

2015 Annual Report



www.curepsp.org

CurePSP®

UNLOCKING THE SECRETS OF BRAIN DISEASE®



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*Pierre Gervais
was diagnosed
with PSP in
September 2014.*

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*Cover photo: Pierre and Jocelyne Gervais
Portrait photography by Doug Menuez/Stockland Martel*

Illustrations by Rick Landers/Carbone Smolen Agency

From the Chair of the Board of Directors



William R. McFarland

2015 was a watershed year for CurePSP. Our longtime President and CEO retired in early January, and a dynamic new President, Dave Kemp, joined CurePSP. A number of new initiatives were begun under Dave's dynamic leadership and more are planned. You can read about the exciting programs and events launched in 2015 on page 4, "From the President."

But first, let me describe our Board to you. We are passionate volunteers, with 76% of us having intimate knowledge of prime of life neurodegenerative diseases — 41% of our Board members have lost a spouse to a prime of life disease and 35% have lost a parent. The remaining Board members are medical professionals and scientists who have chosen to focus on these devastating diseases. We are dedicated, we are motivated, and we are determined to ensure that as soon as possible others do not taste the bitter pill of neurodegenerative disease that we have tasted.

As a Board, we are also driven to best practices drawn from the business world. That does not mean that CurePSP is not a 501c(3) charitable organization, because we certainly are! However, too many not-for-profit organizations fail to establish a culture that stresses certain values. These values include having a clear strategic vision; establishing measurable goals and objectives to achieve that vision; instituting well-defined accountability for results; delegating responsibility for achieving those results; employing staff with skills commensurate for each position; and using strategic partnerships intelligently to leverage our strengths and compensate for our limitations. We are managing CurePSP with the same emphasis on return on investment as any Fortune 500 company.

This is an exciting time for progress in the arena of neurodegenerative disease. Medical science is progressing rapidly and prime of life diseases—which have had no known cause, no known treatment, no known cure and are invariably fatal—are on the cusp of major advances. Only a few classes of common proteins appear to become deviant (for unknown reasons) and then these deviant proteins spread through the brain. One of them, the tau protein, appears to also be related to several neurodegenerative diseases, such as CBD (corticobasal degeneration), MSA (multiple system atrophy), CTE (chronic traumatic encephalopathy), ALS (amyotrophic lateral sclerosis), and other frontotemporal dementias (FTDs) — perhaps even Alzheimer's.

If we can understand these tauopathies, we can also make great strides toward finding a cure for many other neurodegenerative diseases. That is what CurePSP is dedicated to doing!

From the Chair Emeritus

Thank you for the honor and privilege of serving as Chairman of CurePSP.



John T. Burhoe

In June, I stepped down as Chairman and was succeeded by Bill McFarland, who embodies the business acumen needed to continue advancing CurePSP's presence in neurodegenerative disease support and research. Thank you, Bill, for accepting the challenge, which capitalizes on your extraordinary abilities.

I now serve as Chair Emeritus and continue to serve on the Executive Committee. Along with an exceptional Board and talented staff, my role was to oversee the transition of an organization founded around a kitchen table in 1990, into a major participant in neurodegenerative disease research. We took the final steps to complete the transition and develop a more business-like approach by adding Dave Kemp as President, Alex Klein as Vice President-Scientific Affairs, and by opening a New York office to enhance our presence in the industry.

Parallel with these events are the extraordinary advances in research toward the now widely accepted conclusion that many, if not all, neurodegenerative diseases have a single source of the misfolding of proteins in the brain. Both our new approach and research advances have propelled CurePSP into a prominent role in the process to seek a cause and treatment not only of PSP, CBD and MSA but, potentially for ALS, CTE (athletic injuries), post-traumatic stress disorder (PTSD), Parkinson's and, the elephant in the room, Alzheimer's. The recent movie, "Concussion," with actor Will Smith, addresses the above from the perspective of athletic injuries, increasing the visibility of CurePSP's efforts.

As Dr. John Trojanowski of the University of Pennsylvania states, "PSP is a tauopathy, meaning it is exclusively caused by the misfolding of only the Tau protein. Literally all other neurological diseases are caused by the tangling of multiple proteins making research far more complicated." This discovery has propelled CurePSP to center stage with major pharmaceutical companies now seeking us out for research.

CurePSP is driven by men and women with a keen sense of business, but who also have the personal experience of the devastation of neurodegenerative diseases. These are exciting and historic times as we focus on curing not only PSP, CBD and MSA, but potentially many, if not all, neurodegenerative diseases. Strong, but accurate words!

Again, thank you for the honor of serving you.

From the President



David Kemp

CurePSP has had an active year, using donor funds efficiently and effectively in its three areas of focus: care (patient, family and care partner programs); consciousness (awareness and education); and cure (research).

Care

CurePSP's programs and education form a key part of our mission and help to differentiate us from other foundations that are primarily research focused. While we are searching for the cure, we play a critical role in helping patients, their families and other caregivers during trying times when they may have no place else to turn. This mission is embedded in the very soul of CurePSP. We can point to a number of key accomplishments in 2015.

We held our inaugural Family Conference with our first international affiliate, CurePSP-Canada, in Ottawa. It was a highly successful first step to providing much needed support for our friends north of the border, attracting around 120 attendees. The 2016 Canadian Family Conference will be held in Hamilton, Ontario. Family Conferences in the United States will be held for the first time in the San Francisco area, in collaboration with the University of California, San Francisco, and in the New York City area, in collaboration with Columbia University.

Our first Care Partners Retreat took place near Baltimore, and was a great success. Drawing about 30 attendees, the event featured speakers, workshops, massages and a closing cocktail reception and raffle. This is a model for future retreats that will help care partners cope with the enormous stresses and challenges of their demanding work tending to loved ones.

CurePSP created the Respite Fund to ease the financial burden of getting professional, in-home respite care when the need arises. This fund helps to ease the burden of care partners, who often have to be on call 24/7/365.

Support groups form the foundation of our programs, and this year we helped to create five new groups in areas throughout the U.S.

Consciousness

We started to engage in a public awareness campaign around the prime of life brand platform. This approach positions several related diseases, including PSP, that often strike in middle age when people may have family responsibilities, careers and active lives. The prime of life platform creates emotional connection and cultural relevance with people who might have no direct experience with these diseases and helps to generate support for our cause. This campaign is being implemented through print collateral, advertising, publicity and a new website.

Our physician educational video series highlights clinical exams of people with PSP, CBD and MSA, paired with physician lectures on all three diseases. The videos are an enormous benefit to doctors and allied healthcare professionals, who may have limited experience with these diseases.

Employing professional film and still photography, we completed poignant and inspiring patient profiles of families who have been struck with PSP, MSA and FTD as a way of dramatically depicting the devastation caused by prime of life neurodegeneration. We will follow up next year with profiles of patients suffering from amyotrophic lateral sclerosis (ALS), chronic traumatic encephalopathy (CTE) and CBD. These profiles will help to dramatize the devastation of neurodegeneration to those who have never experienced it.

Cure

During the last fiscal year (beginning July 1, 2014), we have funded seven important new research projects and five others previously funded have been completed.

These studies address a number of important areas including:

- Defining drug targets for PSP and CBD
- Functional ability in PSP
- Preclinical models for PSP
- PSP genetic variants
- RNA binding proteins
- Tau pathology, aggregation and clearance

The investigators represent leading institutions globally:

- Asceneuron SA (Switzerland)
- Boston University
- Brigham and Women's Hospital, Boston
- Foundation for Applied Medical Research (Spain)
- The University of New South Wales (Australia)
- University of Alabama
- University of Buffalo
- University of California, Los Angeles
- University of California, San Francisco
- University of California, Santa Barbara
- University of Cambridge (UK)
- University of Texas

Our new Patient Engagement Program (PEP) was formed to help pharmaceutical companies and academic researchers in their implementation of clinical trials. Promising results with animal models have led to trials with human cohorts primarily in PSP. PEP now has contracts with Bristol-Myers Squibb and AbbVie and is in talks with other pharmaceutical companies. Profits from PEP go directly back to CurePSP to support our programs.

Fundraising

Our annual fund (July 1 through November 20, 2015) for this fiscal year has raised nearly \$1 million. Included in this figure is around \$75,000 from 36 fundraising events and activities, with additional funds realized from planned giving bequests. Additional appeals and a new planned giving campaign are scheduled for 2016.

We held events in New York, San Francisco and Baltimore to introduce new donor prospects to our foundation. Our “*Theory of Everything*” research roundtable in New York, brought together 90 attendees from the local philanthropic community and featured leading investigators and doctors in a highly informative program followed by probing discussion. These events are part of our strategy to introduce CurePSP to donors who may not have any direct connection to the prime of life diseases, but are vitally interested in helping to find a cure for neurodegeneration.

To better manage our donor lists, we are in the process of implementing the latest version of Raiser's Edge NXT from our strategic partner, Blackbaud. This fundraising management software will allow us increased proactivity in communication, leading to greater participation rates and revenues. We are also investigating software upgrades that will allow volunteers to better market and manage local events. Our goal is to increase the number and impact of events as a tool for grassroots fundraising.

Of course, the participation of all our donors is critical to the success of the foundation, but the commitment by our major donors is especially important. We will greatly appreciate your continued support in 2016.

Patient Engagement Program (PEP)

As part of CurePSP's mission to find treatment and cure for PSP and other prime of life neurodegenerative diseases, we are actively focused on ensuring that clinical trials of promising compounds are able to proceed by having enough eligible participants. Through the Patient Engagement Program (PEP), we can connect patients more quickly with clinical trials sponsored by pharmaceutical companies, and assist patients throughout their participation in the studies. These trials are a critical step in bringing drug treatments to millions of people suffering from prime of life diseases.



The efforts of PEP fall into three main areas:

1. Educating clinical trial coordinators about PSP.
2. Recruiting patients for clinical trials and helping with retention.
3. Conducting outreach to physicians about clinical trials.

The partnerships made through PEP are our first direct collaborations with pharmaceutical companies. The trials conducted by the pharmaceutical companies are medication trials, while other research efforts are focused on basic science and animal models.

PEP is a subsidiary of CurePSP and is a fee-for-service, profitmaking business that is paid for by pharmaceutical companies. Any funds generated by PEP flow back to CurePSP and will be used to fund our work in the care, consciousness and cure of prime of life diseases.

Basically, PEP is designed to help patients in their “end-to-end” participation by providing case management services to each patient in the trials. CurePSP has always been by the side of patients, caregivers and families affected by PSP and other prime of life neurodegenerative disorders, guiding them through their journeys. They are our number one priority, and these trials are a critical research step to bringing drug treatments to them. With PEP, we are looking forward to working with patients and their families to take this monumental next step toward achieving our goal – safe and effective treatments – together.

PEP will initially target PSP, which is the foundation's primary focus. PSP is currently the subject of intensive research and several clinical trials related to this disease are in development. Because mechanisms in PSP are involved in multiple prime of life disorders – and in other common neurodegenerative diseases, including Alzheimer's disease and Parkinson's disease – many researchers are hopeful that finding an effective treatment for PSP will open new pathways for treatment of other neurodegenerative disorders.

We are extremely excited about PEP and taking this next step of connecting patients more quickly with clinical trials sponsored by pharmaceutical companies, which is critical in bringing drug treatments to millions of sufferers.

Research Grants Completed in 2015



The Role of O-Linked Protein Glycosylation in the Spread of Tau Pathology

Christoph Wiessner, PhD

Asceneuron SA

Lausanne, Switzerland

Summary: Increasing the attachment of a specific sugar molecule (O-GlcNAc) to tau reduces the formation of neurofibrillary tangles (NFTs) and tau pathology, including PSP. This increase can be achieved by inhibiting the enzyme O-GlcNAcase that cuts off the beneficial O-GlcNAc sugar from tau. This study engineered promising O-GlcNAcase inhibitor drug candidates, and the plan is to initiate first human studies in 2016. Potential effects in future studies will be explored, with the goal to clarify the mechanism of the toxicity and test effects of the O-GlcNAcase inhibitor.



Altering Tau Splicing for PSP and Other 4R Tauopathies

Michael Wolfe, PhD

Brigham and Women's Hospital

Boston, Massachusetts

Summary: PSP and CBD are caused by abnormal deposits of a neuronal protein called tau that comes in two general splicing varieties, 4R and 3R. 4R levels are increased during PSP and CBD. The aim of this study was to develop agents that decrease 4R tau at the level of RNA splicing in cell model systems allowing important compound validation that would justify further testing in a mouse model of 4R tau pathology and, ultimately, clinical trials for PSP and CBD. Initial tests to correct 4R/3R protein in the cell culture models have been partially successful. A very clear reduction in 4R tau protein was observed, but the effect was not as pronounced as seen at the RNA level. More research is needed to continue this promising approach of reducing the tau level in PSP patients.



Follow Up Genotyping & Functional Analysis of PSP H1 Haplotype Variants

Pau Pastor, MD, PhD

University of Navarra

Pamplona, Spain

Summary: Most PSP/CBD cases carry no changes in MAPT gene, but the strong association with neighboring genes. Results from next generation sequencing (NGS) experiments of such regions in PSP and healthy subjects identified 37 alterations in the DNA sequence of neighboring genes. The detailed analysis showed potential candidate variants. However, more research is needed to validate this data, so that the causing DNA variants can be used as highly specific disease markers for early PSP/CBD diagnosis for future clinical trials and therapies.

Research Grants Completed in 2015

Mechanisms and Therapy for Tauopathy Based on RNA Binding Proteins



Benjamin Wolozin, MD, PhD

Boston University

Boston, Massachusetts

Summary: The protein TIA-1 (a RNA binding protein) can induce tau misfolding upon co-expression with tau and is present in the brains of people with dementias involving the tau protein. The study focused on screening for chemicals that can inhibit the formation of misfolded tau and characterized the effects of TIA-1 on tau aggregation in the brain. The best compounds appearing to have characteristics most amenable to becoming a potential treatment for PSP were identified. The development of tau-misfolding inhibitory compounds could become or lead to novel therapies for PSP and possibly provide a long sought treatment for this disease.

Tau Dimerization: A Mechanism of Tau Function and Dysfunction?

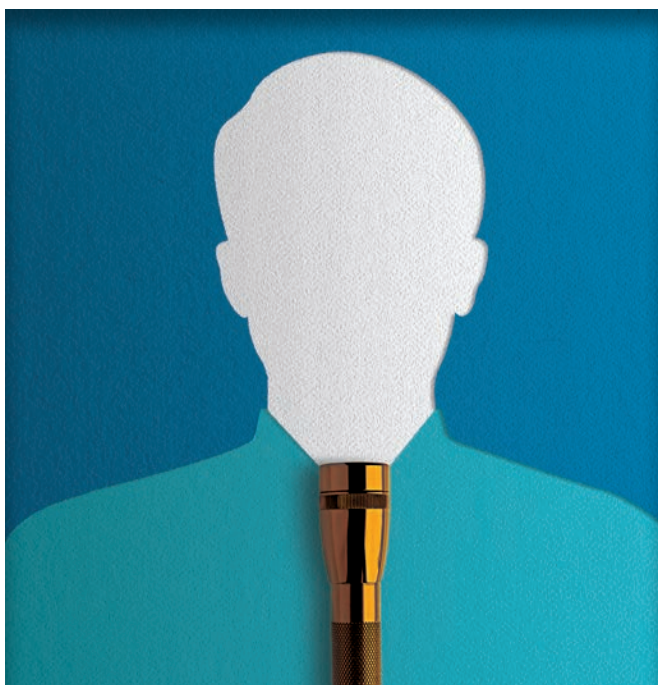


Stuart Feinstein, PhD

University of California, Santa Barbara

Santa Barbara, California

Summary: While we understand many functions performed by tau, our understanding of how it actually performs these functions remains primitive. One half of tau, (the “C-terminal half”), can associate with microtubules and regulate their essential behaviors. However, the ability of this region of tau to perform these critical functions drops dramatically without the other half of the protein (the “N-terminal half”). The mechanism(s) by which the N-terminal half exerts its potent influence(s) upon the C-terminal region remain completely enigmatic. The goal of this study was to test the hypothesis that normal tau function in neurons and determine how tau actions inside the cells are regulated. By better understanding the normal role of tau, novel insights into pathological tau action in PSP and CBD can be investigated.



New Research Grants in 2015



Defining a Novel Drug Target for PSP and CBD

Lars Ittner, MD

*University of New South Wales
Sydney, Australia*

Summary: Endoplasmic reticulum (ER) stress is a cellular process in response to accumulation of abnormally folded proteins in order to remove the aberrant protein load or induce cell death. It is tightly regulated by a number of factors and pathways. Increased ER stress associated with pathological changes to the protein tau has been implicated in the early development of neurodegenerative disease with tau pathology, including PSP. This application will explore the exact molecular roles of these factors and pathways in the context of tau pathology and test whether it is a suitable future target for drug development.



Investigating Functional Ability in PSP

Adam Gerstenecker, PhD

*University of Alabama at Birmingham
Birmingham, Alabama*

Summary: Although the most observable deficits caused by PSP are difficulties with movement, the disorder also has a number of other common features. For example, patients with PSP often have difficulties with cognition and functional ability in both “basic” and “instrumental” activities of daily living. Recent research has demonstrated that the scales used to assess for functional ability in PSP are driven by the movement symptoms characteristic of the disorder. Thus, the identification and understanding of MCI and dementia in PSP is limited. This proposal aims to investigate functional ability in PSP patients. Obtained data will then be analyzed to determine what functional scales and items best correlate with cognition so that better scales of functional ability in PSP can be constructed.



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

Ragnhildur Thora Karadottir, PhD

*University of Cambridge
Cambridge, UK*

Summary: The genome wide association study (GWAS) carried out in PSP patients has identified several genes as risk factors for the disease, including myelin structural proteins, arguing for a possible role of oligodendrocytes, the myelin producing cells, in disease development. However, it is currently unknown how tau modifications affect oligodendrocyte function, and it is even unclear whether human oligodendrocytes express tau or take it up from surrounding neurons. The aim of the present application is to generate oligodendrocytes from induced pluripotent stem cells from PSP patients as well as control subjects. In these human oligodendrocytes the expression and possible modifications of tau protein will be investigated. This study will help in understanding whether oligodendrocytes are key players in the development of pathology in PSP, paving the way to a new mechanism-based therapeutic avenue.

New Research Grants in 2015



The Establishment of a Preclinical Model for Progressive Supranuclear Palsy

Stewart Clark, PhD

*University of Buffalo
Buffalo, New York*

Summary: Progressive supranuclear palsy (PSP) has a myriad of symptoms, the most visible being difficulties in motor function. There are less obvious deficits, such as cognitive impairment and a reduction in the startle reflex to loud acoustic stimuli (ASR). The latter phenomenon may distinguish PSP from other forms of Parkinson's disease (PD). This project will mimic the ASR in pre-clinical rat models and investigate the changes in the brain under the influence of tau and in the context of the ASR. These animal models are the first steps towards drug discovery for PSP and will allow for: 1) improved diagnosis, 2) identification of effective drugs, and 3) the study of the degeneration and pathology that is unique to PSP.



Small-Molecule Modulation of Tau Clearance and Aggregation

Gal Bitan, PhD

*University of California, Los Angeles
Los Angeles, California*

Summary: One of the hallmarks in PSP pathology is the abnormal clumping of tau molecules. Hence, preventing the clumping and the formation of toxic aggregates is an attractive strategy for developing drugs against PSP and other tauopathies. This study has developed an experimental drug called CLR01, which effectively prevents the abnormal clumping of tau and other proteins. Previously, CLR01 was found to be effective in animal models of Alzheimer's disease, Parkinson's disease, and systemic amyloidosis. In the current project, the scientists propose to test the effect of CLR01 in a mouse model of tauopathy and to further develop CLR01 for clinical trials.



Tau in Peripheral Tissues of PSP and CBD

Brittany Dugger, PhD

*University of California, San Francisco
San Francisco, California*

Summary: The brain is connected to the body. Despite this fact, many studies on PSP and CBD focus solely on the brain. The purpose of this project is to determine if pathological changes that are found within the brains of PSP and CBD can be also found within peripheral tissues. This will indicate the feasibility of a biopsy site for improving the clinical diagnostic accuracy of PSP and CBD, equating to better treatments and providing new insights into these horrible diseases. This study will use tissue collected from autopsy confirmed PSP and CBD patients to determine if tau pathology can be found in peripheral tissues that are more readily accessible and typically screened and probed in a healthcare setting. The project is well positioned to create a new paradigm for studying PSP and CBD through understanding how pathologies within the brain may exist in periphery tissues; this will lay the groundwork for a wide range of potential interventions that are truly distinct from approaches currently under investigation.



Specific Targeting of PSP Brain-Derived Tau Oligomers

Rakez Kayed, PhD

*University of Texas Medical Branch
Galveston, Texas*

Summary: Recent studies suggest that neurofibrillary tangles (NFTs) are not the most toxic tau entities in tauopathies, including PSP. Rather, there is evidence that tau oligomers are the cause of toxicity in neurodegenerative diseases. Moreover, tau oligomers isolated from PSP brains are able to multiply themselves. The aim of this proposal is to fully characterize tau oligomers in PSP, establish their critical role in disease pathogenesis, and evaluate potential anti-tau oligomers in order to develop a disease-modifying therapeutic approach. The plan is to achieve these goals using novel anti-tau oligomer-specific monoclonal antibodies (TOMAs). TOMAs have been shown to be effective in preventing and reversing the toxic effects of tau oligomers. In summary, this project will yield results with great capacity to advance diagnostic and therapeutic applications targeting toxic tau oligomers in PSP.



Statements of Financial Position

June 30, 2015 and 2014

ASSETS

	2015	2014
CURRENT ASSETS:		
Cash and Cash Equivalents	\$ 2,545,846	\$ 1,875,613
Cash and Cash Equivalents – Temporarily Restricted	350,870	563,217
Investments-Unrestricted	2,442	—
Pledges Receivable - Unrestricted	—	1,500
Pledges Receivable - Temporarily Restricted	3,700	308,985
Other Receivables	12,850	83,432
Prepaid Expenses	83,266	38,557
Total Current Assets	2,998,974	2,871,304
PROPERTY AND EQUIPMENT - AT COST:		
Office Equipment	70,108	101,672
Furniture and Fixtures	81,248	47,406
Software – Database	54,033	54,033
Website	—	31,253
	205,389	234,364
Less Accumulated Depreciation	173,373	210,911
Net Value of Property and Equipment	32,016	23,453
LONG TERM ASSETS:		
Marketable Securities – Permanent Endowment	380,827	383,411
Deposits	7,058	3,983
Total Other Assets	387,885	387,394
TOTAL ASSETS	\$ 3,418,875	\$ 3,282,151

LIABILITIES AND NET ASSETS

CURRENT LIABILITIES:		
Accounts Payable and Accrued Expenses	\$ 296,387	\$ 91,862
Grants Payable – Due Within One Year	712,902	809,731
Total Current Liabilities	1,009,289	901,593
LONG TERM LIABILITIES:		
Grants Payable – Due After One Year	249,589	466,663
Total Liabilities	1,258,878	1,368,256
NET ASSETS:		
Unrestricted		
Undesignated	1,555,625	1,115,555
Board Designated – Research	—	100,000
Board Designated – Programs and Education	—	5,346
Total Unrestricted	1,555,625	1,220,901
Temporarily Restricted	223,545	309,583
Permanently Restricted	380,827	383,411
Total Restricted	604,372	692,994
Total Net Assets	2,159,997	1,913,895
TOTAL LIABILITIES AND NET ASSETS	\$ 3,418,875	\$ 3,282,151

Statement of Activities and Changes in Net Assets

For the years ended June 30, 2015 and 2014

2015				
	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
REVENUES AND OTHER SUPPORT:				
Contributions	\$ 2,184,730	\$ 103,799	\$ —	\$ 2,288,529
Special Events (Net of \$25,968 in Expenses)	277,300	6,353	—	283,653
Interest and Dividend Income	6,292	6,454	—	12,746
Realized and Unrealized Gains on Investments	—	—	529	529
Grant Adjustment	—	135,495	—	135,495
Net Assets Released from Restrictions	341,252	(338,139)	(3,113)	—
Total Revenues and Other Support	2,809,574	(86,038)	(2,584)	2,720,952
EXPENSES:				
Program Services:				
Research	1,095,450	—	—	1,095,450
Programs and Education	563,093	—	—	563,093
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 Program and Support Services	2,474,850	—	—	2,474,850
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
2014				
	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
REVENUES AND OTHER SUPPORT:				
Contributions	\$ 2,339,915	\$ 775,912	\$ —	\$ 3,115,827
Special Events (Net of \$34,319 in Expenses)	165,834	9,930	—	175,764
Interest and Dividend Income	3,275	7,670	—	10,945
Realized and Unrealized Gains on Investments	—	—	35,179	35,179
Net Assets Released from Restrictions	1,082,143	(1,079,206)	(2,937)	—
Total Revenues and Other Support	3,591,167	(285,694)	32,242	3,337,715
EXPENSES:				
Program Services:				
Research	2,246,935	—	—	2,246,935
Programs and Education	369,558	—	—	369,558
Communications and Public Awareness	143,050	—	—	143,050
Support Services:				
Management and General	108,120	—	—	108,120
Board	40,022	—	—	40,022
Fundraising	257,593	—	—	257,593
Total Program and Support Services	3,165,278	—	—	3,165,278
CHANGE IN NET ASSETS	425,889	(285,694)	32,242	172,437
NET ASSETS AT BEGINNING OF YEAR	795,012	595,277	351,169	1,741,458
NET ASSETS AT END OF YEAR	\$ 1,220,901	\$ 309,583	\$ 383,411	\$ 1,913,895

Leadership and Staff

BOARD OF DIRECTORS

CHAIR

William R. McFarland

VICE CHAIR

Everett R. Cook

TREASURER

George S. Jankiewicz, CPA, CFP, MBA

SECRETARY

Brendan (Mike) Dixon

CHAIR EMERITUS

John T. Burhoe

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Yvette M. Bordelon, MD, PhD

Amy Branch

Heather J. Cianci, PT, MS, GCS

Paul H. Freeman

Jeffrey S. Friedman, MD, PhD

Lawrence I. Golbe, MD

Stephen S. Goldman, PhD

James G. McClellan, CPA/PFS

Ileen J. McFarland

Adam M. Murphy

James J. Shea

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John C. Steele, MD, FRCP

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Janet M. Edmunson, MEd

Murray Goldstein, DO, MPH

James E. Koehnlein

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Patricia C. Richardson

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President

Trish Caruana, MSW

Executive Vice President,

Kathleen Matarazzo Specca

*Vice President, Development
and Donor Relations*

Alex Klein, PhD

Vice President, Scientific Affairs

Doreen Bish

Office Manager

Cecelia Huffman

*Marketing and
Communications Manager*

Jaclyn Zendrian, MA

Conference Manager

Diane Seegull

Accountant

Kelly Saunders

*Gift Processing and
Data Quality Coordinator*

Gina Truitt

Development Assistant

PATIENT ENGAGEMENT PROGRAM (PEP) STAFF

Trish Caruana, MSW

President and Chief Executive Officer

Joanna Lindamore

Business Development Manager

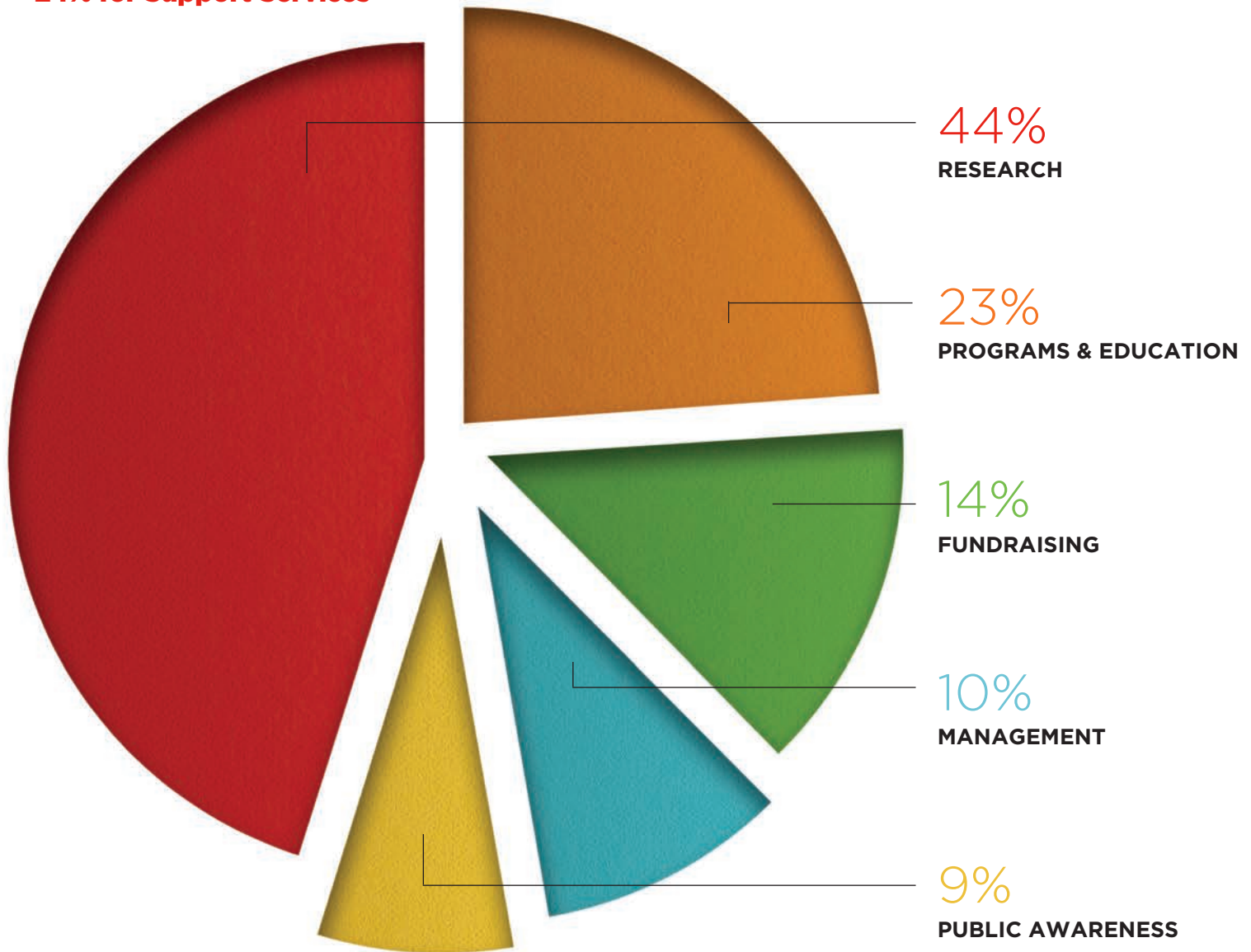
Aryelle Barrett

Program Coordinator

How Your Gifts Were Used

(FY 2015)

76% for Program Services
24% for Support Services



Thank you for your support.

Development and Fundraising

PLANNED GIFTS AND BEQUESTS

Planned giving is a method of supporting CurePSP that enables philanthropic donors to make larger gifts than they could make from their income. A planned gift is any major gift, such as a bequest, charitable remainder trust or other instrument, made during lifetime or at death as part of a donor's overall financial and/or estate planning. During fiscal year 2015, CurePSP received planned gifts or bequests valued at \$1,041,844 from:

Julie E. Repasy Trust
Jack E. Schuss Irrevocable Trust
James Yates Paulding Living Trust
Estate of John and Ruanne Peters
Estate of Peggy Ann Randall



SPECIAL EVENTS

Special Events and fundraising activities are vital to the programs and services of CurePSP and serve as a strong educational tool by creating awareness throughout communities. Special events also help reach new families affected by neurodegenerative diseases.

Thanks to the kindness and generosity of our CurePSP volunteers, 79 special events and/or fundraising activities occurred this fiscal year throughout 29 states and two countries, as well as additional fundraisers that were nationwide. These endeavors included:

- Half and Full Marathons
- 5K Runs
- Walkathons
- Pottery and Craft Shows
- Motorcycle Events
- Continental Divide Hike
- Auctions
- Mountain Climbing
- Car Show
- Honoree Party
- Jewelry and Handbag Parties
- Car Washes
- Dining Out Events
- CurePSP Wristbands, Ribbon Magnets, “Hope” Bracelets and T-shirt Fundraisers
- Birthday Parties
- Wedding Gifts
- Family Writing Campaigns
- Concerts

CurePSP is most grateful to all of our volunteers for their time, talents, kindness and generosity.



Methods of Supporting CurePSP

Building and Strengthening an Enduring Foundation

The method by which you contribute to CurePSP can determine your tax benefits. Every person's situation is unique. The Office of Development and Donor Relations will be happy to discuss with you various methods of giving and provide detailed opportunities for support. All inquiries will be held in the strictest confidence. Commitments made today ensure that CurePSP will maintain its role as a not-for-profit health service and research organization of the highest quality and standards.

Listed below are methods of how you may support the programs and services of CurePSP, which include general support, research, patient and caregiver support, advocacy and education.

Annual Fund – General appeal mailings and emails are regularly sent to CurePSP families several times each year and are the primary way for supporting our programs and services.

Special Events – CurePSP recruits volunteers to support fundraising efforts. Events include golf outings, walkathons, cycling, wine tastings, dances, dinner parties, and much more. In addition, CurePSP encourages constituents who are avid runners to participate in community marathons by piggybacking on an established event in honor of or in memory of a loved one. Piggybacking on community events removes the burden of planning and implementing an event and allows participants to participate for a specific charity.

Major Gifts – Donors are encouraged to make major gifts of at least \$5,000 to support research grants and other designated purposes. Donors may restrict their gifts for these particular uses. Donors that contribute at least \$50,000 for research purposes may also have a special “named research grant” in their honor or in memory of a loved one.

Named Funds – A CurePSP Named Fund provides donors with the opportunity to make gifts that will have a lasting impact while recognizing their family, or honoring or memorializing a loved one. Named Funds may be established through special events, annual donations or a special family writing campaign. An annual donation of at least \$1,000 is required to keep a Named Fund active and recognized. Named Funds of \$1,000 or more receive recognition in the CurePSP Annual Report and may also receive recognition at a family conference, webinar, or on printed materials.

Planned Gifts – The following provides samples of planned giving options:

- Bequests
- Charitable Remainder Trusts
- Gifts of Life Insurance
- Charitable Lead Trusts

If you are interested in establishing a planned gift to support the programs and services of CurePSP, please contact your financial advisor for further information on the best option for you.

For more information on the methods of supporting CurePSP, please contact Kathleen Matarazzo Specca, Vice President of Development & Donor Relations, at specca@curepsp.org or 443-578-5672.

Honor Roll of Donors

For the Period July 1, 2014 through June 30, 2015

CurePSP is indebted to the many donors who have so graciously generated support for programs and services. Gifts acknowledged in this report are for the 12-month period beginning July 1, 2014 through June 30, 2015.

The CurePSP Office of Development and Donor Relations raises funds to support all programs and services including research, patient support, medical education, patient advocacy, caregiver services, public awareness and governmental relations. These essential functions are made possible and accomplished through a wide range of fundraising projects, including the annual fund and direct mail appeals, planned giving, major gifts, endowed funds, named family funds, volunteer recruitment, donor stewardship and local and national special events with our CurePSP families and constituents.

Generous Benefactors

New York Life Insurance Company
The Nathan P. Jacobs Foundation
Mary Beth Repasy Fund
Dan/Merrie Boone Foundation
C2N Diagnostics, LLC
J&S Foundation
Miracle For Mom
Judith Knell Binder Family Foundation
Teach A Man To Fish Foundation
Dianne H. Ruthman Family Foundation
Bridgemill Foundation
Szulik Family Foundation
Light of Day Foundation, Inc.
Fred and Mabel R. Parks Foundation
CBD Solutions
Heavy Duty Truck Repair
Lyndon Selter Parker Trust
Esther A. Palumbo Family Fund
Klaus Althammer
Miriam Bernstein
Amy Branch
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Paul Freeman
Jeffrey Friedman
George Grice
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Harry Hohn
William Janssen
Susan Kane
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Eric Leinwand
Wilson McElhinny
Dave McNaughton
Martha Medcalf
Robert Moore
Edith Parker
E. Spencer Parris
Karen Rainwater
Terence Roche
Ernest Segundo DNM
Garvin Tate
Lesley Undercoffer

Named Funds

\$1,000,000 and above

Peebler PSP Research Foundation
Irene and Abe Pollin CBD Research Fund

\$250,000 to \$999,999

The Karen and Everett Cook Foundation
Eva Freeman Memorial Fund
Morton and Marcine Friedman Foundation
Theresa and Peter Lund Research Fund
Edwin & Pearl Poizner Memorial Fund
Jack and Betty Schuss Memorial Fund
Eloise H. Troxel Memorial Fund

Honor Roll of Donors

For the Period July 1, 2014 through June 30, 2015

Named Funds (continued)

\$50,000 to \$249,999

Elayne and Benno Hurwitz Philanthropic Fund
Ken Jennings Legacy Fund
Robert T. Kirkey Memorial Fund
Dudley Moore Research Fund
Lyndon Selter Parker Trust Fund
Laurence B. Richardson Memorial Fund

\$10,000 to \$49,999

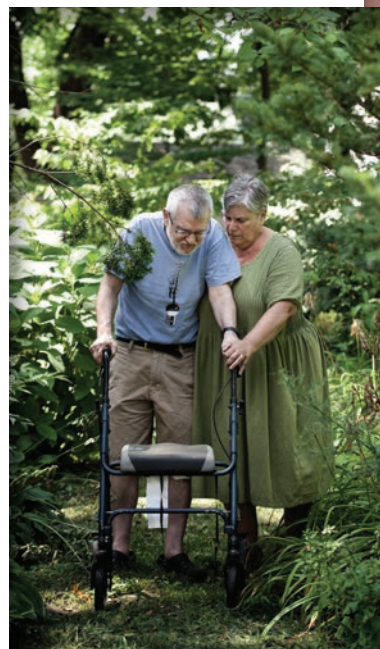
Colette M. Bednarczyk Memorial Fund
Charles R. Edmunson Memorial Fund
Stevens Frink Family Fund
Robert P. Hanrahan Memorial Fund
Devon D. Huffnagle Memorial Fund
Vandana Juneja Memorial Fund
David Livernois Memorial Fund
Carl J. Major Legacy Fund
Jackie Myers Family Fund
Nancy Newell Fund
Norma Oppenlander Memorial Fund
Margaret Parker Memorial Fund
Roberta Schenker Memorial Fund
George Wood Legacy Fund
Zyne Family Trust

\$5,000 to \$9,999

Sami and Annie Totah Family
Terry Watson Memorial Fund

\$1,000 to \$4,999

Dr. Joseph Cavallaro Memorial Fund
Joe Dean Memorial Fund
Natalie L. Friedman Memorial Fund
Joel H. Gilbert Memorial Fund
The Gloria Fund for PSP Awareness & Research
Sylvia Guido Fund
Selma Aronowitz Klass Memorial Fund
Pansey C. Littles Memorial Fund
Dorothy MacDonald Memorial Fund
Sid Millman Memorial Fund
David S. Olander Memorial Fund
Lucille C. Parrilli Memorial Fund
Anthony Spare Memorial Fund





*James E. Wark, MD,
and his wife, Soryl.*

*Dr. Wark is
diagnosed with MSA.*



UNLOCKING THE SECRETS OF BRAIN DISEASE®

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