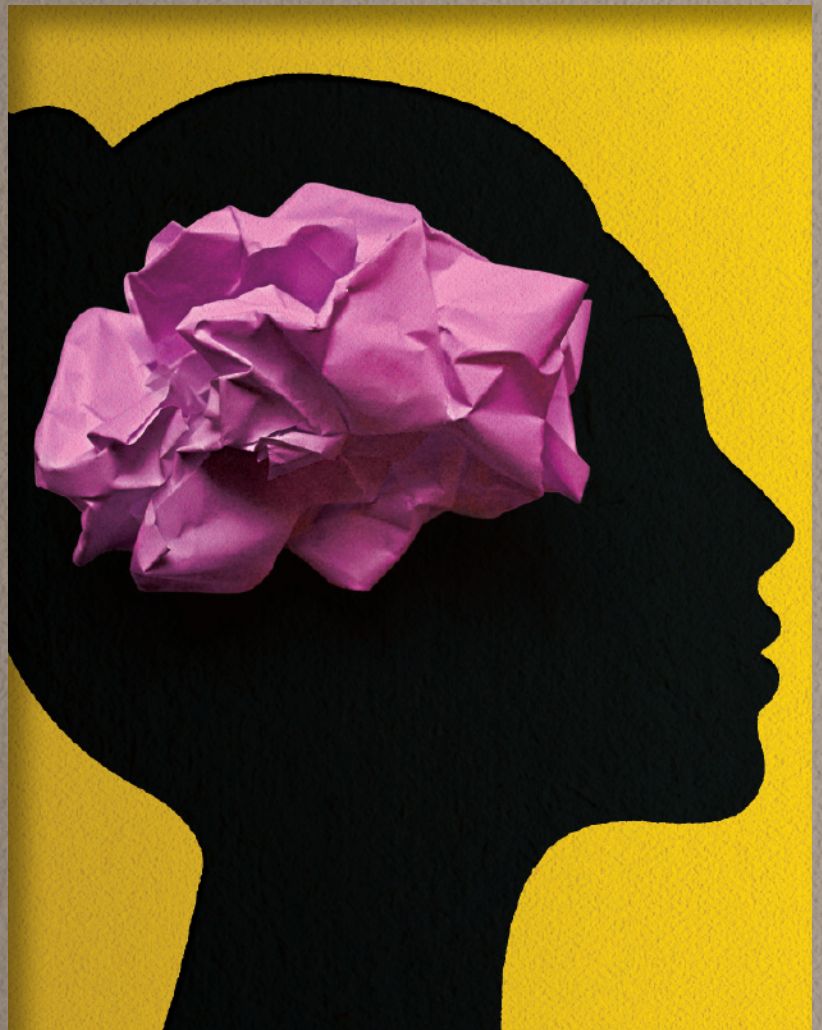


Annual Report

For the fiscal year ended June 30, 2018



Chairman's Report 2018

CurePSP, a 501(c)(3) not-for-profit enterprise first incorporated more than 28 years ago, again reports impressive forward progress in 2018 with even more significant objectives to be achieved in 2019.

Our commitment to patient and caregiver outreach has broadened and deepened, with an expanded volunteer network, additional training, and increased grants through the Cherie Levien Quality of Life Fund to include patients with related diseases. We are adding approved Centers of Care, publishing the second edition of our Patient and Caregiver Guidebook, moving forward with Spanish translation of our printed materials and website content, and publishing printed materials and web content for chronic traumatic encephalopathy (CTE), a disease closely related to PSP that sometimes strikes athletes who have participated in contact sports and military combat veterans. New educational brochures have been completed, addressing topics such as levels of care, healthcare planning and advance directives, palliative and hospice care, and tackling the issues of grief and the end of the caregiver role. We are in the process of establishing or have completed our selection of Regional Volunteer Coordinators to help manage our network, 12 new in-person support groups (bringing us to nearly 60 support groups nationwide), and 15 new peer supporters to better assist in-person support groups and leaders.

Fundraising, always a challenge for a not-for-profit serving patients and families dealing with a rare disease, is growing. We believe fundraising should be relationship-based, providing measurable results that are sustainable over time. For example, we are growing our relationship with the Light of Day Foundation, which has provided more than \$380,000 in matching grants since 2008, which CurePSP has more than doubled. Through “The Hope Tour,” CurePSP and Light of Day will fund worthwhile new projects benefiting our joint disease populations.

We are now using new means of online fundraising, tapping into a younger and largely unsolicited donor base. Our social media presence is growing nicely, with our total Facebook following now more than 10,000. Since launching Facebook fundraisers in September, more than 100 have been created with over \$100,000 raised—all in small contributions from new donors. Legacy Funds 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.

CurePSP has long been dedicated to research into PSP and similar incurable and terminal neurological diseases. CurePSP has funded more than 180 studies and anticipates issuing at least six new Venture Grants—seed funding for early career investigators—in 2019. Dr. Lawrence I. Golbe, an integral participant with CurePSP virtually since its inception and a world-renowned neurologist, has been appointed Director—Scientific Affairs to lead this effort. We are jointly sponsoring research with the Rainwater Charitable Foundation’s Tau Consortium and are the primary organizers of a new PSP Research Roundtable facilitating collaboration with major pharmaceutical companies focused on neurodegeneration. In October 2018, CurePSP and the U.K.’s PSPA jointly sponsored the First International Research Symposium on PSP & CBD at the Royal College of Physicians in London, which attracted some 220 scientists from around the world.

Finally, we continue to focus on operational efficiency and effectiveness. Our accounting and gift processing functions have been consolidated into our New York City office to provide cost savings from having a single facility, improved management oversight, and continued transparency in our finances.

Our passion for patient and caregiver support is uncompromising, our emphasis is on funding research to the maximum we can afford, and our commitment to bringing awareness of these diseases and their devastating effect on patients and families is relentless. We hope you will continue to accompany us in our quest for a cure and our support for the afflicted!



William R. McFarland

With great appreciation for your support,

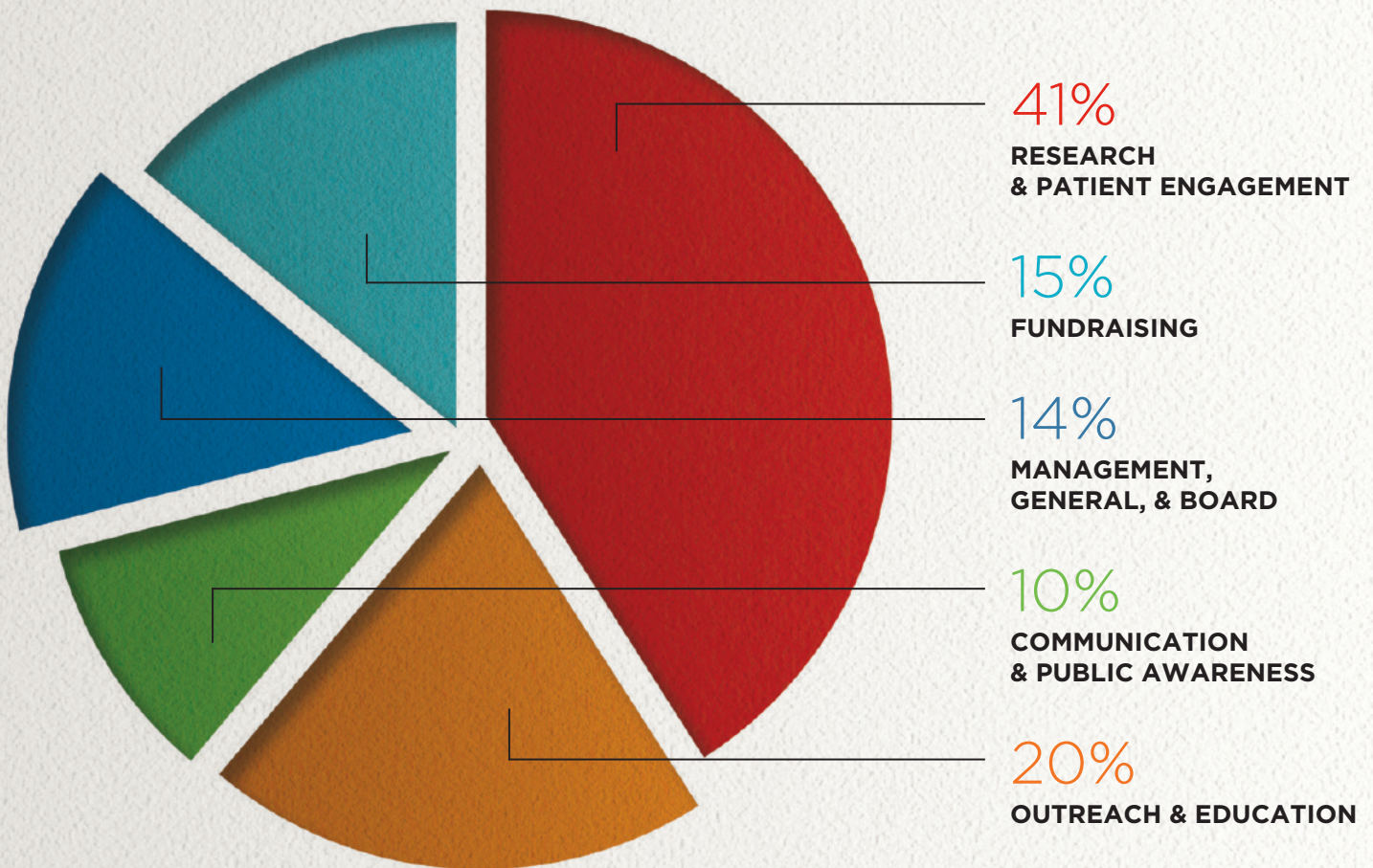
A handwritten signature in blue ink that reads "Bill".

Bill McFarland

Board Chair

How Your Gifts Were Used

(FY 2018)



Thank you for your support.

Consolidated Statements of Financial Position

June 30, 2018 and 2017

ASSETS

	2018	2017
CURRENT ASSETS:		
Cash and cash equivalents	\$2,286,323	\$1,638,963
Cash and cash equivalents - temporarily restricted	751,777	734,996
Investments	—	23,714
Pledges receivable	1,650	4,650
Other receivables	12,728	22,920
Prepaid expenses	86,613	50,959
Inventory	20,859	20,382
Total Current Assets	3,159,950	2,496,584
Property and equipment, net	90,243	158,787
Investments - endowment	452,650	403,444
Deposits	13,482	15,773
TOTAL ASSETS	\$3,716,325	\$3,074,588

LIABILITIES AND NET ASSETS

	2018	2017
CURRENT LIABILITIES:		
Accounts payable and accrued expenses	\$119,986	\$112,391
Grants payable - current	418,996	304,040
Deferred revenue	159,659	—
Total Current Liabilities	698,641	416,431
Grants Payable – non-current portion	112,591	50,000
Total Liabilities	811,232	466,431
NET ASSETS:		
Unrestricted	2,062,060	1,844,255
Temporarily restricted	584,665	505,534
Permanently restricted	258,368	258,368
Total Net Assets	2,905,093	2,608,157
TOTAL LIABILITIES AND NET ASSETS	\$3,716,325	\$3,074,588

Consolidated Statement of Activities

YEAR ENDED JUNE 30, 2018

	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
REVENUE AND SUPPORT:				
Contributions	\$2,203,932	\$252,515	\$ —	\$2,456,447
Special events, net	140,362	1,590	—	141,952
Research roundtable	90,341	—	—	90,341
Patient engagement	5,545	—	—	5,545
Sponsorships	25,500	69,970	—	95,470
Merchandise sales, net	1,931	—	—	1,931
Net realized and unrealized gains(losses)	6,906	15,798	—	22,704
Interest and dividends	5,288	7,548	—	12,836
Gain/(loss) on disposal	(3,503)	—	—	(3,503)
Miscellaneous income	37,733	—	—	37,733
Total Revenue, Gains, and Support	2,514,035	347,421	—	2,861,456
Net Assets Released from Restrictions	268,290	(268,290)	—	—
Total Revenue, Gains, Support, and Releases	2,782,325	79,131	—	2,861,456
EXPENSES:				
Program Services:				
Research	1,046,703	—	—	1,046,703
Outreach and education	514,095	—	—	514,095
Communications and awareness	250,844	—	—	250,844
Patient engagement	4,477	—	—	4,477
Supporting Services:				
Management & general	294,383	—	—	294,383
Board	65,326	—	—	65,326
Fundraising	388,692	—	—	388,692
Total Expenses	2,564,520	—	—	2,564,520
CHANGE IN NET ASSETS	217,805	79,131	—	296,936
NET ASSETS, BEGINNING OF YEAR	1,844,255	505,534	258,368	2,608,157
NET ASSETS, END OF YEAR	\$2,062,060	\$584,665	\$258,368	\$2,905,093

YEAR ENDED JUNE 30, 2017

	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
REVENUE AND SUPPORT:				
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), restated	8,164	26,245	—	34,409
Interest and dividends, restated	1,648	8,746	—	10,394
Gain/(loss) on disposal	(566)	—	—	(566)
Miscellaneous income	415	—	—	415
Total Revenue, Gains, and Support	2,443,098	296,281	—	2,739,379
Net Assets Released from Restrictions	357,123	(357,123)	—	—
Total Revenue, Gains, Support, and Releases	2,800,221	(60,842)	—	2,739,379
EXPENSES:				
Program Services:				
Research	741,950	—	—	741,950
Outreach and education	527,273	—	—	527,273
Communications and awareness	273,786	—	—	273,786
Patient engagement	17,040	—	—	17,040
Supporting Services:				
Management & 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	442,998	(60,842)	—	382,156
NET ASSETS BEGINNING OF YEAR, RESTATED	1,401,257	566,376	258,368	2,226,001
NET ASSETS, END OF YEAR	\$1,844,255	\$505,534	\$258,368	\$2,608,157

Venture Grants Funded in FY2018



Creating and maintaining a dedicated cloud environment and database to host phenotypic and genetic data from the PSP Genetics Consortium cohort

Dr. Giovanni Coppola

University of California, Los Angeles, CA (USA)



The Stephen N. Jasperson Study: Developing treatments for swallowing and communication deficits in PSP

Dr. Michelle S. Troche

Columbia University, New York, NY (USA)



Uncovering unique tau profiles that distinguish PSP from other tauopathies

Dr. Todd J. Cohen

The University of North Carolina at Chapel Hill, NC (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)



Investigating the role of Syntaxin 6 (STX6) for tau protein cell-to-cell transmission

Dr. Thomas Koeglsperger

Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE), Munich (Germany)



iCRISPRi in human neurons and glia to elucidate selective turnover of tau

Dr. John W. Steele

Humboldt State University, Arcata, CA (USA)



The role of TTR1 in mediating tau spread *in vitro* and *in vivo*

Dr. Xiaobo Mao

The Johns Hopkins University School of Medicine, Baltimore, MD (USA)



Defining a novel drug target for PSP and CBD

Dr. Lars Ittner

University of New South Wales, Sydney (Australia)



Functional evaluation of PSP GWAS genes in a tauopathy model *in vivo*

Dr. Edward A. Burton

University of Pittsburgh, PA (USA)



Evaluation of STX6 silencing on the novel AAV-based PSP mouse model

Dr. Tsuneya Ikezu

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



**The Sarah Boone Nesbitt Study:
Oxidative damage and gene
deregulation in PSP and related
disorders**

Dr. Monica Y. Sanchez-Contreras
*University of Washington, Seattle, WA
(USA)*



**Investigating functional ability
in PSP**

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



**Testing phosphodiesterase
inhibitors for treatment of
tauopathy disorders**

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



**Role of oligodendroglial and
astrocytic tau pathology in a
PSP model**

Jacob B. Kantorowitz
*University of Pittsburgh School of Medicine,
Pittsburgh, PA (USA)*



**The Stephen N. Jasperson Study:
Small molecule activators of
phospholipase D and tau clearance
via autophagic flux**

Dr. Haung (Ho) Yu
*Columbia University, New York, NY
(USA)*



**Targeting rho kinases for PSP
and CBD therapeutics**

Benjamin D. Boros
*University of Alabama at Birmingham, AL
(USA)*



**Small-molecule modulation of tau
clearance and aggregation**

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



**iCRISPRa into neurons to regulate
autophagic clearance of tau**

Benjamin M. Woodruff
*Humboldt State University, Arcata, CA
(USA)*



**The establishment of a
preclinical model for progressive
supranuclear palsy**

Dr. Stewart Clark
*State University of New York, Buffalo, NY
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CurePSP thanks its generous donors who make possible our programs and research support.

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Volunteer Events

With special thanks to the organizers of our volunteer events held in FY2018

A Cause for Celebration	Ayush Noori
Albuquerque Support Group	Roxi Padrid
Art Show in Memory of Lucian Chavez, Jr.	Chris Chavez and Branigan Contreras
Bake Sale	Cynthia Rogers
Berlin Marathon Runner	Francesco Cornelio
Dinner for Hope	David and Annie Trotta
Fancy Nance 5K-9	Rick Wolter
Golf for Andrew Szczerba	Kelly Szczerba
Hope Squared Art Auction Reception	Ileen McFarland, Catrina Nieser, and the Dallas Support Group
Iron Man	Amanda Melilo
Karaoke For a Cure	Joy Courtright
LAMAFEST	Al Ventoso
Marilyn's Spring Stroll	Donna Etergineoso
Memorial Walk	Anita Barni
Music Bash in Honor of John Bonelli	Lois Bonelli and Family
Novo Nordisk New Jersey Marathon and Half Marathon and Team Boot, Scoot, and Boogie	The Gervais Family
Picnic In Memory of Joanna	Whitney Christman
Pittsburgh Pirates Fundraiser - Strikeout PSP	Amanda McKendree
Pokémon for PSP	Leon Steinfeld
Putt for PSP	Jack Jennings and Jim Kroemer
Run for CBD - Team Dosie	Abby and Jennifer Sayre
Sprint Distance Triathlon Runner	Andrew Han
Strike Out PSP Softball Tournament	Amanda McKendree
Sue's Day Beach Walk	Michael Studley
Suzanne Wasserman Celebration of Life	Nadine Wasserman and Rafael Stern
Sykes and Cooper Corn Maze	Rachel Callum and Jaime Losco
The CurePSP Awareness and Memorial Walk	Cindy MacDonald, Christina Dean, and Mitch Kanefsky
Top Golf Fundraiser	Kelsey Koziar

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CUREPSP®

UNLOCKING THE SECRETS OF BRAIN DISEASE™

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