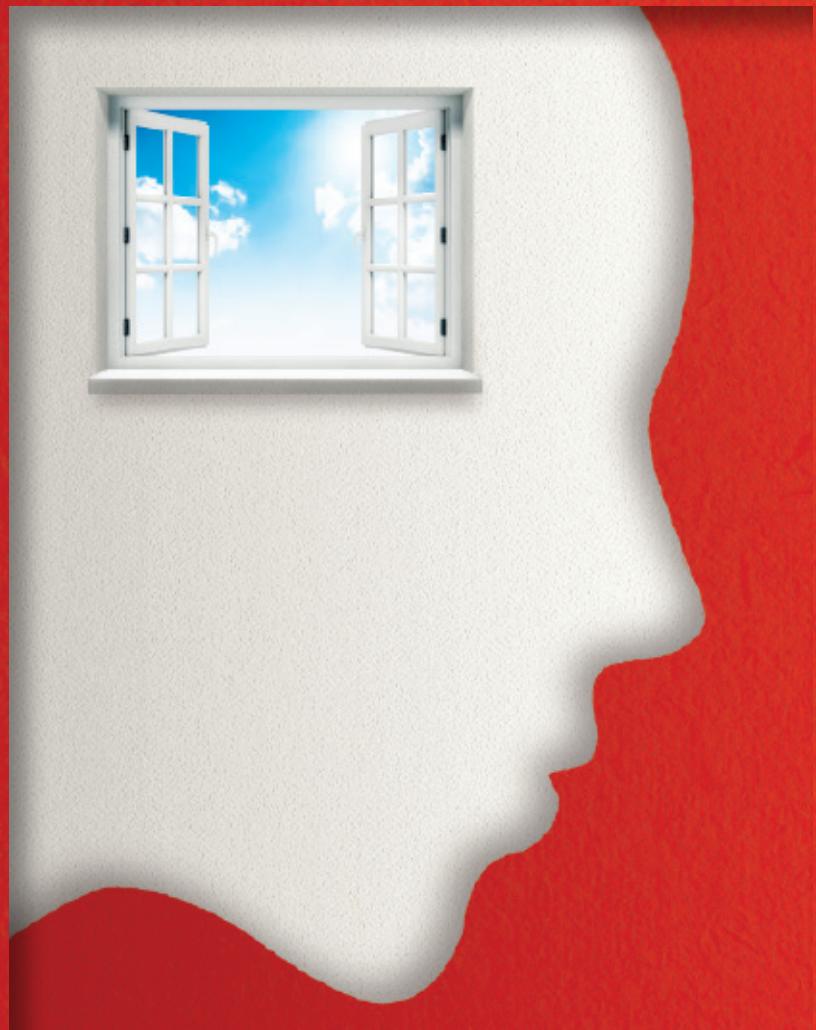


CurePSP®
UNLOCKING THE SECRETS OF BRAIN DISEASE®

2017 Annual Report



CUREPSP.ORG

Chairman's Report 2017

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

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

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

First incorporated as a 501(c)(3) in 1990, our commitment to patient and caregiver outreach is broader and deeper than at any time in the last 27 years. Our dedication to research into progressive supranuclear palsy and other similar neurodegenerative diseases was shown in 2017 by our sponsored Research Symposium and funding of a variety of targeted research projects. Our passion for patient and caregiver support is uncompromising, and our commitment to bringing awareness of these diseases and their devastating effects on patients and families is relentless.



William R. McFarland

Our expanded website continues to earn positive feedback from patients and caregivers, and CurePSP staff continually update content to meet the needs of users. Our Facebook page has become a true forum for patients, families, caregivers, and others; and Twitter and Instagram have been energized to promote fundraising events in order to take full advantage of social media.

We have just released a new Patient and Carepartner Guidebook with all-encompassing information for newly diagnosed patients and carepartners. New support groups have opened, and we continued our immediate telephone response program to assist newly diagnosed patients and families with rapid, up-to-date information.

Volunteers, always an essential component of our initiatives, are kept up to date by a regular email blog, and family conferences are held each year.

We continue to build strong relationships with not-for-profit organizations that share our focus on neurodegenerative diseases such as frontotemporal dementia, Parkinson's disease, and Alzheimer's disease. We are working more closely than ever with the Rainwater Charitable Foundation's Tau Consortium, and we are partnering with Great Britain's PSP Association in our first-ever International Research Symposium on PSP & CBD in London in the fall of 2018.

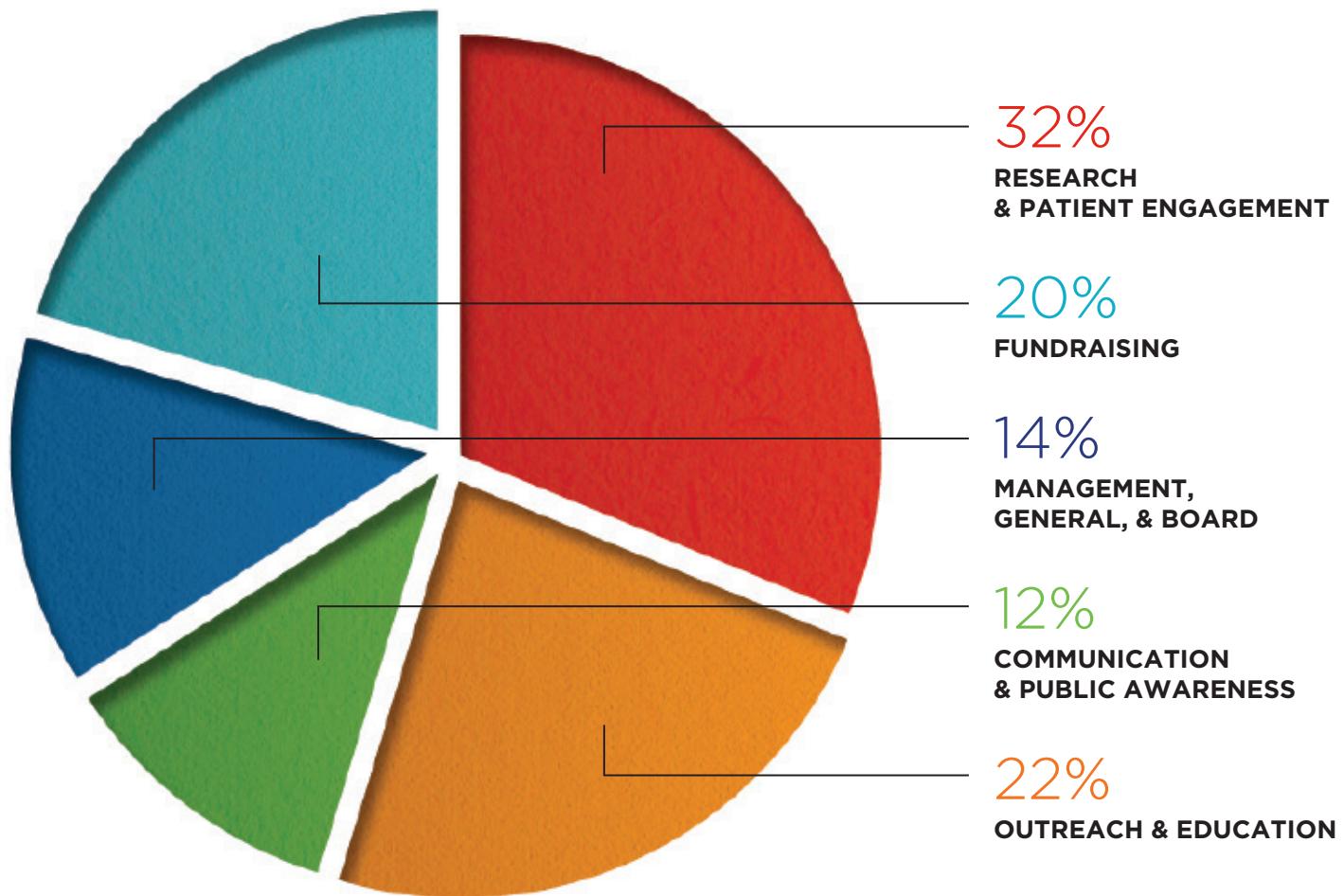
In addition to broad-based support from local fundraisers and smaller contributors, we are becoming strategically positioned to partner with foundations and philanthropists who can further support our cause. Legacy Funds, which facilitate ongoing fundraising around the interests of families who have been impacted by prime of life neurodegeneration and who choose to honor their loved one in perpetuity, have been revitalized.

Our slogan, **Because Hope Matters®**, captures the passion behind our laser focus on these prime of life disorders. The causes of these terrible diseases are slowly being understood, and while there are no effective treatments or cures, there is more optimism than ever before. We hope you will continue to accompany us on our quest for a cure and support for the afflicted!

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

How Your Gifts Were Used

(FY2017)



Thank you for your support.

Statements of Financial Position

June 30, 2017 and 2016

ASSETS

	2017	2016
CURRENT ASSETS:		
Cash and Cash Equivalents	\$ 1,638,963	\$ 1,608,323
Cash and Cash Equivalents – Temporarily Restricted	734,996	932,117
Investments-Unrestricted	23,714	16,172
Pledges Receivable	4,650	3,850
Other Receivables	22,920	13,104
Prepaid Expenses	50,959	34,854
Inventory	<u>20,382</u>	
 Total Current Assets	<u>2,496,584</u>	<u>2,608,420</u>
 Property and Equipment, net	158,787	166,452
 Investments – permanent endowment	403,444	372,118
 Deposits	<u>15,773</u>	<u>15,773</u>
 TOTAL ASSETS	<u><u>\$ 3,074,588</u></u>	<u><u>\$ 3,162,763</u></u>

LIABILITIES AND NET ASSETS

CURRENT LIABILITIES:

Accounts Payable and Accrued Expenses	\$ 112,391	\$ 169,652
Grants Payable – Current	<u>304,040</u>	<u>617,110</u>
 Total Current Liabilities	<u>416,431</u>	<u>786,762</u>
 Grants Payable – non-current portion	50,000	150,000
 Total Liabilities	<u>466,431</u>	<u>936,762</u>

NET ASSETS:

Unrestricted	1,749,317	1,311,400
Temporarily Restricted	455,396	542,483
Permanently Restricted	<u>403,444</u>	<u>372,118</u>
 Total Net Assets	<u>2,608,157</u>	<u>2,226,001</u>
 TOTAL LIABILITIES AND NET ASSETS	<u><u>\$ 3,074,588</u></u>	<u><u>\$ 3,162,763</u></u>

Statement of Activities and Changes in Net Assets

For the years ended June 30, 2017 and 2016

2017

REVENUE AND SUPPORT:

	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Permanently Restricted</u>	<u>Total</u>
Contributions	\$ 2,175,725	\$ 219,065	\$ —	\$ 2,394,790
Special Events, net	188,226	1,175	—	189,401
Patient engagement	17,630	—	—	17,630
Sponsorships	47,750	41,050	—	88,800
Merchandise sales, net	4,106	—	—	4,106
Net realized and unrealized gains/(losses)	3,083	—	31,326	34,409
Interest and Dividends	1,648	8,746	—	10,394
Gain/(Loss) on Disposal	(566)	—	—	(566)
Miscellaneous income	415	—	—	415
Total Revenue, Gains and Support	2,438,017	270,036	31,326	2,739,379
Net Assets Released from Restrictions	357,123	(357,123)	—	—
Total Revenue, Gains, Support, and Releases	2,795,140	(87,087)	31,326	2,739,379

EXPENSES:

Program Services:				
Research	741,950	—	—	741,950
Outreach and Education	527,273	—	—	527,273
Communications and Public Awareness	273,786	—	—	273,786
Patient engagement	17,040	—	—	17,040
Supporting Services:				
Management and General	263,479	—	—	263,479
Board	67,394	—	—	67,394
Fundraising	466,301	—	—	466,301
Total Expenses	2,357,223	—	—	2,357,223
CHANGE IN NET ASSETS	437,917	(87,087)	31,326	382,156
NET ASSETS, BEGINNING OF YEAR	1,311,400	542,483	372,118	2,226,001
NET ASSETS, END OF YEAR	\$ 1,749,317	\$ 455,396	\$ 403,444	\$ 2,608,157

2016

REVENUE AND SUPPORT:

	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Permanently Restricted</u>	<u>Total</u>
Contributions	\$ 2,068,200	\$ 775,482	\$ —	\$ 2,843,682
Special Events, net	180,646	88,515	—	269,161
Patient engagement	72,121	—	—	72,121
Sponsorships	29,400	—	—	29,400
Merchandise sales, net	357	—	—	357
Net realized and unrealized gains/(losses)	(1,112)	—	(8,709)	(9,821)
Interest and Dividends	5,293	10,005	—	15,298
Gain/(Loss) on Disposal	(5,612)	—	—	(5,612)
Miscellaneous income	3,642	—	—	3,642
Total Revenue, Gains and Support	2,352,935	874,002	(8,709)	3,218,228
Net Assets Released from Restrictions	555,064	(555,064)	—	—
Total Revenue, Gains, Support, and Releases	2,907,999	318,938	(8,709)	3,218,228

EXPENSES:

Program Services:				
Research	837,618	—	—	837,618
Outreach and Education	701,207	—	—	701,207
Communications and Public Awareness	504,471	—	—	504,471
Patient engagement	200,927	—	—	200,927
Supporting Services:				
Management and General	309,019	—	—	309,019
Board	76,905	—	—	76,905
Fundraising	522,077	—	—	522,077
Total Expenses	3,152,224	—	—	3,152,224
CHANGE IN NET ASSETS	(244,225)	318,938	(8,709)	66,004
NET ASSETS, BEGINNING OF YEAR	1,555,625	223,545	380,827	2,159,997
NET ASSETS, END OF YEAR	\$ 1,311,400	\$ 542,483	\$ 372,118	\$ 2,226,001

Open Grants in FY 17



Targeting Rho Kinases for PSP and CBD Therapeutics

Benjamin D. Boros

*University of Alabama
at Birmingham, AL (USA)*



Oxidative Damage and Gene Deregulation in PSP and Related Disorders

Dr. Monica Y. Sanchez-Contreras

*University of Washington
Seattle, WA (USA)*



Understanding MAPT Sub-Haplotypes and Alternative Splicing

Dr. Kathryn Bowles

*Mount Sinai School of Medicine
New York, NY (USA)*



iCRISPRi in Human Neurons and Glia to Elucidate Selective Turnover of Tau

Dr. John W. Steele

*Humboldt State University
Arcata, CA (USA)*



Care Where It Counts: Support to Reduce Isolation and Ensure Well-Being for Patients and Caregivers

Dr. Jori Fleisher

*Rush University
Chicago, IL (USA)*



iCRISPRa into Neurons to Regulate Autophagic Clearance of Tau

Benjamin M. Woodruff

*Humboldt State University
Arcata, CA (USA)*



Evaluation of STX6 Silencing on the Novel AAV-Based PSP Mouse Model

Dr. Tsuneya Ikezu

*Boston University School of Medicine
Boston, MA (USA)*



Small-Molecule Modulation of Tau Clearance and Aggregation

Dr. Gal Bitan

*University of California
Los Angeles, CA (USA)*



Disease in a Dish Model of PSP

Dr. Shona Joy

*Neural Stem Cell Institute
Albany, NY (USA)*



The Establishment of a Preclinical Model for Progressive Supranuclear Palsy

Dr. Stewart Clark

*State University of New York
Buffalo, NY (USA)*



MOBP, STX6 & EIF2AK3 Expression and Distribution in PSP Brains

Dr. Rohan De Silva

*University College, London
London (UK)*



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

Dr. Ragnhildur Thora Karadottir

*University of Cambridge
Cambridge (UK)*



Tau in Peripheral Tissues of PSP and CBD

Dr. Brittany Dugger

*University of California
San Francisco, CA (USA)*



Specific Targeting of PSP Brain-Derived Tau Oligomers

Dr. Rakez Kayed

*University of Texas
Galveston, TX (USA)*



Investigating Functional Ability in PSP

Dr. Adam Gerstenecker

*University of Alabama
at Birmingham, AL (USA)*



Impact of Arginase1 Over-Expression and SAT1 Deficiency During Tauopathies

Dr. Daniel C. Lee

*University of South Florida
Tampa, FL (USA)*



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

Dr. Michael D. Geschwind

*University of California
San Francisco, CA (USA)*



Testing Phosphodiesterase Inhibitors for Treatment of Tauopathy Disorders

Dr. Natura Myeku

*Columbia University
New York, NY (USA)*



Defining a Novel Drug Target for PSP and CBD

Dr. Lars Ittner

*University of New South Wales
Sydney, NSW (Australia)*



PSP Whole Exome Study

Dr. Gerard Schellenburg

*University of Pennsylvania
Philadelphia, PA (USA)*



Understanding the Relative Contributions of Genetic Risk Factors in PSP

Dr. Aimee Kao

*University of California
San Francisco, CA (USA)*



Small Molecule Activators of Phospholipase D and Tau Clearance Via Autophagic Flux

Dr. Haung (Ho) Yu

*Columbia University
New York, NY (USA)*

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For the Period July 1, 2016 through June 30, 2017

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Volunteer Events

With Special Thanks to the Following CurePSP Volunteer Events

3rd Annual Ride to CurePSP	Mark Passe
Albuquerque Support Group	Roxi Padrid
Al's Pals	Mike Cassandro
Art Show in Memory of Lucian Chavez, Jr.	Chris Chavez and Branigan Contreras
Charity Workout	Erica Varble
Columbia Triathlon and Duathlon	Emily Margolis
Corn Maze in Memory of Buck Sykes	Rachel Callum
CurePSP Awareness and Memorial Walk	Christina Dean, Cindy MacDonald, and Mitch Kanefsky
Dark Shadows Auction	Kathryn Leigh Scott
Donna Bennett Training 1-Hour Strength & Conditioning	Donna Bennett
Fundraising Dinner	Patrick Johnson
Golf for Andrew Szczerba	Kelly Szczerba
Hiking the Pacific Crest Trail	Susan Muck
I Got Golf On The Brain	Meg Robinson
Jean Day	Karen Telarico
Karaoke for a Cure	Joy Courtright
Karate For A Cure	Joshua Wiesel
Lu LaRue	Becka Carvell
Marilyn's Spring Stroll	Donna Etergineoso
McIntyre Spin	Stephanie McIntyre
Michigan Support Group Fundraiser	Mary Meghler
Miracle for Mom Charity Golf Tournament	Adam Murphy
Montour Trail Half-Marathon	Susan MacLaughlin
Music Bash in Honor of John Bonnelli	Lois Bonnelli
Novo Nordisk New Jersey Marathon and Half Marathon	Dan Stevens, Sophie Gervais Stevens, Jocelyne Gervais, Leigh Gervais Genkinger, Kim Gervais, and Eric Gervais
NYC Marathon	Kim Feinman
PSP Awareness and Education Day	Satvik Vasireddy
Putt for PSP	Jack Jennings and Jim Kroemer
Rotary Club Awareness Day	Shushma Patel
Run For CBD - Team Dosie	Abby Sayre
Sue Walsh and Teaming Up For Ted	Sue Walsh
Tres Rios Triathlon	Karen Russo
Wine and Cheese Fundraiser	Ileen McFarland and the Dallas Support Group
Wine in the Hill Country	Kary Cataldie
Writing Campaign for Maria Molinero	Connie Velez
Yosemite Half Marathon	Rita Magliocco

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