

# Annual Report 2014

curePSP®

Foundation for PSP | CBD and Related Brain Diseases

*Curing, Caring, Commitment*

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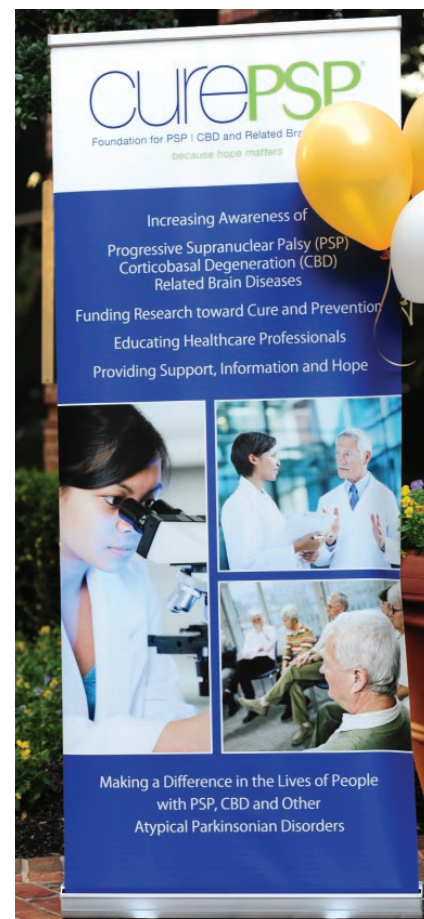
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# Dedication to John C. Steele, MD, FRCP



*Dr. John Steele, with his son, Alex, and grandson, Jonathan, at CurePSP's Milestones and Horizons event at Johns Hopkins University on October 17, 2014.*

CurePSP is honored to dedicate its 2014 Annual Report to John C. Steele, MD, FRCP.

This dedication marks the 50th anniversary of the identification of progressive supranuclear palsy and is in recognition of Dr. Steele's extraordinary commitment to finding a cure for neurodegenerative diseases.



With his visionary contributions to the world of medicine, he has touched those affected by rare brain disorders. Through his knowledge and leadership, Dr. Steele has empowered CurePSP to expand research around the world and advance the science that may lead to treatment, prevention or cure for PSP and related disorders.

The Board of Directors and staff extend their deepest appreciation to Dr. Steele for his splendid gifts and service that have created hope for the future.

# From the Chair of the Board of Directors



**John T. Burhoe**

This annual report is dedicated to Dr. John C. Steele.

In October 2014, CurePSP had the privilege of honoring Dr. Steele on the fiftieth anniversary of his, Dr. Richardson's, and Dr. Olszewski's identification of progressive supranuclear palsy. Next year, CurePSP will celebrate its twenty-fifth anniversary in which Dr. Steele has also been a guiding force. We salute him for his invaluable contribution to CurePSP's growth and success. Thank you, Sir, for your leadership, knowledge, guidance and wisdom.

Last year, I ended my message to you as follows:

*"We are at a critical point where CurePSP can continue as one of many worthy organizations pursuing a common goal, or, we can lead this effort, utilizing our motivation, passion, talent and associations to find the cure not only for PSP, but potentially all neurodegenerative diseases. Please join us on this journey."*

And indeed you did! This year, we posted an increase in gifts to \$3 million dollars, making the future bright financially. Thanks to the Board, the staff, and particularly to YOU for your generosity and commitment. We also initiated a major project with Drs. Lee and Trojanowski, of the University of Pennsylvania, which focuses on the development of a tau immune therapy for PSP and CBD. We are also in the process of expanding our outreach through the development of a Canadian affiliate, as well as broadening our relationship with the Tau Consortium and other peer organizations.

The Foundation has also expanded collaborations with the pharmaceutical industry, which have sought out CurePSP because of its "orphan disease" status that "fast tracks" the approval cycle through the governmental regulation maze. This and the now accepted scientific premise that PSP, CBD and MSA have a potential connection with other major neurological diseases, including Alzheimer's, is an incentive for pharma's involvement with CurePSP.

That's running like a business, that's being a leader and thinking "outside the box" which underscores our and your aggressive spirit.

Thank you for your trust, your support and your friendship.

In the Navy, my old Executive Officer on the USS Liddle (APD-60) always ended his Orders of the Day with:

**"PRESS ON REGARDLESS"**

I commit to you that this board and staff will "press on regardless" until we can solve these enigmas called PSP, CBD and MSA.

# From the President-CEO



## **Richard Gordon Zyne, MS, DMin**

*After 10 years of dedicated service, Richard Gordon Zyne, MS, DMin, has retired as President-CEO. He has been succeeded by David Kemp, who will assume the title of President.*

To Board of Directors, Staff, Patients and Carepartners, Donors, and the Healthcare and Scientific Community:

The last ten years have been some of the most rewarding times of my life as President-CEO of CurePSP. It has been a time of commitment and dedication to a superior cause and mission. I leave the organization with a full and deep sense of achievement and success. I am convinced that this Foundation has helped thousands of people with PSP and CBD and has opened up many new doors through innovative research and in the understanding of the basic rudiments of these terrible diseases. To be a part of this process has truly been an honor and a blessing.

All organizations change and grow and CurePSP has the opportunity to move in a new direction, especially in an expanding role in funding research and even in drug discovery and development. This is very exciting and a move in this direction can only expedite and facilitate our vision of a world free of PSP, CBD and related brain disorders.

I wish the board of directors of CurePSP much success in its expanding ventures to find a treatment, therapy or cure for rare neurodegenerative disease and I wish the staff much strength as it works with the board to support patients and caregivers in their daily struggles.

I want to thank all the wonderful people over the years who have been supportive of my efforts and who have looked at the work of the Foundation as one of ministry and high service. May I wish you all God's blessings and thank you for this opportunity to serve.

# Strategic Vision 2015

CurePSP's mission is to increase awareness of progressive supranuclear palsy, corticobasal degeneration, and other atypical Parkinsonian disorders; fund research toward treatment, cure and prevention; educate healthcare professionals; and provide support, information and hope for affected persons and their families. With this in mind, the Foundation has established its Strategic Vision 2015 with criteria for long-range planning and decision-making.

## CURING

*Developing treatments and therapies for PSP, CBD, MSA and related brain disorders, including basic and clinical research; research leading to the development of pharmaceuticals; and advocating for patients to encourage research, public funding and drug development.*

- Research
- Advocacy and Partnership Development

## CARING

*Developing programs and services to improve quality of life; providing educational resources for patients, carepartners, physicians and allied health professionals; and increasing public awareness of CurePSP's mission.*

- Patient and Carepartner Support
- Education for Medical and Healthcare Professionals
- Public Awareness

## COMMITMENT

*Managing, building, and strengthening the Foundation's governing body, financial resources, human resources, and operations.*

- Governance
- Development
- Infrastructure

## RESEARCH

### Strategic Goals

- Advance the understanding of PSP, CBD and related disorders by funding research focusing on identifying the causes and risk factors involved and developing both early stage diagnostic tests and treatments or interventions

### Research Road Map

The *Research Road Map* CurePSP's framework for a comprehensive array of projects that may lead to treatments, therapies and even a cure for PSP, CBD and related neurodegenerative disorders. The Foundation recognizes that the fight against these disorders can now take a new direction, capitalizing on recent discoveries, existing ongoing work, and new hypotheses. CurePSP will fund research initiatives in five areas—genes, prions, proteins, models and markers.

### Research Projects

CurePSP will fund investigator-initiated research projects in the areas outlined in the *Research Road Map*, including *Special Initiative Grants (SIG)* designated for innovative and high-risk research ideas. The Foundation will strengthen existing collaborations and build new partnerships with institutions and peer organizations conducting research that impacts the disorders. CurePSP will continue to support *The Eloise H. Troxel Memorial Brain Bank* at the Mayo Clinic.

### International Research Symposium

CurePSP will continue to conduct the annual International Research Symposium which allows recent CurePSP grantees to present their results while encouraging collaboration among scientists. The event also helps to generate interest among the National Institutes of Health, universities, medical institutions and funding organizations.

### Training Research Fellowships

CurePSP will fund the annual *Urso Summer Student Program* in PSP research and explore the implementation of a career development award for early-stage academic researchers.

## ADVOCACY AND PARTNERSHIP DEVELOPMENT

### Strategic Goals

- Advocate on various public policy issues such as orphan drug development and improved benefits for individuals affected with PSP, CBD and related disorders
- Educate governmental leaders about research and quality of life for people living with the disorders
- Encourage biotech innovation for rare disease treatments via science-driven public policy by partnering and collaborating with private medical institutions, pharmaceutical entities and the public sector
- Partner with peer organizations to foster and fund both basic and clinical research projects
- Coordinate with federal agencies which affect research, services and drug development for our constituents

## Objectives

### Legislative Advocacy

CurePSP will continue to participate in legislative advocacy in coordination with organizations such as the Parkinson's Action Network (PAN), the National Organization for Rare Disorders (NORD), Rare Disease Legislative Advocates (RDLA), and others.

### Drug Discovery and Development Collaborations

CurePSP will commit to bringing new treatment options to our patient population and serve as a unique resource connecting trial sponsors, medical professionals and our patient population. The Foundation will leverage philanthropic, corporate and government support to create resources that support clinical trials.

## PATIENT AND CAREPARTNER SUPPORT

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### Strategic Goals

- Maintain position as a global resource for patients and carepartners by providing information to help improve well-being, daily living skills, and quality of life
- Continue to be a primary link to a network of support, ensuring accessibility of information, education and counsel for patients and carepartners
- Serve as a comprehensive educational resource for health care institutions and peer organizations

### Objectives

#### Patient and Carepartner Resources

CurePSP will disseminate educational materials for patients, carepartners, and healthcare professionals that are accurate, comprehensive and current via digital and print mediums.

#### Support Networks and Volunteer Program

CurePSP will expand support networks and provide ongoing training for support groups and peer supporter volunteers.

#### Canadian Affiliate

CurePSP will develop and implement a Canadian affiliate, in coordination with Canadian volunteers. This new organization will help meet the needs of Canadian patients, carepartners, and families affected by the disorders.

#### Peer Organization Collaborations

CurePSP will partner with peer patient advocacy organizations to develop collaborative opportunities such as co-hosting educational events for patients, carepartners and healthcare providers.

#### Annual Family Conferences

CurePSP will coordinate and conduct annual family conferences which will provide educational and support opportunities for patients, carepartners, volunteers, and healthcare professionals.

#### International Leadership

CurePSP will collaborate with international partners in Europe and Canada in order to better serve a global audience.

#### Patient Registry

CurePSP will support the development of a patient registry for PSP and CBD and will be an active advocacy organization participating in the NIH-funded project, Advancing Research and Treatment of Frontotemporal Lobar Degeneration (ARTFL).

## EDUCATION FOR HEALTHCARE PROFESSIONALS

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### Strategic Goals

- Provide scientific and clinical information and resources regarding PSP, CBD and related disorders, including their diagnoses, symptoms, and treatments, to neurologists,

physical therapists, occupational therapists, speech-language pathologists, nurses and social workers

- Offer professional training through print and web-based communications and conferences
- Develop relationships with healthcare providers at major institutions and medical centers across the United States to promote jointly-hosted educational ventures

### Objectives

#### Neurologists and Physician Education

CurePSP will use its Physician Education Committee, composed of neurologists and other physicians, to explore ways of promoting awareness of the disorders and providing educational resources for professionals.

#### Partnership with National Parkinson's Foundation (NPF) Centers of Excellence

CurePSP will assist with conferences at NPF Centers of Excellence for patients and carepartners, as well as mini-conferences for therapist education.

## PUBLIC AWARENESS

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### Strategic Goals

- Develop general public awareness of PSP, CBD and related disorders through print and digital mediums, providing disease education and general information about the organization
- Enhance its image, identity, branding, and position as the foremost organization for those affected by atypical Parkinsonian disorders

### Objectives

#### Public Awareness

CurePSP will establish a Public Awareness Committee to help guide public relations and awareness efforts by identifying opportunities and making recommendations on potential initiatives.

#### Media Relations

CurePSP will develop a strategy that increases public awareness of PSP, CBD and related disorders. The Foundation will build relationships with media industry contacts that are in a position to promote the Foundation's cause.

#### Web, Social Media and Interactive Media

CurePSP will improve and enhance website content and functionality to better benefit visitors and constituents alike. The Foundation will strengthen its public perception as the source for PSP and CBD-related information by creating and sharing both original content and existing content through print and social media platforms.

# CURING – Research

## Searching for Cures, Treatments and Therapies



### From the Chair of the Research Committee

Jeffrey S. Friedman, MD, PhD

I'd like to begin this year's letter with a note of gratitude to Dr. Yvette Bordelon, who stepped down from her position as Chair of the Research Committee earlier this year. Yvette served with great insight, compassion and commitment to the research community, physicians, and to patients and families affected by PSP and CBD. I am happy to report that Dr. Bordelon continues to serve on the Research Committee, where her counsel, clinical expertise and calm demeanor are greatly valued!

The Year in Review: 2014 was an eventful and evolutionary year for the research portfolio of CurePSP. Last year, we introduced the concept of *Special Initiative Grants (SIG)* and presented the *Research Road Map*—our guide to research priorities over the next several years. This year, we awarded our second SIG to University of Pennsylvania researchers

Dr. Virginia Lee and Dr. John Trojanowski, who are investigating immune therapy targeting the tau protein. A fundraising collaboration between CurePSP, Penn Medicine and Drs. Lee and Trojanowski has been very successful in bringing in the resources to fund this important work. CurePSP expects to fund at least one additional SIG in 2015, with several possible projects under active consideration.

It is a particularly exciting time to be involved in PSP and CBD research and patient advocacy, as our patient population has become a focus for several drug companies, particularly for new drugs that act on the tau protein. During 2014, we engaged in discussion with several pharmaceutical companies, ranging from the largest multinationals to single product startups planning to enter clinical trials in the near future. These discussions ranged from basic information on disease diagnosis, natural history and treatment to requests for advice on trial design and help with patient recruitment. We are very encouraged by this interest, and are actively engaged with academics, companies and sister patient advocacy organizations to do all we can to accelerate the development and testing of therapeutics for PSP and CBD. All signs point to 2015 as being a very active year for clinical trials targeting our patient population.

While the coming year will be exciting on the clinical research side, we must continue to identify and fund the most promising basic science today, in order to prepare the Foundation for the next series of therapeutic interventions to improve the lives of our patients and family members. Investigator-initiated research proposals will remain our primary source of novel scientific ideas and directions for new grants. New for 2015, when there are specific research domains (biomarkers, early diagnostics, protein homeostasis, novel candidate genes) that the Research Committee believes are important to address, we will prepare requests for applications in order to increase the number of applications targeting these areas of special interest.

Finally, CurePSP was proud to host the Milestones & Horizons event in October 2014 to honor Dr. John C. Steele and his co-authors on the 50th anniversary of the publication of their insightful paper with the first clinical/pathologic description of PSP, followed by CurePSP's 2014 International Research Symposium the next day. These events demonstrated the power of lifelong commitment to patients and how incremental progress in research over many years sets the stage for the exciting developments that are unfolding today.





## From the Chair of the Scientific Advisory Board

Lawrence I. Golbe, MD

This has been a record year for CurePSP's research program. We presently have 25 grants in progress, the most since we started to fund grants back in 1997.

The grantees range from Titus John, a college student at North Carolina State University who is studying the benefit of deep brain stimulation in PSP, to Dr. Stanley Prusiner, a Nobel Laureate at the University of California, San Francisco, who is creating the first rat with PSP. They range from Dr. Natura Myeku of Columbia University, in her first year out of training, studying whether restoring the health of the brain cells' garbage disposal system can clear tau tangles, to Drs. John Trojanowski and Virginia Lee of the University of Pennsylvania, two of the world's leading experts in neurodegenerative diseases, who are developing a PSP vaccine.

Some other exciting projects are assessing a quick skin biopsy as a diagnostic test for PSP; an analysis of the contributions of the genes that were implicated in the cause of PSP by our whole-genome search published in 2011; an examination of chemical modification to DNA, other than alterations in the genetic code itself, that might contribute to the cause of PSP; and a test of whether tiny fragments of DNA called "anti-sense oligonucleotides" can prevent abnormal tau from exerting its toxic action.

CurePSP's annual International Research Symposium, held this year on October 18 in Baltimore, was the biggest ever, with 72 attendees from around the world. The jam-packed day included eight reports from researchers who had completed their CurePSP-funded work over the past year, nine invited experts discussing the state of the science in their specific area and three poster presentations of fast-breaking research developments. The invited experts were an all-star team of many of the top people in the world of PSP and tau protein research: Drs. John Trojanowski and Virginia Lee of the University of Pennsylvania, Dr. Günter Höglinger of the Munich Technical University in Germany, Dr. Adam Boxer of the University of California San Francisco, Dr. Dennis Dickson of the Mayo Clinic Jacksonville, Dr. Karen Duff of Columbia University, Dr. Todd Golde of the University of Florida, and Dr. Warren Hirst of Pfizer Neuroscience Research.

Perhaps the highlight of the day was the first public presentation of CurePSP's whole exome sequencing project by Dr. Gerard Schellenberg of the University of Pennsylvania. This project worked out the exact genetic code in DNA from patients with PSP. However, in order to draw definite conclusions, we need more corresponding information from "controls"—people without PSP who are otherwise similar to the PSP group. The results so far are pointing to a gene designated "LRRK2" as the worst of several bad actors in PSP. This gene is already known to be the most common cause of hereditary forms of Parkinson's disease. Whether the result is PD or PSP could depend on different mutations in the same gene, or co-occurrence of mutations in other genes, or different environmental exposures. If the LRRK2 finding stands up on further analysis by Dr. Schellenberg and his co-workers, this would be a huge breakthrough in the understanding of PSP, suggesting that LRRK2-based treatments that are already under development for PD could, perhaps with a little tweaking, also work for PSP.

PSP has become a popular research topic in recent years. No doubt CurePSP's grant program has contributed, but the main reason is that researchers have been seeing PSP as a possible key to Alzheimer's disease (AD), which, of course, is a major public health problem. While the protein that aggregates and exerts toxicity in PSP is tau, in AD, both tau and beta-amyloid play those roles. Until the last two or three years, beta-amyloid was considered the primary culprit, but since then, tau has emerged as probably the more important. Cure PSP! As a "pure tauopathy," PSP is easier to study in lab animals. As a more rapidly progressive condition, PSP is easier to study in clinical trials. Although, at any one time, only 5,000 Americans have a doctor's diagnosis of PSP, so finding a treatment would permit a small biotech company or academic lab to attract the investment capital or big research grants needed allow them to try to make the jump to Alzheimer's treatment. Just as important, it would benefit YOU—people with PSP and their families—whose energy, donations and constant encouragement are the wind in the researchers' sails.

# CURING – Research

## Searching for Cures, Treatments and Therapies

### A Unique Partnership between Penn Medicine and CurePSP

CurePSP will consider funding research grant awards of greater size and duration than those available in our regular investigator-initiated grants program. This process is called the *Special Initiative Grants (SIG)* Program, which is an essential mechanism for funding major components and projects as established in the Foundation's \$15 million *Research Road Map*.

This year, CurePSP awarded a *Special Initiative Grant* through its *Research Road Map* to Penn Medicine's Center for Neurodegenerative Disease Research (CNDR) to advance their work in developing a tau immune therapy to combat these devastating illnesses. Tau is a key to the cure of neurodegenerative diseases. Because tau tangles are present in all major neurodegenerative disorders, developing a tau immune therapy for PSP would provide valuable clues to treating the millions who suffer from related diseases.

This new partnership between CurePSP and Penn Medicine aims to build upon existing funding and accelerate progress toward a cure for neurodegenerative diseases, including:

- Progressive supranuclear palsy (PSP)
- Corticobasal degeneration (CBD)
- Alzheimer's disease (AD)
- Parkinson's disease (PD)
- Frontotemporal dementia (FTD)
- Amyotrophic lateral sclerosis (ALS)
- Multiple system atrophy (MSA)

#### **Penn Medicine's Distinctive Research Program**

Two of the nation's top researchers in neurodegenerative disease, Virginia M.-Y. Lee, PhD, MBA and John Q. Trojanowski, MD, PhD, direct the CNDR. Drs. Lee and Trojanowski are credited with seminal discoveries in each of the major neurodegenerative diseases, including the pivotal finding that the "tangles" in Alzheimer's brains contain the protein tau. These tangles are also found in related brain diseases such as PSP, Parkinson's, FTD, and ALS (Lou Gehrig's disease). Since this breakthrough discovery, Drs. Lee and Trojanowski—a husband and wife team—have dedicated their lives to finding ways to treat these diseases by targeting tau pathology.

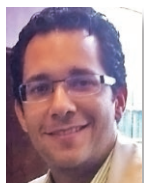


Thirty years of collaborative experience with industry, academic, and clinical partners give Drs. Lee and Trojanowski a practical edge in drug development. The CNDR can facilitate the complex process of bringing promising new treatments to the patients who need them.

Now is the right time to support a tau immune therapy for neurodegenerative diseases. Recent advances in immune therapy make it possible to stimulate the body's own immune cells to target and eliminate abnormal tau. Immune therapy could arrest the spread of abnormal tau within the brain, bringing related brain diseases like PSP, Alzheimer's, Parkinson's, FTD, and ALS to a halt.

## Research Grants Completed in 2014

### Mechanisms of Tau and ER Stress for Novel PSP and CBD Therapeutics



**José F. Abisambra, PhD**  
*University of South Florida*  
*Tampa, Florida*

**Type of Project:** Tau: Genetics, Biochemistry and Treatment Target

**Summary:** The whole-genome analysis funded by CurePSP and published in 2011 discovered that the gene coding for a protein called PERK was abnormal in PSP. PERK helps the cell dispose of misfolded proteins. This project inserted genes for PERK into cultured brain cells, finding that it suppressed the production of tau and alpha-synuclein (the protein that misfolds and aggregates in Parkinson's disease) but not other proteins. This means that PSP (and Parkinson's) may be the result of insufficient or defective PERK and may be prevented or treated by enhancement of PERK.

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### Effect of Coenzyme Q-10 in PSP: A Randomized, Multicenter, Placebo-Controlled, Double Blind Study



**Diana Apetauerova, MD**  
*Lahey Clinic*  
*Burlington, Massachusetts*

**Type of Project:** Clinical and Laboratory Treatment-Oriented Research

**Summary:** An important abnormality in brain cells in PSP is reduced ability to make energy from sugar and oxygen. An important step in that process relies on coenzyme Q-10. This treatment trial gave that nutrient to 32 patients with PSP and placebo to another 30. Only 36 of the 62 enrolled patients completed the 12 months of treatment. Those on the active drug progressed by 5.9 points (standard deviation 10) on the PSP Rating Scale (where 0 is normal and 100 is the worst possible), while those on placebo progressed an average of 11.8 points (sd 8.6). Although this did not quite reach statistical significance ( $p=0.07$ ), it may have done so with a larger group or fewer dropouts. Together with the results of an equally small but statistically positive 2008 German study, this work suggests that coenzyme Q-10 deserves closer consideration as symptomatic or protective treatment for PSP.

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### The Eloise H. Troxel Memorial Brain Bank



**Dennis Dickson, MD**  
*Mayo Clinic*  
*Jacksonville, Florida*

**Type of Project:** Brain Bank

**Summary:** Started in 1998, CurePSP's Brain Bank now has 1,316 brains, 60% with proven PSP, 11% CBD, 9% MSA, 7% Parkinson's or dementia with Lewy bodies, and 13% other. The average rate of donation has been increasing, and is now at approximately 100 per year. However, in the last six months reported (March to August 2014), there were 60 brains donated, for an annualized rate of 120. In the past year, the Brain Bank has shared samples with researchers at Mayo Clinic, University of Pennsylvania and University College London, as well as with drug companies Regulus, Inc. and Bristol-Myers Squibb. Each donating family receives a copy of the formal autopsy report along with a lay-language explanation.

# CURING – Research

Searching for Cures, Treatments and Therapies

## Models to Determine the Toxicity of Tau Aggregates



**T. Chris Gamblin, PhD**

*University of Kansas*

*Lawrence, Kansas*

**Type of Project:** Anatomic and Histopathological Surveys

**Summary:** The researchers created genetic variants of a roundworm (*Caenorhabditis elegans*) and of a fungus (*Aspergillus nidulans*) as tools for PSP research. Each organism is commonly used in biological research. The new versions would be particularly useful in determining how abnormal tau causes PSP/CBD. Each inserted gene variant was a tau abnormality that is known to occur in at least some humans with PSP/CBD. Cultures of these worm and fungi colonies will be useful going forward in understanding the basic cellular processes that cause PSP/CBD.

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## Epigenetic Modifications in PSP



**Ulrich Müller, MD, PhD**

*University Hospital of*

*Giessen and Marburg*

*Marburg, Germany*



**Günter Höglinger, MD**

*Technical University Munich*

*Munich, Germany*

**Type of Project:** Tau: Genetics, Biochemistry and Treatment Target

**Summary:** Methylation is a common way for genes to be regulated up or down. Methyl groups, which are simply a carbon atom with three hydrogen atoms, bind to specific points on a gene, determining the extent to which that area of the gene is encoded into proteins. Using 101 autopsy brain tissue samples from persons with PSP in CurePSP's Eloise H. Troxel Memorial Brain Bank and 92 control samples, this project found 9 sites in 3 genes to have more methylation than controls and 18 sites in 11 genes to have less. These newly incriminated genes may point to new drug targets and diagnostic tests.

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## Splice Variant Markers for PSP



**Judith Potashkin, PhD**

*Rosalind Franklin University of Medicine and Science*

*Chicago, Illinois*

**Type of Project:** Tau: Genetics, Biochemistry and Treatment Target

**Summary:** In the search for a blood test for PSP, a promising lead involves messenger RNA, a critical part of the process by which DNA directs the production of protein. Furthermore, measuring a group of mRNAs related to the same cellular function provides more diagnostic power than any one mRNA. This project combined the two approaches, the individual mRNA results in PSP having been published previously. This study found that the mRNA for "ptpn1" (protein tyrosine phosphatase, nonreceptor type 1) was most promising, being produced at a low level in their 26 patients with PSP. The next tasks are to confirm the finding in a larger group and to understand the role of ptpn1 in PSP.

## Urso Student Fellowship – A Clinical Staging System for PSP



**Emily Beisser**  
*Bucknell University  
Lewisburg, Pennsylvania*



**Lawrence I. Golbe, MD**  
*Rutgers Robert Wood Johnson Medical School  
New Brunswick, New Jersey*

**Type of Project:** Clinical and Laboratory Treatment-Oriented Research

**Summary:** The PSP Rating Scale, published in 2007, is widely used and reliable, but requires 10 minutes and some neurological skills. Clinical care and research would benefit from a simple staging system requiring a few seconds and minimal skills. This project devised several such candidate systems using results from the existing PSP Rating Scale in 337 patients. The one that correlated best with the overall PSPRS ( $R^2 = 0.62$ ) considered the issues most closely related to serious complications: difficulty swallowing solids, difficulty swallowing liquids, gait, and ability to sit from a standing position. Each is graded 0 (normal) to 4 and totaled. The resulting totals and stages are: Stage 0: 0, Stage 1: 1-4, Stage 2: 5-8, Stage 3: 9-12, Stage 4: 13-15 and Stage 5: 16. This proposed staging system must be validated in other patients at other centers.

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## New Research Grants Completed in 2014

### Selective Cell Vulnerability in Multiple System Atrophy

**Eduardo Benarroch, MD**

*Mayo Clinic  
Rochester, Minnesota*

**Type of Project:** Non-Tau Based Pathologies, Mitochondrial, Radicals, Cell Death

**Summary:** The MSA Coalition solicited and chose this project to be funded by CurePSP. Donated brain tissue with both the glial cytoplasmic inclusions of MSA and the Lewy bodies of Parkinson's disease (both of which are based on the protein alpha-synuclein) will be characterized regarding the exact locations of the two types of abnormality and the results correlated with the patients' signs and symptoms during life. The same will be done for brains with pure MSA pathology and with pure PD pathology. The goal is to understand what sets of degenerating brain cells might best serve as targets of treatment or prevention.

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### Spreading of a Synuclein Pathology in Multiple System Atrophy



**Kelly Del Tredici-Braak, MD, PhD**  
*University of Ulm  
Ulm, Germany*



**Heiko Braak, MD**  
*University of Ulm  
Ulm, Germany*

**Johannes Brettschneider, MD**  
*University of Ulm  
Ulm, Germany*

**Type of Project:** Non-Tau Based Pathologies, Mitochondrial, Radicals, Cell Death

**Summary:** The MSA Coalition solicited and chose this project to be funded by CurePSP. This project will use 60 donated brains with autopsy-proven MSA to determine where in the brain the characteristic abnormalities seem to be starting, where they spread first, and which types of brain cells seem the most vulnerable. This requires that the cases have had the disease at various stages at the time of death. The results may provide clues to which brain cells should be targeted in the development of preventive measures and may also clarify the cause(s) of the disease.

# CURING – Research

Searching for Cures, Treatments and Therapies

## **MOBP, STX6 and EIF2AK3 Expression and Distribution in PSP Brains**



**Rohan de Silva, DPhil**  
*University College London*  
*London, United Kingdom*

**Type of Project:** Non-Tau Based Genetic Studies

**Summary:** The three genes newly incriminated by CurePSP's 2011 marker-based whole-genome search (see the description of G. Schellenberg's project) are abbreviated EIF2AK3, STX6 and MOBP. Each can, in theory, be plausibly linked to what we know of the cellular events in PSP. However, we must now assess whether these genes are expressed abnormally in the brain regions most affected by the disease. This project will do that using brain tissue generously donated by the families of patients with PSP to the Queen Square Brain Bank in London.

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## **The Eloise H. Troxel Memorial Brain Bank**



**Dennis Dickson, MD**  
*Mayo Clinic*  
*Jacksonville, Florida*

**Type of Project:** Brain Bank

**Summary:** The Eloise H. Troxel Memorial Brain Bank is a critical part of CurePSP's research program. It facilitates the collection of PSP, CBD and MSA brain tissue from deceased patients and provides these samples to investigators for further research toward potential treatments and cures. Families that arrange brain tissue donation receive final confirmation of pathologic diagnosis via direct examination of the tissue, which can dispel the ambiguity that often surrounds a patient's diagnosis up to, and even after, death.

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## **Development and Validation of the Unified CBD Rating Scale**



**Lawrence I. Golbe, MD**  
*Rutgers Robert Wood Johnson*  
*Medical School*  
*New Brunswick, New Jersey*



**Irene Litvan, MD**  
*University of California, San Diego*  
*San Diego, California*

**Type of Project:** Clinical and Laboratory Treatment-Oriented Research

**Summary:** While there is a good clinical rating scale for PSP, there is none for CBD. Challenges in creating one include the wide variability in the signs and symptoms, as well as the uncertainty of the accuracy of the clinical diagnosis. This project is funded by a Swedish charity called CBD Solutions and administered by CurePSP. A group of specialized centers will collaborate to recruit enough patients with CBD to validate a scale for that disorder, which will be based on the neurological examination. A separate project funded by CBD Solutions will devise a CBD scale based on functional status, as determined by history provided by the patient and/or caregiver.

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## **Understanding the Relative Contributions of Genetic Risk Factors in PSP**



**Aimee Kao, MD, PhD**  
*University of California, San Francisco*  
*San Francisco, California*

**Type of Project:** Non-Tau Based Genetic Studies

**Summary:** Using the results of CurePSP's 2011 marker-based whole-genome analysis, this project will create stem cells with a tau mutation and others with a mutation in EIF2AK3. The stem cells are from a patient with PSP who also had another tau mutation known to be a risk factor for the disease. The project will assess the tendency of the cells to degenerate and will assess the effect on that degeneration of a drug called ISRIB that inhibits the protein encoded by EIF2AK3.

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### Impact of Arginase 1 Over-Expression and SAT1 Deficiency during Tauopathies



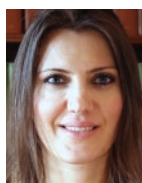
**Daniel C. Lee, PhD**  
*University of South Florida*  
*Tampa, Florida*

**Type of Project:** Molecular and Cellular Abnormalities

**Summary:** A biochemical pathway called the polyamine system appears to play a role in maintaining the health of brain cells and protecting against degeneration. The enzyme arginase-1 is part of that pathway. The enzyme SAT-1 reduces polyamines. This project will use mice that have been genetically engineered to be deficient in SAT-1 to assess the role of the polyamine pathway in preventing tau aggregation.

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### Synaptic Tau-Proteasome Dysfunction and a Potential Therapeutic Strategy



**Natura Myeku, PhD**  
*Columbia University*  
*New York, New York*

**Type of Project:** Tau: Genetics, Biochemistry and Treatment Target

**Summary:** An early event in the brain cell damage in tauopathies appears to be mis-localization of tau protein within the cell. This project hypothesizes that too much tau in the part of the cell near the synapses overwhelms the ability of the cell to dispose of excessive tau in those areas, leading to tau aggregation. A second part of the study is to attempt to reduce tau aggregation by administering a protein that increases the activity of the proteasome (one of the cell's garbage disposal systems) specifically in the area of the synapses.

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### Follow up Genotyping & Functional Analysis of PSP H1 Haplotype Variants



**Pau Pastor, MD, PhD**  
*University of Navarra*  
*Pamplona, Spain*

**Type of Project:** Tau: Genetics, Biochemistry and Treatment Target

**Summary:** Sequencing of the tau gene in 14 patients with PSP and 10 healthy individuals by Dr. Pastor's lab has revealed 37 variants that appear to associate with the disease. This new set of experiments will insert into zebrafish a tau gene with those variants and assess their effect on the development of the brain. This will provide insight into just what the PSP variants are doing to set up the degenerative process and may reveal new drug targets that might interrupt that process.

# CURING – Research

Searching for Cures, Treatments and Therapies

## Whole Exome Sequencing Project



**Gerard Schellenberg, PhD**

*University of Pennsylvania*

*Philadelphia, Pennsylvania*

**Type of Project:** Tau: Genetics, Biochemistry and Treatment Target

**Summary:** CurePSP funded a study published in 2011 that compared 1,114 patients with PSP to controls with regard to 500,000 genetic “markers” spanning the entire genome. The markers were merely common genetic variations of known location. If a certain variation occurred more often in PSP than in controls, we would conclude that a gene contributing to the cause of PSP was nearby. That study identified four previously unsuspected genes as probable contributors. Now, the technology has advanced and CurePSP has sponsored a project to work out the exact code sequence the entire “exome,” which is all of the areas of the genome that encode proteins. The final results are nearly here, pending analysis of more control individuals.

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## Elucidating PSP Genotype-Phenotype Relationships Using Human Isogenic iPSCs



**Lawrence S. B. Goldstein, PhD**

*University of California, San Diego*

*San Diego, California*

**John W. Steele, PhD**

*University of California, San Diego*

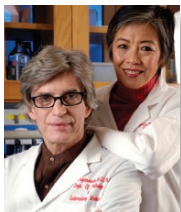
*San Diego, California*

**Type of Project:** Non-Tau Based Genetic Studies

**Summary:** The most important known genetic risk factor for PSP is a change in a single nucleotide (a genetic “letter”) in the tau gene, called rs242557. This project will investigate the details of how this change contributes to the cause of PSP by creating stem cells taken from a skin biopsy from a patient with PSP who has that gene variant. The stem cells will be turned into brain cells, which will then be tested for their response to various drugs that have been found in animal models to improve tau function.

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## Disease Modifying Tau Immune Therapy for PSP and CBD



**John Q. Trojanowski, MD, PhD**

**Virginia M.-Y. Lee, PhD**

*University of Pennsylvania*

*Philadelphia, Pennsylvania*

**Type of Project:** Tau: Genetics, Biochemistry and Treatment Target

**Summary:** Attempts several years ago to treat Alzheimer’s disease with a vaccine failed because the immune system “over-reacted,” attacking the brain in general. That trial gave an abnormal protein in the hopes that the immune system would manufacture antibodies. The new approach for PSP would give antibodies themselves. Although antibodies do not readily enter brain cells, there is now known to be a step in the spread of PSP through the brain where the tau protein is in transit between brain cells and therefore vulnerable to antibody attack. This project has a target of five years to the start of clinical trials.

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



**Christoph Wiessner, PhD**

*Asceneuron SA*

*Lausanne, Switzerland*

**Type of Project:** Tau: Genetics, Biochemistry and Treatment Target

**Summary:** In the past two years, it has been discovered that a sugar called “O-linked- $\beta$ -N-acetylglucosamine” can be attached to the tau protein, thereby reducing the ability of tau to move from one brain cell to another, spreading PSP through the brain. An enzyme called O-GlcNAcase performs the attachment and, like many enzymes, is subject to inhibition by drugs. This project will use cultured brain cells to study the role of “O-GlcNAcation” in the cell-to-cell transmission of abnormal tau, a process that is now considered critical to the spread of the disease through the brain.

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## Altering Tau Splicing for PSP and Other 4R Tauopathies



**Michael Wolfe, PhD**

*Brigham and Women's Hospital*

*Boston, Massachusetts*

**Type of Project:** Molecular and Cellular Abnormalities

**Summary:** In the neurofibrillary tangles of PSP, most of the tau occurs in its “4-repeat” form, which means that it has four sites that bind to microtubules in the performance of its normal function. Normal brain cells have equal amounts of 4-repeat and 3-repeat tau. To regain this balance, this project will insert mutations that have been found to cause a PSP-like disorder into cultured brain cells and then add mitoxantrone, an existing anti-cancer drug that was found to bind to RNA at a specific site that determines whether the resulting tau protein molecule will have four or three repeats. Then they will assess the cells for tau aggregation and overall health. If this succeeds, then mitoxantrone or its relatives may work as treatment for PSP.

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## Urso Student Fellowship – Effects of Chronic Deep Brain Stimulation of the Pedunculopontine Nucleus



**Titus John**

*University of North Carolina*

*Chapel Hill, North Carolina*

**Robert Pearlstein, PhD, MS**

*Duke University*

*Durham, North Carolina*

**Type of Project:** Clinical and Laboratory Treatment-Oriented Research

**Summary:** This is part of the groundwork for a trial of deep brain stimulation (DBS) for PSP. The brain area to be stimulated is the pedunculopontine nucleus (PPN), which is not an area used in Parkinson's disease DBS. An early step in the process is to assess the effect of PPN DBS on the electrical activity of brain areas that are connected to it. This experiment found that PPN DBS for a period of seven days reduced the sensitivity of the nearby pedunculopontine tegmental nucleus.

# CARING – Programs and Education

Making a Difference in the Lives of People with  
PSP, CBD and Other Atypical Parkinsonian Disorders



## From the Chair of the Programs and Education Committee

Ileen J. Watson

CurePSP is committed to providing essential support for people with PSP, CBD and MSA as well as educating healthcare professionals who provide treatment and therapy. The need for more effective patient and family support is significant and we just can't do enough to assist those who are suffering with any one of these atypical Parkinsonian diseases.

The Programs & Education (P&E) Committee strives to improve services to meet the many needs of those with the disease and their carepartners and, in doing so, we too become a partner in their journey. All of our committee members have their own unique experiences with PSP, CBD or MSA and I believe this has contributed to their knowledge and dedication to help others. There are no perfect answers when a person is dealing with these diseases. Although there may be common symptoms, the disease often presents differently in each person. The one thing we know for sure is that there is currently no cure, so we must look

to CurePSP's research program to find one. Meanwhile, it is our responsibility to make the journey more manageable and to help people feel less alone and isolated. The medical community can only do so much and that is where we step in, providing support groups, family conferences, ongoing educational programs, and hope!

Educating the medical community is paramount to meeting CurePSP's goals. Most people with the diseases and their carepartners become frustrated, waiting months, if not years, to receive an accurate diagnosis. This can be shocking but, in the long run, that knowledge can be powerful.



There is no limit to the support that the people with the diseases need all over the world. To this end, we are helping to establish a Canadian affiliate to provide much-needed programs and educational tools to Canadians who are suffering from PSP, CBD and MSA.

CurePSP has made a major effort to assist families who wish to participate in our brain tissue donation program. Through the generous contribution of a long-time donor, CurePSP helps offset the cost of brain donations. Brain donation is critical to research and the key to finding a cure.

Each year, CurePSP expands its programs, services and research and is the world's foremost patient advocacy organization for PSP, CBD and MSA. Our efforts have been rewarded and, although we have a long road ahead of us, we have made major leaps forward. We provide hope and that is an important part of ensuring the best possible quality of life. As CurePSP continues to fight these diseases in the laboratory, we will continue to meet the needs of people with the diseases and their carepartners. This past year has opened many new doors to improving our services and the challenge is to walk through those doors with an outstretched hand and a heart full of hope. We are grateful for this ongoing opportunity to serve you and your family.

## **Programs and Education Report**

### **Supporting Patients and Carepartners**

In 2014, CurePSP received more requests for information than ever before and those numbers continue to grow as more people affected by PSP, CBD and MSA discover the Foundation's support services. Digital distribution of information is increasing, as are requests from healthcare providers who are searching for educational materials. CurePSP is the primary resource for patients, carepartners, medical professionals and the general public, providing education, support and a way to connect with others.

The Foundation's annual conference was hosted in collaboration with the Colorado Neurological Institute this past year. The Rocky Mountain Family Conference included presentations on topics such as the nature of the diseases, current research studies, and the benefits of physical, occupational and speech-language therapy for those living with the disease. Today, CurePSP is working on its next conference, to be held in Gainesville, Florida on February 7, 2015. The attendance at CurePSP's conferences continues to increase each year. These events give people the opportunity to meet and join with others who are coping with these diseases.

Face-to-face support groups continue to expand in areas where groups have not existed in the past, as well as in areas that are underserved. Online support groups have branched off, with some groups becoming more general in nature, while others have focused more on a certain segment of those affected by the disease.

In November 2013, CurePSP was invited by the Patient-Centered Outcomes Research Institute (PCORI) to participate in their advisory panel on rare diseases, along with other patient advocacy organizations including the Michael J. Fox Foundation, Parkinson's Action Network, and the Association for Frontotemporal Degeneration. CurePSP continues to follow the development of patient and family-centric research. The Foundation also began laying the groundwork for a patient registry which has already helped build alliances with various pharmaceutical companies interested in developing compounds to treat patients with PSP, CBD and MSA.

CurePSP is excited to announce the genesis of its first international affiliate, CurePSP Canada. Much of the groundwork began in 2014, including the rallying of Canadian volunteers and the development of its Board of Directors. CurePSP Canada is hard at work compiling resources, designing a website, networking with volunteers and other organizations, and developing their first family conference, to be held in Ottawa in the spring of 2015.

### **Educating the Healthcare Community**

Through CurePSP's networking efforts at the American Physical Therapy Association's 2013 national conference, the Foundation developed a training program for physical therapists and speech-language pathologists, which was held at Emory University in 2014. Attendees were awarded continuing education credits for their participation in this training.

CurePSP collaborates with healthcare institutions and healthcare providers throughout the United States and Canada to develop in-person and web-based educational opportunities. In July 2013, the Foundation presented at the American Parkinson Disease Association's (APDA) annual conference on atypical Parkinsonian disorders, hosted by the Mayo Clinic in Minnesota. CurePSP also helped educate nurses about the diseases while attending the Edmond J. Safra Philanthropic Foundation's Visiting Nurse Faculty Program in Baltimore in May 2014.

The Foundation's educational materials for healthcare providers are unique in that they provide a background of each disease and a treatment plan for physical and occupational therapists, speech-language pathologists and social workers. In 2014, CurePSP conducted a study on these materials and submitted its findings to the International Parkinson and Movement Disorder Society. The submission was accepted as a teaching tool of excellence and CurePSP was invited to present its findings at the 18th International Congress of Parkinson's Disease and Movement Disorders in Stockholm, Sweden in June 2014.

# CARING – Programs and Education

## Making a Difference in the Lives of People with PSP, CBD and Other Atypical Parkinsonian Disorders

During 2014, CurePSP developed a video training series for neurologists, which will be completed in fiscal year 2015. Reaching this audience is essential in helping to further the goal of educating healthcare professionals, raising awareness of the diseases in the medical community, and promoting earlier and more accurate diagnoses. The video training includes footage of people with PSP, CBD and MSA and highlights and discusses their symptoms from a clinical perspective.

### **Advocacy on Behalf of People with PSP, CBD and Related Disorders**

CurePSP participated in numerous patient advocacy events and activities during the year on behalf of people with PSP, CBD and related brain diseases. The most prominent event this past year was when CurePSP's President-CEO, Dr. Richard Gordon Zyne, presented to the United States Senate at a Capitol Hill briefing sponsored by the National Organization for Rare Disorders (NORD) in March 2014. Dr. Zyne presented a paper entitled, Rare Brain Diseases in a Changing Healthcare Landscape, which provided members of the Senate and staffers with an overview of the challenges of coping with rare neurodegenerative disorders.



### **Drug Discovery and Development**

CurePSP is now actively involved in drug discovery and development and working in partnership and collaboration with academic institutions and various entities of the pharmaceutical industry. Through these new relationships and participation in orphan drug conferences during the year, CurePSP has learned that:

1. The development of appropriate patient registries and natural history studies is essential for clinical trials and drug development.
2. Working with biotech and pharmaceutical companies is the way to understand the drug development landscape and to cultivate mutually beneficial relationships.
3. Engaging early with the Food and Drug Administration (FDA) and understanding the regulatory process is essential for orphan drug development.
4. Developing new drugs and therapies is a long process involving risk-taking and the potential for pitfalls and failures.

Based on these keys factors, CurePSP is taking the following actions during 2015:

1. Hiring a full-time Director of Scientific Affairs.
2. Implementing a patient registry through an NIH-funded consortium.
3. Broadening its Scientific Advisory Board to include researchers and scientists with expertise in drug development and biotechnology.
4. Working with umbrella organizations to understand and navigate the drug regulatory process.

## **Patient Registry**

In 2014, the National Institutes of Health (NIH) awarded \$29 million to the Rare Diseases Clinical Research Network (RDCRN), which is dedicated to furthering translational research and investigating new treatments for patients with rare diseases. The RDCRN focuses on facilitating collaboration, study enrollment and data sharing among rare disease researchers and patient advocacy organizations. It is comprised of consortia with representatives from 98 patient advocacy groups, including CurePSP.

The NIH funding initiative will establish six new RDCRN consortia, one of which is Advancing Research and Treatment of Frontotemporal Lobar Degeneration (ARTFL), led by Adam Boxer, MD, PhD, a prominent neurodegenerative disease researcher and CurePSP grantee with the University of California, San Francisco. Dr. Boxer's consortium will explore the potential for new treatments for frontotemporal lobar degeneration (FTLD), corticobasal degeneration (CBD) and progressive supranuclear palsy (PSP). While ARTFL will be headquartered at the University of California, San Francisco, new clinical studies and trials for FTLD, CBD and PSP will be hosted at multiple sites across North America, leading to increased opportunity for participation by patients.

A patient registry is a required component of ARTFL and will allow patients and their families to register to be contacted for the in-person evaluations that form the basis of each research project. Eventually, the patient registry will be able to collect other data such as online cognitive tests, family history and other information that would be relevant in preparing for clinical trials of new therapies that target tau and other forms of neurodegeneration.

We recognize the importance of research through partnerships and collaborative efforts, and CurePSP is pleased to be an active partner in Dr. Boxer's consortium. The Foundation will recruit and encourage patients to participate in these new studies.

## **Public Awareness**

In 2014, CurePSP was honored to receive a four star rating by Charity Navigator, one of the leading organizations in charity evaluation. The four star rating is reserved for charities that have displayed the highest level of excellence in both service and fiduciary responsibilities. CurePSP also became recognized as an Accredited Charity by the Better Business Bureau, meeting all 20 standards of charitable accountability.

Another major highlight this year was the creation of credit-card size medical alert cards, which list the symptoms of PSP, CBD and MSA as they might appear to someone unfamiliar with the diseases. Patients can present the medical alert card when appropriate to help others understand the disease and provide better care for the patient.

As the world shifts toward greater use of mobile devices, CurePSP has continued to develop its social media presence. In addition to meaningfully engaging its followers every week, CurePSP launched an "I Hate PSP" t-shirt campaign, which helped raise awareness by distributing the shirts to donors and having them post a photo proudly displaying their shirt on social media. The Foundation also partnered with the EveryLife Foundation to execute a text-to-donate campaign during the month of November, in which the EveryLife Foundation matched all money raised by participants.

Transforming CurePSP's website into an important source of information for those affected by PSP, CBD and MSA is a top priority of the Foundation. This year, CurePSP added a translating tool to its site that allows visitors from all over the world to gain better access to information about the diseases. The Foundation also added an important search tool that enables visitors to find movement disorder specialists in their particular locale. CurePSP also increased its visibility on the web by disseminating press releases publicizing new research grants and important fundraising events. In an effort to increase the reach of educational information, CurePSP recorded its family conference in Denver, Colorado and made those recordings available to the public via both the Foundation's YouTube channel and DVD.

# COMMITMENT – Finance and Development

Building and Strengthening an Enduring Foundation

## STATEMENTS OF FINANCIAL POSITION

JUNE 30, 2014 AND 2013

### ASSETS

	2014	2013
CURRENT ASSETS:		
Cash and Cash Equivalents	\$ 1,875,613	\$ 861,143
Cash and Cash Equivalents – Temporarily Restricted	563,217	943,747
Pledges Receivable - Unrestricted	1,500	1,000
Pledges Receivable - Temporarily Restricted	308,985	13,850
Other Receivables	83,432	6,409
Prepaid Expenses	38,557	26,636
Total Current Assets	2,871,304	1,852,785
PROPERTY AND EQUIPMENT - AT COST:		
Office Equipment	101,672	99,406
Furniture and Fixtures	47,406	42,700
Software – Database	54,033	54,033
Website	31,253	31,253
	234,364	227,392
Less Accumulated Depreciation	210,911	205,223
Net Value of Property and Equipment	23,453	22,169
LONG TERM ASSETS:		
Marketable Securities – Permanent Endowment	383,411	351,244
Deposits	3,983	3,983
Total Other Assets	387,394	355,227
TOTAL ASSETS	\$ 3,282,151	\$ 2,230,181

### LIABILITIES AND NET ASSETS

CURRENT LIABILITIES:		
Accounts Payable and Accrued Expenses	\$ 91,862	\$ 76,403
Grants Payable – Due Within One Year	809,731	368,570
Total Current Liabilities	901,593	444,973
LONG TERM LIABILITIES:		
Grants Payable – Due After One Year	466,663	43,750
Total Liabilities	1,368,256	488,723
NET ASSETS:		
Unrestricted		
Undesignated	1,115,555	786,077
Board Designated – Research	100,000	—
Board Designated – Programs and Education	5,346	8,935
Total Unrestricted	1,220,901	795,012
Temporarily Restricted	309,583	595,277
Permanently Restricted	383,411	351,169
Total Restricted	692,994	946,446
Total Net Assets	1,913,895	1,741,458
TOTAL LIABILITIES AND NET ASSETS	\$ 3,282,151	\$ 2,230,181

## STATEMENT OF ACTIVITIES AND CHANGE IN NET ASSETS

### FOR THE YEAR ENDED JUNE 30, 2014 AND 2013

<b>2014</b>				
	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

<b>2013</b>				
	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
REVENUES AND OTHER SUPPORT:				
Contributions	\$ 936,720	\$ 518,125	\$ —	\$ 1,454,845
Special Events (Net of \$21,183 in Expenses)	206,888	41,766	—	248,654
Interest and Dividend Income	2,932	5,486	—	8,418
Realized and Unrealized Gains on Investments	—	—	29,537	29,537
Grant Adjustment	—	125,000	—	125,000
Net Assets Released from Restrictions	933,687	(929,950)	(3,737)	—
Total Revenues and Other Support	2,080,227	(239,573)	25,800	1,866,454
EXPENSES:				
Program Services:				
Research	1,235,276	—	—	1,235,276
Programs and Education	383,804	—	—	383,804
Communications and Public Awareness	148,510	—	—	148,510
Support Services:				
Management and General	104,345	—	—	104,345
Board	38,724	—	—	38,724
Fundraising	236,685	—	—	236,685
Total Program and Support Services	2,147,344	—	—	2,147,344
CHANGE IN NET ASSETS	(67,117)	(239,573)	25,800	(280,890)
NET ASSETS AT BEGINNING OF YEAR	862,129	834,850	325,369	2,022,348
NET ASSETS AT END OF YEAR	\$ 795,012	\$ 595,277	\$ 351,169	\$ 1,741,458

# COMMITMENT – Finance and Development

Building and Strengthening an Enduring Foundation

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Kelly Saunders

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## Honor Roll of Donors

For the Period July 1, 2013 through June 30, 2014

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, 2013 through June 30, 2014. Due to space limitations, we only include donors who have given gifts of at least \$1,000 in this report. A full donor Honor Roll may be seen on our website, [www.curepsp.org](http://www.curepsp.org).

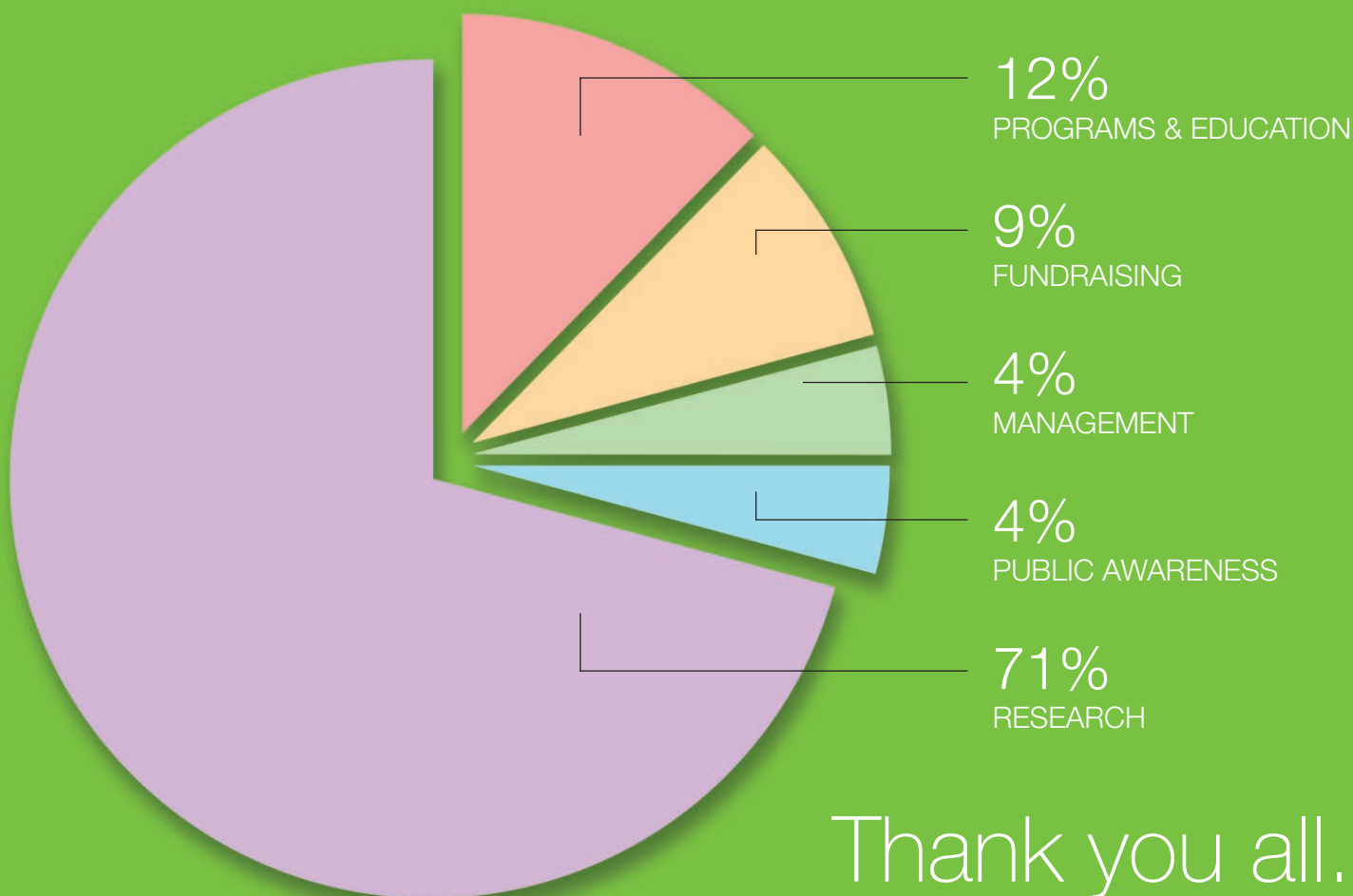
CurePSP's Development Department raises funds to support all programs and services including research, patient support, medical education, patient advocacy, caregiver services, public awareness, and governmental relations. These essential functions are made possible and accomplished through a wide range 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.

While every effort has been made to ensure the accuracy of our donor lists, errors and omissions in this report may have occurred. Our supporters are assured of our appreciation for their generosity, and we apologize for any inaccuracies in this report. We would kindly appreciate having them brought to our attention and we will make every effort to present corrections in subsequent publications.

During FY 2014, (July 1, 2013 through June 30, 2014) CurePSP received 8,500 donations in excess of \$3.3 million from more than 7,100 generous donors.

### HOW YOUR GIFTS WERE USED – FY 2014

87% FOR PROGRAM SERVICES | 13% FOR SUPPORT SERVICES



# COMMITMENT – Finance and Development

## Building and Strengthening an Enduring Foundation

### The Legacy Society

CurePSP offers donors many giving opportunities to support the programs of the Foundation, including research, patient support, education, and general operations. All contributions are gratefully appreciated and acknowledged for their generosity.

The Legacy Society is a exceptional group of benefactors who have responded to the call of long-term commitment and leadership by contributing cumulative donations exceeding \$10,000. Contributions by Legacy Society benefactors have been made through direct and current gifts of cash or property but may also be made through planned gifts such as bequests, life insurances, or trusts. Legacy Society benefactors have a strong commitment to CurePSP and are recognized by this special presentation in the Annual Report and Honor Roll of Donors.

Since the Foundation's inception, Legacy Society benefactors have contributed more than \$18,000,000 to CurePSP.

### Transformational Benefactors

Transformational Benefactors are those institutions, entities or individuals who have made a major and consistent impact on the Foundation through their contributions and their services over the years.

Mr. Jay C. Troxel - 2006

Mr. Charles D. Peebler, Jr. and the Peebler PSP Research Foundation - 2008

Mr. Abe Pollin & Mrs. Irene Pollin – 2009

### Legacy Society Benefactors

Cumulative gifts and commitments through June 2014.

#### DIAMOND BENEFACTORS

CUMULATIVE GIFTS OF \$1,000,000 AND ABOVE

Peebler PSP Research Foundation, Inc.

Mr. Abe Pollin & Mrs. Irene Pollin

Irene & Abe Pollin CBD Research Fund

Julie E. Repasy Trust

Mr. Jay C. Troxel

#### PLATINUM BENEFACTORS

CUMULATIVE GIFTS OF \$500,000 TO \$999,999

Morton and Marcine Friedman Foundation

Mr. & Mrs. Steve Poizner

Edwin & Pearl Poizner Memorial Fund

Eloise H. Troxel Memorial Fund

#### GOLD BENEFACTORS

CUMULATIVE GIFTS OF \$100,000 TO \$499,999

Hazel Reed Baumeister Trust

CBD Solutions

Karen and Everett Cook Foundation

Mr. Brendan M. Dixon

Ms. Joyce Estes

Mr. Justin Franco, III

Eva Freeman Memorial Fund

Mr. Paul H. Freeman

Mr. Donald E. Graham

Mr. Jack Hedrick

Ms. Eva Howarth

Elayne & Benno Hurwitz Philanthropic Fund

Theresa and Peter Lund Research Fund

Mr. Peter A. Lund

Mr. Brett Milgrim

Dudley Moore Research Fund

Lyndon Selter Parker Trust

Fred and Mabel R. Parks Foundation  
Perot Foundation  
Rainwater Charitable Foundation  
Laurence B. Richardson Memorial Fund  
Ms. Patricia C. Richardson  
Estate of Hannah Rubin  
Jack and Betty Schuss Memorial Fund  
Estate of Ruth Tarlow Urso  
Frank W. Weymouth Living Trust

### **SILVER BENEFACTORS**

CUMULATIVE GIFTS OF \$50,000 TO \$99,999

Anonymous  
Mr. Klaus Althammer  
Mr. & Mrs. Douglas Bloom  
CAP Foundation  
Mr. & Mrs. E. Paul Casey  
Mrs. Barbara Fox  
Burt Harkins Family Foundation  
Mr. William H. Herrman  
Ken Jennings Legacy Fund  
Mrs. Mary V. Kirkey  
Robert T. Kirkey Memorial Fund  
Mr. Frederick Koallick  
Light of Day Foundation, Inc.  
Eugene McDermott Foundation  
Mr. James E. McGookey  
Esther A. Palumbo Family Fund  
Mrs. Edith B. Parker  
Ms. Ruth K. Peters  
Estate of Blanche Ruppert  
Mr. & Mrs. William A. Schreyer  
Mr. Jack Schuss  
Mrs. Julia S. Shackelford  
Irvin & Ruth Swartzberg Family Foundation  
Mrs. Lesley J. Undercofler  
Claude D. Vannoy Estate  
Mr. David Wallace  
Wallis Foundation

### **BRONZE BENEFACTORS**

CUMULATIVE GIFTS OF \$10,000 TO \$49,999

100 Women in Hedge Funds Foundation  
Anonymous  
Mrs. Sarita Agrawal  
Akers Foundation, Inc.  
Shana Alexander Charitable Foundation  
Mr. & Mrs. Dennis Alter  
The Altus One Fund, Inc.  
American Endowment Foundation  
L&N Andreas Foundation  
Edward H. Andrews Foundation  
Annenberg Foundation  
Mr. & Mrs. Donald Baker  
Ball Corporation  
Bank of America Foundation, Inc.  
Dr. & Mrs. Bruce A. Barnett  
Mr. James C. Barron  
Mr. Charles F. Barry  
Ms. Gloria A. Bartas  
The Gary Dean Beck Family Foundation



# COMMITMENT – Finance and Development

## Building and Strengthening an Enduring Foundation

Mr. Paul W. Bednarczyk  
Colette M. Bednarczyk Memorial Fund  
Mr. David A. Bell  
Mr. William Benjamin  
Ms. Deborah Berger  
Mrs. Miriam Bernstein  
Dr. Allen H. Bezner  
Ms. Amy Branch  
Bridgemill Foundation  
Alex Brown & Sons Incorporated  
Mr. William Budge  
Mr. Charles Burlingham, Jr.  
Mrs. Mary K. Callaway  
Mrs. D. Wayne Calloway  
Mr. & Mrs. John Campbell  
Mr. and Mrs. Richard M. Cashin  
Ms. Cheri R. Cernak  
Estate of Billie M. Clark  
Mrs. Beverly Ann Clark  
Mrs. Janice Clements  
Club Assist c/o Alan W. Bradshaw  
CMGRP, Inc.  
Collinwood Middle School  
Mr. & Mrs. Curt Conover  
Conover Foundation, Inc.  
Crestar Foundation  
Mr. Charles Cummins  
Mrs. Elizabeth A. Daft  
Mr. Dee C. Daniels  
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Mr. Robert E. Derse  
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Ms. Barbara Fedor  
Mr. & Mrs. Ronald J. Ferris

Floyd Charitable Lead Unitrust  
Ms. C. Rae Franey  
Mr. Alan C. Freeman  
Mr. & Mrs. Andrew M. Freeman  
Mr. & Mrs. Joe Friedman  
Drs. Jeffrey S. & Jennifer Friedman  
Stevens Frink Family Fund  
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William M. Fuller Foundation  
Mr. W. R. Fulljames  
Col. Grady D. Gafford, Ret.  
Mr. & Mrs. Robert Gallois  
Geller & Co. LLC  
Give With Liberty/Liberty Mutual Foundation Match  
Mrs. Faye Glazer  
Mr. Peter T. Grauer  
Mr. Stewart Greenebaum  
Ms. Victoria L. Greenleaf  
Dr. George L. Grice  
Estate of Oliver Grotelueschen  
Mr. & Mrs. Martin D. Gruss  
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Herbert Hamburger Estate  
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Mr. and Mrs. Timothy Hanley  
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Hearst Corporation  
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Hoag Family Foundation  
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Horsley Bridge Partners  
Mr. Sydney Huffnagle  
Devon D. Huffnagle Memorial Fund  
Ms. Carol M. Hutchinson  
The Interpublic Group of Companies  
Jackson Charitable Foundation  
The Nathan P. Jacobs Foundation  
Mr. Richard Janney & Ms. Joanne E. Armstrong  
Mr. Levi Johnson

Vandana Juneja Memorial Fund  
 David & Alexandra Kamin  
 Vernice Kaphingst Charitable Remainder Trust  
 Mr. & Mrs. John B. Kelley, Jr.  
 Mr. Donald W. Kelton  
 Mr. & Mrs. Thomas Kempner  
 Mr. & Mrs. Peter Kimmelman  
 Mr. & Mrs. James E. Koehnlein  
 Mr. & Mrs. Christopher Korves  
 Lapin Foundation  
 Mrs. Deloris A. LaRue  
 Mr. & Mrs. Bruce R. Lauritzen  
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 Dr. Benjamin B. LeCompte, III  
 Mr. Laurence C. Leeds Jr.  
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 Mr. Bruce Liimatainen  
 Mr. Sidney Lindenbaum  
 David Livernois Memorial Fund  
 Leon Lowenstein Foundation, Inc.  
 Mr. & Mrs. H. F. Maassab  
 Mr. Philip Mactaggart  
 Carl J. Major Legacy Fund  
 Ms. Anne Marion  
 Martin Family Trust  
 Martine Avenue Productions, Inc.  
 Mr. Colin McCafferty  
 MCJ Foundation  
 Dr. & Mrs. Kenneth A. McKusick  
 Mr. & Mrs. Sean McLaughlin  
 Mr. Dave McNaughton  
 Mr. & Mrs. Paul McNulty  
 Mrs. Martha Medcalf  
 Meredith Corporation  
 Merrill Lynch & Co., Inc.  
 Mrs. Cynthia Miles  
 The Minneapolis Foundation  
 Modern Woodmen of America  
 William A. & Elizabeth B. Moncrief Foundation  
 Mr. Philip H. Moore



Mr. & Mrs. John A. Moran  
 Jackie Myers Family Fund  
 Mr. Matthew Nastuk  
 Mr. & Mrs. Denny Neagle  
 Nancy Newell Fund  
 Nexen Petroleum U.S.A., Inc.  
 Mr. Richard Nye & Ms. Francesca Stantill  
 Mrs. Ellen J. Olean  
 Mr. John D. Olson  
 Mr. Joseph C. Oppenlander  
 Norma Oppenlander Memorial Fund  
 Mr. Stanley C. Pace  
 Mr. & Mrs. Daniel Paduano  
 Pannonia Foundation  
 Mrs. Susan D. Parker  
 Margaret Parker Memorial Fund  
 Mr. E. Spencer Parris  
 Patton Family Foundation  
 Mrs. Phyllis R. Perreault  
 Mr. & Mrs. Duane Phillips  
 Phoenix World Wide Enterprises  
 Ms. Mari-Anne Pisarri  
 Mr. & Mrs. Frank Pizzitola  
 Ms. Sharon Pratt

# COMMITMENT – Finance and Development

## Building and Strengthening an Enduring Foundation

Ms. Carol Prugh  
Qualcomm, Inc.  
Quanex Foundation  
Mr. & Mrs. William E. Quinn, Sr.  
Ms. Karen W. Rainwater  
Mr. John B. Ricker, III  
Mr. John B. Ricker, Jr.  
Mr. & Mrs. Brent T. Rider  
Estate of A. John Ridge  
Mrs. Sandra L. Riley  
Mrs. Clarice Rosen  
Mr. Haim Saban  
Roberta Schenker Memorial Fund  
Mr. & Mrs. Paul C. Schorr, III  
Mr. Roy R. Schwartz  
Mr. Ernest Segundo, Sr.  
Mr. Norman A. Sensinger, Jr.  
Alice Shaver Foundation  
Mr. & Mrs. Paul S. Simon  
Mrs. Ruth Eleanor Singer  
Edward W. Smith Jr. Foundation  
Ms. Gail Smith  
Mr. & Mrs. Richard W. Smith  
Mr. & Mrs. Thomas Smith  
Sony Computer Entertainment America, Inc.  
Sports Tutor  
Mr. & Mrs. John Sprague  
Mr. & Mrs. Michael Steinhardt  
Ms. Eleanor R. Stewart  
Mr. & Mrs. Henry Stiepel  
Mr. & Mrs. Lane P. Stokes  
Ms. Emily H. Susskind  
Mr. Richard J. Sussman  
Szulik Family Foundation  
Mr. Gerald Teel  
Mr. & Mrs. J. Liener Temerlin  
Janis Temple Bequest  
Mr. & Mrs. Nathan Thorne  
Mr. Oakleigh Thorne  
Mr. & Mrs. Donald Tober

Mr. Daniel P. Tully  
United Way of Southeastern Pennsylvania  
United Way of Tri-State  
Mrs. Kathleen Veeh  
Mr. John R. Voigt  
Mr. William B. Vollbracht  
Mr. & Mrs. Eugene M. Waldron, Jr.  
Mr. William S. Walsh, Jr.  
Edgar B. & Jane Wyatt Ward Fund  
Estate of Joan Warkick  
Mr. David Weinberg and Ms. Michele Smith  
Sidney J. Weinberg Foundation  
Perelson Weiner LLP  
Mrs. Beverly G. Weiser  
Mr. Eric S. Wesolek  
Mrs. Dorothy Whitaker  
Mr. & Mrs. John C. Whitehead  
Mrs. Marguerita A. Whitney  
Ms. Mary Wilhelm  
Willkie, Farr & Gallagher LLP  
Mr. John H. Wilson  
Mrs. Lenore Winsberg  
Mrs. Marie K. Zimmerman  
Zyne Family Trust



## Light Of Day Foundation Brings New Light to CurePSP Through Matching Gift Campaign

Thanks to the Light Of Day Foundation, CurePSP's matching gift campaign raised more than \$80,000 – a huge success! The Light Of Day Foundation matched dollar for dollar in support of all programs and services. Their kindness and generosity is helping thousands of CurePSP families while supporting worldwide research efforts to find the cause, treatment and cure for PSP, CBD and related brain diseases. CurePSP is most grateful for their continued support.



The Light Of Day Foundation is a New Jersey-based 501(c)(3) charity which utilizes the power of music to raise money and awareness in its battle to defeat Parkinson's and related neurodegenerative diseases such as ALS and PSP. The primary fundraising efforts are an annual series of concerts held in Asbury Park, New Jersey. Founded by New Jersey music industry veteran Bob Benjamin, who was diagnosed with Parkinson's at age 38, and with the help of his friend's concert promoter Tony Pallagrosi, musicians Joe D'Urso and Joe Grushecky, journalist Jean Mickle and others, Light Of Day has raised nearly \$3 million worldwide since its inception in 2000. What began as a single concert at The Stone Pony, New Jersey's legendary rock club, has grown into seventy shows in thirteen countries across North America, Europe and Australia.



# COMMITMENT – Finance and Development

## Building and Strengthening an Enduring Foundation



### From the Chair of the Major Gifts Committee

Amy Branch

What momentous times. 50 years ago, Dr. John C. Steele, who with Drs. J. Clifford Richardson and Jerzy Olszewski, uncovered the mysteries of progressive supranuclear palsy (PSP). In honor of these pioneers, we gathered in Baltimore, on the campus of our partner, Johns Hopkins University, for CurePSP's Milestones and Horizons event. CurePSP recognizes and appreciates the collaboration of Dr. Oliver Sacks and Jonathan Weiner in delivering a fitting tribute to the work of Dr. Steele. Also, 2015 marks the 25th year of service for CurePSP, recognized worldwide for its work on clinical and therapeutic treatments for those with neurodegenerative diseases.

We received, this past year, \$3.3 million in generous gifts from over 7,100 donors, along with \$1.3 million in bequests and planned gifts. On behalf of CurePSP, please allow me to express my sincere appreciation for the many supporting the important work of our foundation. I am humbled at the passion and commitment of a community who wants to find a cure and deliver care and treatment as much as we do. You are making a difference.

And, yes, we understand the responsibility that comes with being good stewards of these dollars.

What will your donation do? CurePSP's \$15 million *Research Road Map* delivers a targeted approach to research involving tested experimental tools, models, and markers. Our goal is to identify the top 30-50 drug targets, screen and test them before engaging in clinical trials with our partners in industry and academia. We are also working to translate genetic findings into real treatments.

The new *Special Initiative Grant* under the *Research Road Map* funds the research of Nobel Laureate, Dr. Stanley Prusiner of the University of California, San Francisco. His work in transgenic mouse models has laid important groundwork: a biomarker that identifies proteins 10 to 15 years prior to the onset of dementia symptoms and an antibody that has prevented the spread of toxic tau protein. With tau's identified significance, CurePSP currently underwrites promising research into a tau immune therapy in our second *Special Initiative Grant*, in partnership with Penn Medicine's Center for Neurodegenerative Disease Research (CNDP) and Drs. Virginia Lee and John Trojanowski. Their lab developed cell-based models of tau aggregation and propagation, platforms that identify targets and therapeutics that can reduce tau pathology. The tau protein plays a critical role not only in PSP, but in many other neurodegenerative diseases, including Alzheimer's disease, ALS (Lou Gehrig's disease), and possibly, Parkinson's disease.

Our new Strategic Vision – *Curing, Caring, Commitment* – has centered focus on funding research toward treatment, cure, and prevention with an allocation of 71% of our budget. The remainder of funds allocated are directed toward increasing awareness of PSP, CBD, and other atypical Parkinsonian disorders; educating healthcare professionals; all the while providing support, information, and hope for those people and their families affected by the disease; and finally, strengthening the foundation of CurePSP.

Emphasis on research in rare neurodegenerative diseases that strike in the prime of life, quickly debilitating and leading to early death, is at our core. The research we fund may unlock treatments and cures for these and many other, more common, neurodegenerative conditions, such as Alzheimer's disease, ALS, FTDs, and possibly, Parkinson's.

The reason? Progressive supranuclear palsy (PSP) is a “fulcrum” disease for research, offering a number of key advantages to scientists in their investigations of these prime of life diseases, as it is a pure tauopathy. CurePSP is the leading organization supporting research into PSP.

Your financial support provides maximum leverage for money invested, not only against a cure for this terrible ailment, but in the efforts to unlock treatment and cure for more common neurodegenerative diseases. And, yes, CurePSP is just beginning to embrace venture philanthropy. To achieve the kind of recent success we’ve seen from other forward-thinking philanthropic organizations, we’ll need to continue to take major steps forward.

These include:

**Scaling investments in drug discovery.** The *Research Road Map* targets \$3 million to research in this area.

**Continuing to develop a strong scientific staff.** CurePSP is actively recruiting an in-house head of Scientific Affairs to strengthen our core of scientific expertise working alongside the Scientific Advisory Board.

**Building partnerships with like-minded organizations.** We are pleased to partner with leaders in the public and private sectors including the Association for Frontotemporal Degeneration (AFTD), Alzheimer’s Drug Discovery Foundation (ADDF), The Bluefield Project, and the University of California, San Francisco to build a patient registry to ensure the fast tracking of clinical trials. Our collaboration extends to Johns Hopkins University, the Mayo Clinic Jacksonville and its CurePSP Brain Bank, and the University of Pennsylvania, Perelman School of Medicine. In the private sector, we are collaborating with pharmaceutical companies like Bristol-Myers Squibb. As with business, we will look at synergies that lead to success. The answer is in all of us.

**Finding a cure.** With the current state of research, we believe an effective treatment, and possibly even a cure, for PSP, CBD, and related prime of life brain diseases is within our reach. We are confident venture philanthropy will help us get there.

There are many organizations involved in neurodegenerative disease research. Are you wondering why you should support CurePSP?

- ▶ CurePSP has been solely focused on progressive supranuclear palsy (PSP) and corticobasal degeneration (CBD) for 25 years and has greater expertise in these diseases than any other organization.
- ▶ CurePSP has funded over 160 research grants since 1997. Moreover, we’ve played a critical role in moving numerous drug candidates through the drug discovery pipeline.
- ▶ CurePSP has relationships with leading scientists and clinicians from around the world involved in neurodegenerative disease investigation and treatment, some of whom serve on our scientific advisory board.

START HERE: Donate to a cure, a treatment, to supporting patients, families, and caregivers.

As Chair of the Major Gifts Committee, I would like to ask for your support. Donations from individuals, families, and foundations enable CurePSP to be a catalyst for medical research and improved patient care. We won’t stop until we find a cure and solutions that improve patients’ lives to slow, stop, or reverse the progression of these diseases.

Many of us involved carry a sense of duty to work with determination and to unite efforts to create a world free from brain diseases. We are grateful for your support, fellow crusaders, in the fight to find a cure for PSP, CBD, and related brain diseases.

# COMMITMENT – Finance and Development

## Building and Strengthening an Enduring Foundation

### Research Road Map Campaign Gifts and Pledges

CurePSP initiated the Research Road Map at the end of FY2013 as a framework for a comprehensive array of projects that may eventually lead to treatments, therapies and even a cure for PSP, CBD and related neurodegenerative brain disorders. The Foundation recognizes that the fight against PSP can now take a new direction, capitalizing on recent discoveries, exciting ongoing work and new hypotheses. We propose to fund research initiatives in five major areas of focus: genes, prions, proteins, models, and markers.

Thank you to all the donors who supported this important campaign between May 2013 and October 2014.

#### VISIONARIES FOR A CURE

GIFTS OF \$250,000 AND ABOVE

CBD Solutions

Jack and Betty Schuss Memorial Fund

#### SEEKERS OF HOPE

GIFTS OF \$50,000 TO \$249,999

Perot Foundation

Eugene McDermott Foundation

Fred and Mabel R. Parks Foundation

#### RESEARCH PARTNERS

GIFTS OF \$5,000 TO \$49,999

100 Women in Hedge Funds Foundation

Anonymous

Mr. William Benjamin

Boston Family Office

Ms. Amy Branch

Ms. Cheri R. Cernak

Mr. Everett Cook

Mr. Robert E. Derse

Mr. Brendan M. Dixon

Mr. Paul H. Freeman

Drs. Jeffrey S. & Jennifer Friedman

Mr. Jack Hedrick

Mr. William H. Herrman

Johnson & Johnson Family of Companies

Mr. Frederick Koallick

Mr. Philip Mactaggart

Dr. Thornton B. Mason and Dr. Ingrid Warmuth

Mr. Bill McFarland

Mrs. Martha Medcalf

Mr. Joseph C. Oppenlander

Pannonia Foundation

Mr. E. Spencer Parris

Ms. Patricia C. Richardson

Sayers Foundation, Inc.

Mr. & Mrs. John Sprague

Mr. Richard J. Sussman

Mr. & Mrs. Nathan Thorne

Mrs. Lesley J. Undercofler

Zyne Family Trust

#### ADVOCATES

GIFTS OF \$1,000 TO \$4,999

Mr. & Mrs. Mark Agee

Ms. Nidhi Agrawal

AIG Matching Grants Program

Atlas Family Foundation

B&L Distributing Co., Inc. of SC/NC

Ball Corporation

Dr. & Mrs. Bruce A. Barnett

Dr. Burton Benjamin

Ms. Helen Watson Blodgett

Mr. & Mrs. Douglas Bloom

Dr. Yvette Bordelon and Dr. Carlos Portera-Cailliau

Mr. John T. Burhoe

Ms. Cynthia Cernak

Mr. & Mrs. Rob Cernak

Mr. Dee C. Daniels  
 Mr. Delmont A. Davis  
 Mrs. Gerry Dippe  
 Mrs. Janet M. Edmunson  
 Mr. Massimo Ferragamo  
 Mr. & Mrs. Thomas Flexner  
 Ms. Lorraine Ford  
 Mr. Luigi Franceschina  
 Mr. & Mrs. Robert Gallois  
 Dr. Anne Gant  
 Dr. Stephen Goldman  
 Mr. Dalf Hammerich  
 Ms. Jenna Hang  
 Hill Management Services, Inc.  
 Hospira Employee Giving Campaign  
 Elayne and Benno Hurwitz Philanthropic Fund  
 Illinois Tool Works Foundation  
 Ionian Management  
 David & Alexandra Kamin  
 Elbrun and Peter Kimmelman Family Foundation, Inc.  
 Mr. & Mrs. Christopher Korves  
 Mr. & Mrs. Peter S. Kraus  
 Ms. Annette Landesman  
 Mrs. Karen Larsen  
 Dr. Benjamin B. LeCompte, III  
 Mrs. Lexi Leopold  
 Mrs. Jane Lukas  
 Microsoft Giving Campaign  
 Mitsui Sumitomo Marine Management USA, Inc.  
 Mr. & Mrs. Monty Montgomery  
 Mr. Matthew Nastuk  
 Ms. Lynn Nesbitt  
 Ms. Barbara Novick  
 Mr. & Mrs. Stuart I. Oran  
 Mr. Prabhudas Patel  
 Mrs. Phyllis R. Perreault  
 Mr. & Mrs. William E. Quinn, Sr.  
 Mrs. Sandra L. Riley  
 Mr. Norman Robnett

Mr. David Saltzman  
 Mr. Mitsunobu Samoto  
 Mr. Norman A. Sensinger, Jr.  
 Mr. Ravi Shankar  
 Edward W. Smith Jr. Foundation  
 Dr. Babs Soller  
 Mr. & Mrs. Chester Speed  
 Dr. John C. Steele  
 Ms. Eleanor R. Stewart  
 Dr. Stephanie Sweetana  
 Mr. & Mrs. Donald Tober  
 Mr. Frank Torres  
 Dr. John Q. Trojanowski & Dr. Virginia Lee  
 Mr. & Mrs. Eric Volcheff  
 Ms. Ileen Watson  
 Mr. David Weinberg & Ms. Michele Smith  
 Mr. Spence Wilson

## GENERAL SUPPORTERS

GIFTS OF \$1 TO \$999

724 Gifts

**TOTAL: \$1,176,423**

828 TOTAL GIFTS



# COMMITMENT – Finance and Development

## Building and Strengthening an Enduring Foundation

### 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. Individuals, groups or businesses may establish a named fund which publicizes their commitment to the mission of CurePSP. An annual donation of at least \$1,000 is required to keep a named fund active and recognized.

**Generous contributions through June 30, 2014 have been made to the named funds below.**

#### **\$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 and Pearl Poizner Memorial Fund  
Jack and Betty Schuss Memorial Fund  
Eloise H. Troxel Memorial Fund

#### **\$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  
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  
Joel H. Gilbert Memorial Fund  
The Gloria Fund for PSP Awareness and 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

## 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 in lifetime or at death as part of a donor's overall financial and/or estate planning. During fiscal year 2014, CurePSP received planned gifts or bequests valued at more than \$1.3 million from:

**Ruth K. Peters**

**Julie E. Repasy Trust**

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## 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 local communities. Special events also help reach new families affected by atypical Parkinsonian disorders.

Thanks to the kindness and generosity of our CurePSP volunteers, 66 special events and/or fundraising activities occurred this fiscal year in 19 states, as well as additional fundraisers that were nationwide to support our mission. The following provides a list of fundraising events and their locations:

Ambler, PA	Ambler YMCA Spring Into Summer 5K - Team CurePSP
Annapolis, MD	Terry Watson Writing Campaign
Atlanta, GA	Atlanta Marathon - Team CurePSP
Belmont, NY	Marilyn's Spring Stroll
Bloomfield, MI	Michigan Tailgate Fundraiser
Brooklyn, NY	Brooklyn 5K - Team CurePSP
Camarillo, CA	Meera Rao Dance Debut
Charlottesville, VA	Monticello Man Triathlon - Team CurePSP
Chicago, IL	Barbara Fedor Fundraisers
Denver, CO	Poppin4PSP – Basketball Marathon
Denver, CO	Colfax Marathon - Team CurePSP
East Rockaway, NY	Bernard Klein Twilight Dinner
Enterprise, FL	Annual CurePSP 5K & 15K Relay
Friendship, NY	Rolly Miles Golf Tournament
Ft. Walton Beach, FL	Bring Back the Heat Derby Party
Jamestown, NC	Carol Kerr Walk
Kenmore, WA	Barney Myer Hummingbird Cards
Lakeville, MA	Cranberry Tri-Fest
Las Vegas, NV	Maura's 9th Birthday Fundraiser
Lebanon, PA	CurePSP Youth Benefit Concert
Lititz, PA	40 Undercover Benefit Concert

# COMMITMENT – Finance and Development

## Building and Strengthening an Enduring Foundation

### **Special Events** continued

Los Angeles, CA	LA Marathon - Team CurePSP
Marco Island, FL	10th Annual CurePSP Awareness & Memorial Walk
Maryland, NY	Madison Handbag Event
Marysville, MI	2nd Annual Michigan Golf Tournament
Medford, NY	Tomlet Garage Sale
Montour, PA	Montour Trail Half Marathon - Team CurePSP
Nationwide	Butterfly Note Cards
Nationwide	CurePSP Hope Bracelet Fundraisers
Nationwide	CurePSP Merchandise (Café Press)
Nationwide	CurePSP Ribbon Magnet Fundraisers
Nationwide	CurePSP Wristband Fundraisers
Nationwide	Good Search
Nationwide	Safeway Good Neighbor
Nationwide	Vehicle Donation Center
Nationwide	Capital One - CurePSP Credit Card
Nationwide	LinkedIn Jewelry
Nationwide	I Hate PSP T-shirt Fundraiser
Nationwide	CurePSP Kindle Fire Giveaway
Nationwide	Writing Campaigns
Nationwide	Wedding Gift Fundraisers
Nationwide	Multiple Giving Campaigns
Nationwide	Text to Donate
Oxnard, CA	Dziak Dog Walk
Patrick, SC	Earl Walton "Try" Athlon
Philadelphia, PA	Philadelphia Support Group Bake Sale
Phoenix, AZ	Gloria Sebastiani Writing Campaign
Shoals, IN	The Robert Peoples Run for Hope 5K
Sleepy Hollow, NY	Sleepy Hollow Half Marathon - Team CurePSP
Smithtown, NY	Stella & Dot Jewelry Show
South Portland, ME	Charles R. Edmunson Writing Campaign
Syracuse, IN	8th Annual Putt for PSP
Unadilla, NY	Jeans Month Fundraiser
Washington, DC	Paul Blank Invitational Football Game
Washington, DC	Nikhil's Saldana's Birthday
West Jordan, UT	Falsone Family Fundraisers
White, GA	Dine for PSP

## Report of Gifts \$1,000 and Above

Gifts and commitments, July 1, 2013 through June 30, 2014.

100 Women in Hedge Funds Foundation

Anonymous

ACBL Charity Foundation

Mr. & Mrs. Mark Agee

Ms. Nidhi Agrawal

Ms. Swati Agrawal

Dr. & Mrs. David Alexander

Mr. Klaus Althammer

Dr. Sharon Amaya

America's Charities

American Endowment Foundation

ARES Operations, LLC

Mrs. Delysia Ashwood-McNair

Atlas Family Foundation

Mr. Robert Auritt

Ball Corporation

Bank of America Foundation, Inc.

Mrs. Shirley Barber

Mr. Haley Barbour

Dr. & Mrs. Bruce A. Barnett

Mr. Charles F. Barry

Mr. Paul W. Bednarczyk

Dr. Burton Benjamin

Mr. William Benjamin

Mr. Tobias J. Bermant

Mrs. Miriam Bernstein

Judith Knell Binder Family Foundation

Ms. Helen Watson Blodgett

Mr. & Mrs. Douglas Bloom

Mr. & Mrs. Scott Bochler

Dr. Yvette Bordelon and Dr. Carlos Portera-Cailliau

Boston Family Office

Ms. Amy Branch

Bridgemill Foundation

Mr. Frederic A. Brossy

Ms. Ann T. Bruno

Mrs. Doreen Bryant

Mr. John T. Burhoe

Mr. Charles Burlingham, Jr.

Cadence Design Systems, Inc.

Cafe Press

Mrs. Mary K. Callaway

Camp Roosevelt Camp Reunion

Camping World/Good Sam, LLC

Capital One

Mr. & Mrs. E. Paul Casey

CBD Solutions

Ms. Cheri R. Cernak

Ms. Cynthia Cernak

Mr. & Mrs. Rob Cernak

Conover Foundation, Inc.

Mr. Everett Cook

Mr. Charles Cummins

Ms. Cathy A. Currie

Mr. Andy Cvitanov

Mr. Dee C. Daniels

Mr. Delmont A. Davis

Mr. & Mrs. James F. Delansky

Mr. Robert E. Derse

Mr. Brendan M. Dixon

Mrs. Ann H. Dunwody

Mrs. Janet M. Edmunson

Eglin Federal Credit Union

Ms. Jennie Emore

Ms. Barbara Fedor

Mr. Massimo Ferragamo

Ms. Barbara Ferris

Mrs. Dale Ferris

Final Mile Race Management, LLC

Mr. & Mrs. Thomas Flexner

Mr. Larry Forbish

Ms. Lorraine Ford

Mr. Luigi Franceschina

Mrs. Kelly Franks

Mr. Paul H. Freeman

Drs. Jeffrey S. & Jennifer Friedman

Mr. & Mrs. Robert Gallois

Mr. William Ganey

Gibson-Prugh Family

Mr. Philip R. Gilleland and Ms. Myrna H. Huntley

Give With Liberty/Liberty Mutual Foundation Match

Mrs. Faye Glazer

Dr. Stephen Goldman

Mrs. Pamela T. Gomes

# COMMITMENT – Finance and Development

## Building and Strengthening an Enduring Foundation

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Mr. Melvyn L. Lefkowitz  
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Light of Day Foundation, Inc.  
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Mr. & Mrs. Mark Magowan  
Martin Family Trust  
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Dr. Faisal Merchant  
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Microsoft Giving Campaign  
Mrs. Cynthia Miles  
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Ms. Lynn Nesbitt  
Mrs. Marjorie G. Neuwirth  
Mr. & Mrs. Peter Newell  
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 Ms. Karen W. Rainwater  
 The Real Estate Group, Inc.  
 Julie E. Repasy Trust  
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 Retro-Tech Systems, Inc.  
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 Mr. David Saltzman  
 Sayers Foundation, Inc.  
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 Mr. Ravi Shankar  
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 Edward W. Smith Jr. Foundation  
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 The Swartzberg Zoller Family Foundation  
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 Mr. Brian Yocum  
 Mrs. Sally Yocum  
 YourCause, LLC for Hewlett-Packard  
 Zyne Family Trust

Unfortunately, space does not permit us to recognize all of our generous donors. For a complete list of donors who gave \$1-\$999, please reference the 2014 Honor Roll of Donors on our website.

**\$1-\$999**

**6,789 DONORS, TOTAL GIFTS OF \$613,488**

**7,106 TOTAL DONORS IN FY2014**

**TOTAL GIFTS IN FY2014 OF \$3,334,031**

# COMMITMENT – Finance and Development

## Building and Strengthening an Enduring Foundation

### Methods of Supporting CurePSP

The method by which you contribute to CurePSP can determine your tax benefits. Every person's situation is unique. The Foundation's 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.

**Through the 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.

**Through 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.

**Through Major Gifts** – Donors are encouraged to make major gifts of at least \$5,000 for 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.

**Through 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 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.

**Through 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.

**Through The Legacy Society** – Donors who give total cumulative gifts exceeding \$10,000 are permanently acknowledged as members of The Legacy Society and receive recognition in the 2014 Annual Report and Honor Roll of Donors.

For more information on all of the above "methods of supporting CurePSP," please contact Kathleen Matarazzo Specca, Vice President of Development & Donor Relations, via email at [specca@curepsp.org](mailto:specca@curepsp.org) or at 800-457-4777, x5672.

### Foundation for PSP | CBD and Related Brain Diseases

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Canada: 866-457-4777

Web: [www.curepsp.org](http://www.curepsp.org)

Email: [info@curepsp.org](mailto:info@curepsp.org)





Foundation for PSP | CBD and Related Brain Diseases

*Curing, Caring, Commitment*

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