds and managing projects in neuroscience among the many nations of the EU. He has put his management skills to work in rationalizing and organizing CurePSP’s research funding and project-management function to more productively deploy our donated funds. Through his skills as a speaker and scientific diplomat, he has raised the profile of CurePSP in the neuroscience community and developed strategic partnerships with institutions and other nonprofits in the field.

**Trish Caruana, MSW**  
Vice President – Patient & Carepartner Advocacy  
Trish is a veteran with the foundation who has expanded and improved our programs in patient and family support and education and awareness in the medical and healthcare community. Trish is spearheading the launch of the Cherie Levien Quality of Life Fund that will provide greatly expanded support for in-home care for families of patients who are pressed physically and financially by the demands of caregiving. At the same time, Trish is expanding the Patient Engagement Program, which is working with large pharmaceutical manufacturers to manage the clinical trials that are critical to bringing drugs to market.

**Joanna Teters**  
Office Manager  
Joanna fields the many weekly calls from patients and families and handles them with empathy and sensitivity. She also distributes our kit of informational materials to those who are just encountering the diseases and are eager to learn more. Joanna works with Trish on volunteer relations, keeping our network of support-group leaders and peer-group supporters informed of latest developments and our web site up to date with their latest contact information. And, like any good office manager, Joanna keeps things running smoothly and efficiently.

**Jaclyn Zendrian, HMCC**  
Director of Events  
Jaclyn has helped the foundation to improve the programming and presentation of foundation events like Family Conferences, Carepartner Retreats, in-service training days and the annual Research Symposium. At the same time, she has worked with volunteers to create new fundraising opportunities by expanding existing events and creating new ones. This year’s Research Symposium, held in the greater New York City area, was our biggest and best yet, with more than 140 registrants from all over the world. A new volunteer event, “Wine in the Hill Country,” raised more than $40,000.
From the President

**Sabrina Da Rocha**  Events Coordinator
Sabrina is a new addition to the team, having honed her skills at Robert Half International and the *New York Daily News*. Sabrina has effectively helped to plan and manage events as well as promote them on social media. Through her background as an NCAA Division I athlete, she has developed relationships with school athletic programs that have led to fundraising and awareness opportunities at televised athletic events.

**Lucas Metherall**  Marketing Manager
Lucas also is new with CurePSP, but has quickly used his social media college major and experience to raise awareness of the foundation and create online communities across several relevant channels. Lucas manages CurePSP’s new web site, promotes events, builds media relationships, handles printed materials including our popular newsletter and has developed our new online store with an expanded selection of merchandise. Lucas initiated a Facebook advertising program that, while small, is showing terrific return on investment.

**Diane Seegull**  Accounting Manager
Diane is based in our Baltimore-area office, where she handles all accounting and financial reporting, purchasing, human resources and the management of gift processing. Diane runs a “tight ship,” which ensures that donor funding is managed carefully and used effectively. She has proactively initiated many operational and process improvements that have made us a smoother-running organization.

**Kelly Saunders**  Gift Processing and Data Quality Coordinator
Kelly has been with CurePSP for several years and knows the organization “inside and out.” She is expert in the use of our Raiser’s Edge database software and meticulous in processing donations, keeping records updated and issuing Tribute and Legacy gift reports to families. She also is a friendly and responsive point of contact for donors who have questions, want to recognize a loved one with a donation, need an issue resolved or simply want a caring and sympathetic ear. Kelly is based in our Maryland office and reports to Diane.

I salute our fine staff for their performance and accomplishments and am proud to introduce them to you. They form a dynamic team that will take CurePSP successfully into the future.

For the cure,

David Kemp
How Your Gifts Were Used

(FY 2016)

Thank you for your support.
# Statements of Financial Position

## June 30, 2016 and 2015

## Assets

<table>
<thead>
<tr>
<th></th>
<th>2016</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Current Assets:</strong></td>
<td></td>
<td></td>
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<tr>
<td>Cash and Cash Equivalents</td>
<td>$1,608,323</td>
<td>$2,545,846</td>
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<td>Cash and Cash Equivalents – Temporarily Restricted</td>
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<td>Other Receivables</td>
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<td>Investments - permanent endowment</td>
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<td>Deposits</td>
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<td>7,058</td>
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<tr>
<td><strong>Total Assets</strong></td>
<td>$3,162,763</td>
<td>$3,418,875</td>
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## Liabilities and Net Assets

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<thead>
<tr>
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<th>2016</th>
<th>2015</th>
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<tr>
<td><strong>Current Liabilities:</strong></td>
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<td>Accounts Payable and Accrued Expenses</td>
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<td>Grants Payable – Current</td>
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<td><strong>Total Current Liabilities</strong></td>
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<td>Grants Payable – non-current portion</td>
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<td><strong>Total Liabilities</strong></td>
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<td>1,555,625</td>
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<td>223,545</td>
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<td>Permanently Restricted</td>
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<td>380,827</td>
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<tr>
<td><strong>Total Net Assets</strong></td>
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<td>2,159,997</td>
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<tr>
<td><strong>Total Liabilities and Net Assets</strong></td>
<td>$3,162,763</td>
<td>$3,418,875</td>
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Statement of Activities and Changes in Net Assets

For the years ended June 30, 2016 and 2015

<table>
<thead>
<tr>
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<th>Temporarily Restricted</th>
<th>Permanently Restricted</th>
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<td><strong>REVENUE AND SUPPORT:</strong></td>
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<tr>
<td>Contributions</td>
<td>$ 2,068,200</td>
<td>$ 775,482</td>
<td>$</td>
<td>$ 2,843,682</td>
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<td>Special Events, net</td>
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<td>Patient engagement</td>
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<td>72,121</td>
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<td>Sponsorships</td>
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<td>Merchandise sales, net</td>
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<td>Net realized and unrealized gains/(losses)</td>
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<td>(5,591)</td>
<td>(9,821)</td>
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<td>Interest and Dividends</td>
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<td>10,005</td>
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<td>15,298</td>
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<td>Gain/(Loss) on Disposal</td>
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<td>(5,612)</td>
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<td>Miscellaneous income</td>
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<td><strong>Total revenue, Gains and Support</strong></td>
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<td>874,002</td>
<td>(5,591)</td>
<td>$3,218,228</td>
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<td>Net Assets Released from Restrictions</td>
<td>558,182</td>
<td>(555,064)</td>
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<td>Program Services:</td>
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<td>Supporting Services:</td>
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<td>Management and General</td>
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<td><strong>Total expenses</strong></td>
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<td><strong>CHANGE IN NET ASSETS</strong></td>
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<td></td>
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<tr>
<td><strong>NET ASSETS, BEGINNING OF YEAR</strong></td>
<td>1,555,625</td>
<td>223,545</td>
<td>380,827</td>
<td>2,159,997</td>
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<tr>
<td><strong>NET ASSETS, END OF YEAR</strong></td>
<td>$1,311,400</td>
<td>$ 542,483</td>
<td>$ 372,118</td>
<td>$2,226,001</td>
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2015

<table>
<thead>
<tr>
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<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Permanently Restricted</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>REVENUE AND SUPPORT:</strong></td>
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<td>Contributions</td>
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<td>$ 103,799</td>
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<td>Net realized and unrealized gains/(losses)</td>
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<td>529</td>
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<td>Interest and Dividends</td>
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<td><strong>EXPENSES:</strong></td>
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<td></td>
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<tr>
<td>Program Services:</td>
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<td>Research</td>
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<td>Support Services:</td>
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<td>Management and General</td>
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<td>Board</td>
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<td>Fundraising</td>
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<td>352,932</td>
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<tr>
<td><strong>Total expenses</strong></td>
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<td><strong>CHANGE IN NET ASSETS</strong></td>
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<td></td>
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<tr>
<td><strong>NET ASSETS AT BEGINNING OF YEAR</strong></td>
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<td>309,583</td>
<td>383,411</td>
<td>1,913,895</td>
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<tr>
<td><strong>NET ASSETS AT END OF YEAR</strong></td>
<td>$1,555,625</td>
<td>$ 223,545</td>
<td>$ 380,827</td>
<td>$2,159,997</td>
</tr>
</tbody>
</table>
Small Molecule Activators of Phospholipase D and Tau Clearance via Autophagic Flux

Dr. W. Haung (Ho) Yu
Columbia University
Taub Institute
New York, NY (USA)

Defining a Novel Drug Target for PSP and CBD

Dr. Lars Ittner
University of New South Wales (UNSW Australia)
School of Medical Sciences
Sydney, NSW (Australia)

Investigating Functional Ability in PSP

Dr. Adam Gerstenecker
University of Alabama at Birmingham
Department of Neurology
Birmingham, AL (USA)

The Establishment of a Preclinical Model for Progressive Supranuclear Palsy

Dr. Stewart Clark
University at Buffalo
Department of Pharmacology and Toxicology
Buffalo, NY (USA)

Small-Molecule Modulation of Tau Clearance and Aggregation

Dr. Gal Bitan
University of California, Los Angeles
Department of Neurology
Los Angeles, CA (USA)

Tau in Peripheral Tissues of PSP and CBD

Dr. Brittany Dugger
University of California, San Francisco Institute for Neurodegenerative Diseases
San Francisco, CA (USA)

Understanding the Relative Contributions of Genetic Risk Factors in PSP

Dr. Aimee Kao
University of California, San Francisco Department of Neurology
San Francisco, CA (USA)

MOBP, STX6 & EIF2AK3 Expression and Distribution in PSP Brains

Dr. Rohan deSilva
University College London
Institute of Neurology
London (UK)

Impact of Arginase1 Over-Expression and SAT1 Deficiency during Tauopathies

Dr. Daniel C. Lee
University of South Florida, Tampa College of Pharmacy & Pharmaceutical Sciences
Tampa, FL (USA)


Dr. Michael D. Geschwind
University of California, San Francisco Department of Memory and Aging Center
San Francisco, CA (USA)
Development of New PSP Mouse Model (URSO Student Fellowship)

Mr. Mina Botros
Boston University
School of Medicine,
Department of Pharmacology
Boston, MA (USA)

Consensus Conference for the Revision of the Diagnostic Criteria of PSP (Scientific Conference Sponsoring)

Dr. Günter Höglinger
Klinikum rechts der Isar der TU Muenchen
Department of Neurology
Munich (Germany)

Characterization of Tau and Its Pathology in Oligodendrocytes Derived from Induced Pluripotent Stem Cells from Patients with PSP-like Phenotype

Dr. Ragnhildur Thora Káradóttir
University of Cambridge
Wellcome Trust - MRC Stem Cell Institute
Cambridge, (UK)

Eloise H. Troxel Brain Bank

Dr. Dennis Dickson
Mayo Clinic
Jacksonville, FL (USA)

PSP Whole Exome Study

Dr. Gerard Schellenberg
University of Pennsylvania
Department of Pathology and Laboratory Medicine
Philadelphia, PA (USA)

Specific Targeting of PSP Brain-Derived Tau Oligomers

Dr. Rakez Kayed
University of Texas, Galveston
Department of Neurology
Galveston, TX (USA)

Spreading of a Synuclein Pathology in Multiple System Atrophy

Dr. Johannes Brettschneider
University of Ulm
Department of Neurology
Ulm (Germany)

Elucidating PSP Genotype-Phenotype Relationships Using Human Isogenic iPSCs

Dr. John W. Steele
University of California, San Diego
Department of Cellular and Molecular Medicine
La Jolla, CA (USA)

Synaptic Tau-Proteasome Dysfunction and a Potential Therapeutic Strategy

Dr. Natura Myeku
Columbia University
Taub Institute
New York, NY (USA)

Disease Modifying Tau Immune Therapy for PSP and CBD

Dr. John Trojanowski and Dr. Virginia Lee
University of Pennsylvania
Department of Pathology & Laboratory Medicine
Philadelphia, PA (USA)

Transgenic Rats Expressing Wild-Type and Mutant Tau

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<td>Tracy Guarino</td>
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<td>Tuck Langland</td>
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<td>Udayan Das Roy</td>
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<td>Wanna B. Hinchee</td>
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<td>Will Bergner</td>
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<td>William D. Forsyth</td>
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<td>YourCause, LLC Trustee for Chevron</td>
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<td>Matching Employee Funds</td>
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<td>Yvonne Chan</td>
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Volunteer Events

With Special Thanks to the Following CurePSP Volunteer Events

Kathryn Leigh Scott
Leslie Christensen
Renee Sterling
The Jennings and Kroemer families
Rebecca Host and family
JoElla Rea
Todd Fisher
Randy and Kevin Subramany
Robert Wolfe
Michael Dickson
Patrick Dixon
Cindy MacDonald, Mitch Kanefsky, Christina Dean
Nico Howson
Linda Lipsky, Debbie Gerondale
Joseph Dinnen
Laura Young, Chris Luzecky, Kathy Gangloff, and Cory Barry
Debra Feldman
Donna Etergineososo
Susan McLaughlin
Shabbir Chandabhai
Kimberly Feinman
Dan Stevens, Sophie Gervais Stevens, Jocelyne Gervais, Leigh Gervais Genkinger, Kim Gervais with Eric Gervais
James Anastas
Jeff Collins and David Polston
Karen Layman and Alyssa Perry
Adam Murphy
Kashmira Nayak, Rishabh Nayak

Julia Price
Randy and Kevin Subramany
Carrie Sieck
Tish Kerry
Melanie Garcia and Titan Fitness

Auction of “Dark Shadows” memorabilia
Akron Marathon
Annual 5K/15K Relay Race
Annual Putt For PSP
Annual Robert Peoples 5K Run For Hope
Annual Southern Illinois CurePSP 5K Run For Hope
Augusta Half Ironman Marathon
Civilian Military Combine
Coast-to-Coast Charity Bicycle Ride
Columbus Half Marathon
Continental Divide Trail Hike
CurePSP Awareness and Memorial Walk
Dickie’s Ride
Diehard Run Charity Bike Ride
Frozen Bonsai Half Marathon
Left, Right and Center Game Night
Linked Jewelry
Marylin’s Spring Stroll
Montour Trail Half Marathon
Mt. Kilimanjaro Climb for PSP
New York City Marathon
Novo Nordisk 5K
New York City Marathon
Ocotillo Rain and Thunder Bluegrass Band
Painting with a Purpose
Pizza and Beer Benefit
Rhythm of Dreams presents “A Tribute to R.D. Burman” in memory of Vandan Nayak
T-Shirt Fundraiser
Urbanathlon Sprint
Village of Clarkston Vendor and Craft Fair
Walk From Katoomba to Jenolan Caves
Zumba for Hope
Leadership and Staff

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President and Chief Executive Officer

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