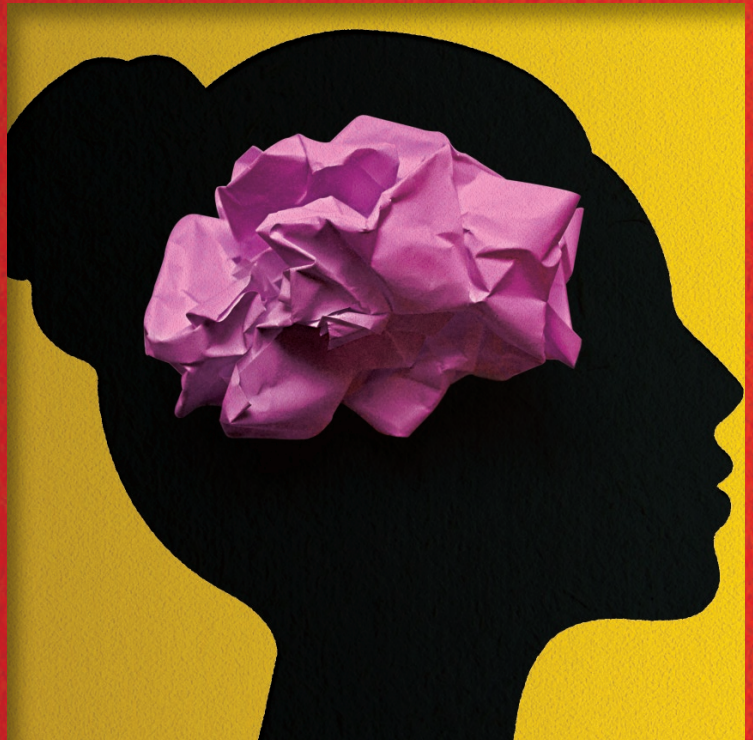


2016 Annual Report



CUREPSP.ORG

Chairman's Report 2016

CARE. *Care for those suffering from the scourge of “prime of life” progressive neurological diseases.*

CONSCIOUSNESS. *Education to physicians and allied healthcare professionals and public awareness.*

CURE. *Research to find a cure for these dreaded diseases.*



William R. McFarland

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.

Chairman's Report 2016

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



In this Annual Report, our Board Chairman Bill McFarland details some of the many accomplishments of the foundation as well as the challenges that lie ahead.

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.



David Kemp

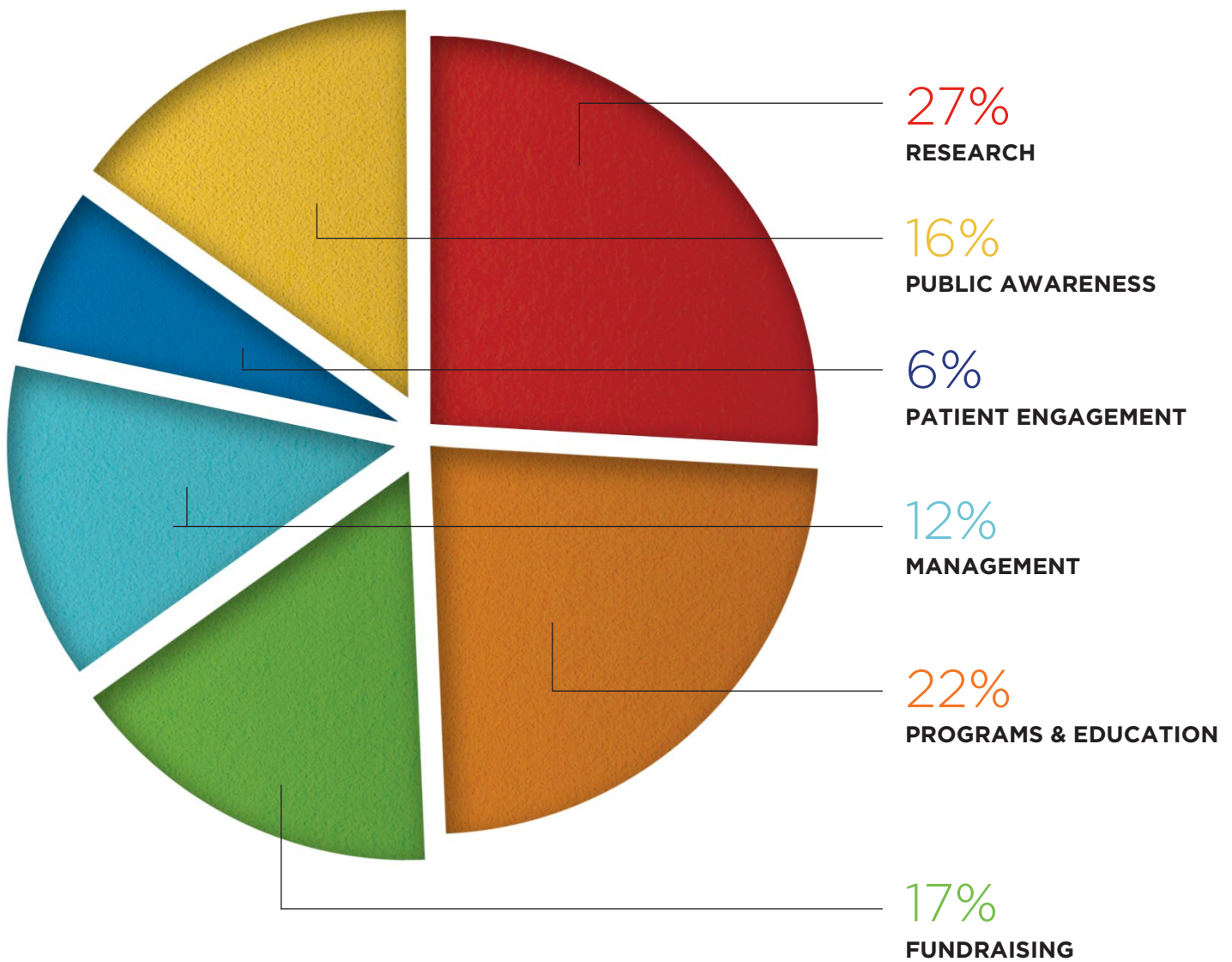
I salute our fine staff for their performance and accomplishments and am proud to introduce them to you. They form a dynamic team that will take CurePSP successfully into the future.

For the cure,

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

How Your Gifts Were Used

(FY 2016)



Thank you for your support.

Statements of Financial Position

June 30, 2016 and 2015

ASSETS

	2016	2015
CURRENT ASSETS:		
Cash and Cash Equivalents	\$ 1,608,323	\$ 2,545,846
Cash and Cash Equivalents – Temporarily Restricted	932,117	350,870
Investments-Unrestricted	16,172	2,442
Pledges Receivable	3,850	3,700
Other Receivables	13,104	12,850
Prepaid Expenses	<u>34,854</u>	<u>83,266</u>
Total Current Assets	<u>2,608,420</u>	<u>2,998,974</u>
Property and Equipment, net	166,452	32,016
Investments - permanent endowment	372,118	380,827
Deposits	<u>15,773</u>	<u>7,058</u>
TOTAL ASSETS	<u>\$ 3,162,763</u>	<u>\$ 3,418,875</u>

LIABILITIES AND NET ASSETS

CURRENT LIABILITIES:		
Accounts Payable and Accrued Expenses	\$ 169,652	\$ 296,387
Grants Payable – Current	<u>617,110</u>	<u>712,902</u>
Total Current Liabilities	786,762	1,009,289
Grants Payable – non-current portion	<u>150,000</u>	<u>249,589</u>
Total Liabilities	<u>936,762</u>	<u>1,258,878</u>
NET ASSETS:		
Unrestricted	1,311,400	1,555,625
Temporarily Restricted	542,483	223,545
Permanently Restricted	<u>372,118</u>	<u>380,827</u>
Total Net Assets	<u>2,226,001</u>	<u>2,159,997</u>
TOTAL LIABILITIES AND NET ASSETS	<u>\$ 3,162,763</u>	<u>\$ 3,418,875</u>

Statement of Activities and Changes in Net Assets

For the years ended June 30, 2016 and 2015

2016

	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
REVENUE AND SUPPORT:				
Contributions	\$ 2,068,200	\$ 775,482	\$ —	\$ 2,843,682
Special Events, net	180,646	88,515	—	269,161
Patient engagement	72,121	—	—	72,121
Sponsorships	29,400	—	—	29,400
Merchandise sales, net	357	—	—	357
Net realized and unrealized gains(losses)	(4,230)	—	(5,591)	(9,821)
Interest and Dividends	5,293	10,005	—	15,298
Gain/(Loss) on Disposal	(5,612)	—	—	(5,612)
Miscellaneous income	3,642	—	—	3,642
Total revenue, Gains and Support	2,349,817	874,002	(5,591)	3,218,228
Net Assets Released from Restrictions	558,182	(555,064)	(3,118)	—
Total revenue, gains, support and releases	2,907,999	318,938	(8,709)	3,218,228
EXPENSES:				
Program Services:				
Research	837,618	—	—	837,618
Outreach and Education	701,207	—	—	701,207
Communications and Public Awareness	504,471	—	—	504,471
Patient engagement	200,927	—	—	200,927
Supporting Services:				
Management and General	309,019	—	—	309,019
Board	76,905	—	—	76,905
Fundraising	522,077	—	—	522,077
Total expenses	3,152,224	—	—	3,152,224
CHANGE IN NET ASSETS	(244,225)	318,938	(8,709)	66,004
NET ASSETS, BEGINNING OF YEAR	1,555,625	223,545	380,827	2,159,997
NET ASSETS, END OF YEAR	\$ 1,311,400	\$ 542,483	\$ 372,118	\$ 2,226,001

2015

	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
REVENUE AND SUPPORT:				
Contributions	\$ 2,184,731	\$ 103,799	\$ —	\$ 2,288,529
Special Events (Net of \$25,968 in Expenses)	277,300	6,353	—	283,653
Net realized and unrealized gains(losses)	—	—	529	529
Interest and Dividends	6,292	6,454	—	12,746
Grant Adjustment	—	135,495	—	135,495
Total revenue, Gains and Support	2,468,323	252,101	529	2,720,953
Net Assets Released from Restrictions	341,252	(338,139)	(3,113)	—
Total revenue, gains, support and releases	2,809,574	(86,038)	(2,584)	2,720,952
EXPENSES:				
Program Services:				
Research	1,095,450	—	—	1,095,450
Programs and Education	563,094	—	—	563,094
Communications and Public Awareness	225,443	—	—	225,443
Support Services:				
Management and General	185,566	—	—	185,566
Board	52,366	—	—	52,366
Fundraising	352,932	—	—	352,932
Total expenses	2,474,851	—	—	2,474,851
CHANGE IN NET ASSETS	334,724	(86,038)	(2,584)	246,102
NET ASSETS AT BEGINNING OF YEAR	1,220,901	309,583	383,411	1,913,895
NET ASSETS AT END OF YEAR	\$ 1,555,625	\$ 223,545	\$ 380,827	\$ 2,159,997

Open Grants in FY 16



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)*



Tau in Peripheral Tissues of PSP and CBD

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



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)*



Investigating Functional Ability in PSP

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



MOBP, STX6 & EIF2AK3 Expression and Distribution in PSP Brains

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



The Establishment of a Preclinical Model for Progressive Supranuclear Palsy

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



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)*



Small-Molecule Modulation of Tau Clearance and Aggregation

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



A Review and Proposal for New Research Studies on Guam and in Umatac Village, 2013: Assessment of Guam PDC/ALS in 2013-2014

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

Dr. Stanley B. Prusiner
*University of California, San Francisco
 Institute for Neurodegenerative Diseases
 San Francisco, CA (USA)*

Honor Roll of Donors

For the Period July 1, 2015 through June 30, 2016

CurePSP thanks its generous donors who make possible our programs and research support

\$100,000 and above

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The Nesbitt Charitable Fund
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Kathryn Leigh Scott	Auction of “Dark Shadows” memorabilia
Leslie Christensen	Akron Marathon
Renee Sterling	Annual 5K/15K Relay Race
The Jennings and Kroemer families	Annual Putt For PSP
Rebecca Host and family	Annual Robert Peoples 5K Run For Hope
JoElla Rea	Annual Southern Illinois CurePSP 5K Run For Hope
Todd Fisher	Augusta Half Ironman Marathon
Randy and Kevin Subramany	Civilian Military Combine
Robert Wolfe	Coast-to-Coast Charity Bicycle Ride
Michael Dickson	Columbus Half Marathon
Patrick Dixon	Continental Divide Trail Hike
Cindy MacDonald, Mitch Kanefsky, Christina Dean	CurePSP Awareness and Memorial Walk
Nico Howson	Dickie’s Ride
Linda Lipsky, Debbie Gerondale	Diehard Run Charity Bike Ride
Joseph Dinnen	Frozen Bonsai Half Marathon
Laura Young, Chris Luzecky, Kathy Gangloff, and Cory Barry	Left, Right and Center Game Night
Debra Feldman	Linked Jewelry
Donna Etergineoso	Marylin’s Spring Stroll
Susan McLaughlin	Montour Trail Half Marathon
Shabbir Chandabhai	Mt. Kilimanjaro Climb for PSP
Kimberly Feinman	New York City Marathon
Dan Stevens, Sophie Gervais Stevens, Jocelyne Gervais, Leigh Gervais Genkinger, Kim Gervais with Eric Gervais	Novo Nordisk 5K
James Anastas	New York City Marathon
Jeff Collins and David Polston	Ocotillo Rain and Thunder Bluegrass Band
Karen Layman and Alyssa Perry	Painting with a Purpose
Adam Murphy	Pizza and Beer Benefit
Kashmira Nayak, Rishabh Nayak	Rhythm of Dreams presents “A Tribute to R.D. Burman” in memory of Vandan Nayak
Julia Price	T-Shirt Fundraiser
Randy and Kevin Subramany	Urbanathlon Sprint
Carrie Sieck	Village of Clarkston Vendor and Craft Fair
Tish Kerry	Walk From Katoomba to Jenolan Caves
Melanie Garcia and Titan Fitness	Zumba for Hope

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