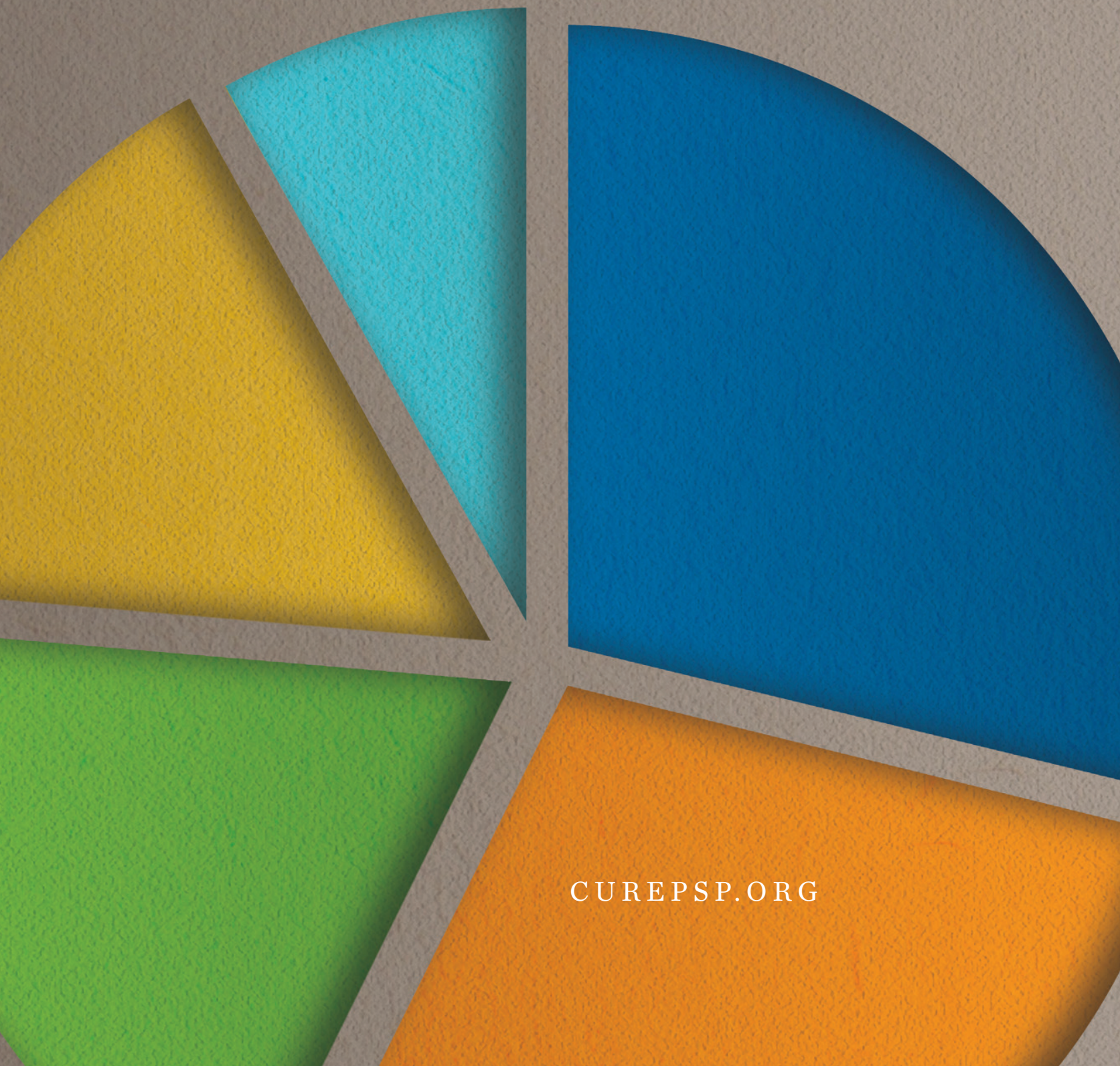


Annual Report

For the fiscal year ended June 30, 2020



CUREPSP.ORG

Report of the Board Chair 2020

Over the last several years, CurePSP has been carefully moving toward a leadership transition. It is my great pleasure to announce that Kristophe Diaz, PhD, our Vice President–Scientific Affairs, will be assuming a greatly expanded leadership role at CurePSP on July 1, 2021, moving toward January 1, 2022, when he will assume full leadership responsibility. The letter from Kristophe below describes his vision for the future of CurePSP, a vision your Board of Directors is most enthusiastic about. However, this transition would never have been possible without the skilled leadership and proficient guidance of Dave Kemp over the last six and one-half years. As many supporters of CurePSP will attest, this organization has vastly improved since Dave joined us in 2015. Our operational efficiency has improved substantially; our patient and caregiver outreach and support have grown tremendously; and our financial underpinnings are significantly stronger. At the same time, our second-to-none staff is virtually identical in size. This is due in large part to Dave Kemp’s management acumen.

It is our hope and expectation that Dave will continue to play a significant role at CurePSP after December 31, 2021, even as he spends more time on his other pursuits without the full weight of CurePSP so heavily on his shoulders. In his letter below, Kristophe outlines his vision of CurePSP’s future, which builds on your foundation’s past achievements. Please join me in welcoming Kristophe in his new role.

With great appreciation for your support,

Bill McFarland
Board Chair

Bill



William R. McFarland

Message from Dr. Kristophe Diaz

When I joined CurePSP in January 2020, I received incredible support from our community, staff, and board members. Thanks to this support, I quickly grasped CurePSP’s impressive achievements and significant impact over the past 30 years. As Vice President–Scientific Affairs, I have continued developing programs and partnerships that advance our scientific understanding of PSP and related neurodegenerative disorders. In parallel, I have worked on partnerships and collaborations that focus on shortening the time to a cure. It is a privilege to continue this work, doing even more as the senior executive of CurePSP.

CurePSP is a unique and essential organization. Unique because of our three pillars: Care, Consciousness, and Cure. To address the challenges facing patients, we must focus on *all* aspects of what it takes to advance our mission. Essential because CurePSP unites the voice of patients and caregivers to the decisions researchers and the industry must make as they pursue a new cure for PSP, CBD, MSA, and related neurodegenerative disorders.

Curing these diseases requires complex collaborations and synergy between multidisciplinary knowledge spaces. Patient groups, academic researchers, private and public funders, technology and computational innovators, and the biotechnology and pharmaceutical sectors must all work together for our common cause. CurePSP will strive to accelerate important convergences while providing support to all those we serve.

As we move forward together, I will make sure the voice of those we serve is influential. CurePSP will advance partnerships, such as our work with the Rainwater Charitable Foundation. With them, we will fund more impactful drug discovery programs and core capabilities. Our organization will aspire to help the pharmaceutical industry understand the needs of patients and deliver better clinical trials and real-world studies so that new therapies and treatments can be effectively assessed and developed.

It will be an honor to continue and increase our direct support to patients, caregivers, and families. Wonderful examples include the Cherie Levien Quality of Life Fund, which enables immediate assistance to the neediest. CurePSP Centers of Care connect patients and their families to dedicated medical hubs around the country. We will work with them to increase the number of regional and national support groups and to reach out to underserved and more diverse communities. To prepare for this goal, we have translated our supporting materials in several languages including Spanish, French, Portuguese, and Hindi.

I am proud of our staff and our supporters, and I am lucky to have Dave Kemp by my side to advise me during the transition. Success in this role depends on input from our benefactors, sponsors, and financial advocates—and I need to hear from you. Thank you for your continued support and your drive toward Care, Consciousness, and a Cure!

With gratitude and respect,

Kristophe Diaz, PhD
Vice President–Scientific Affairs

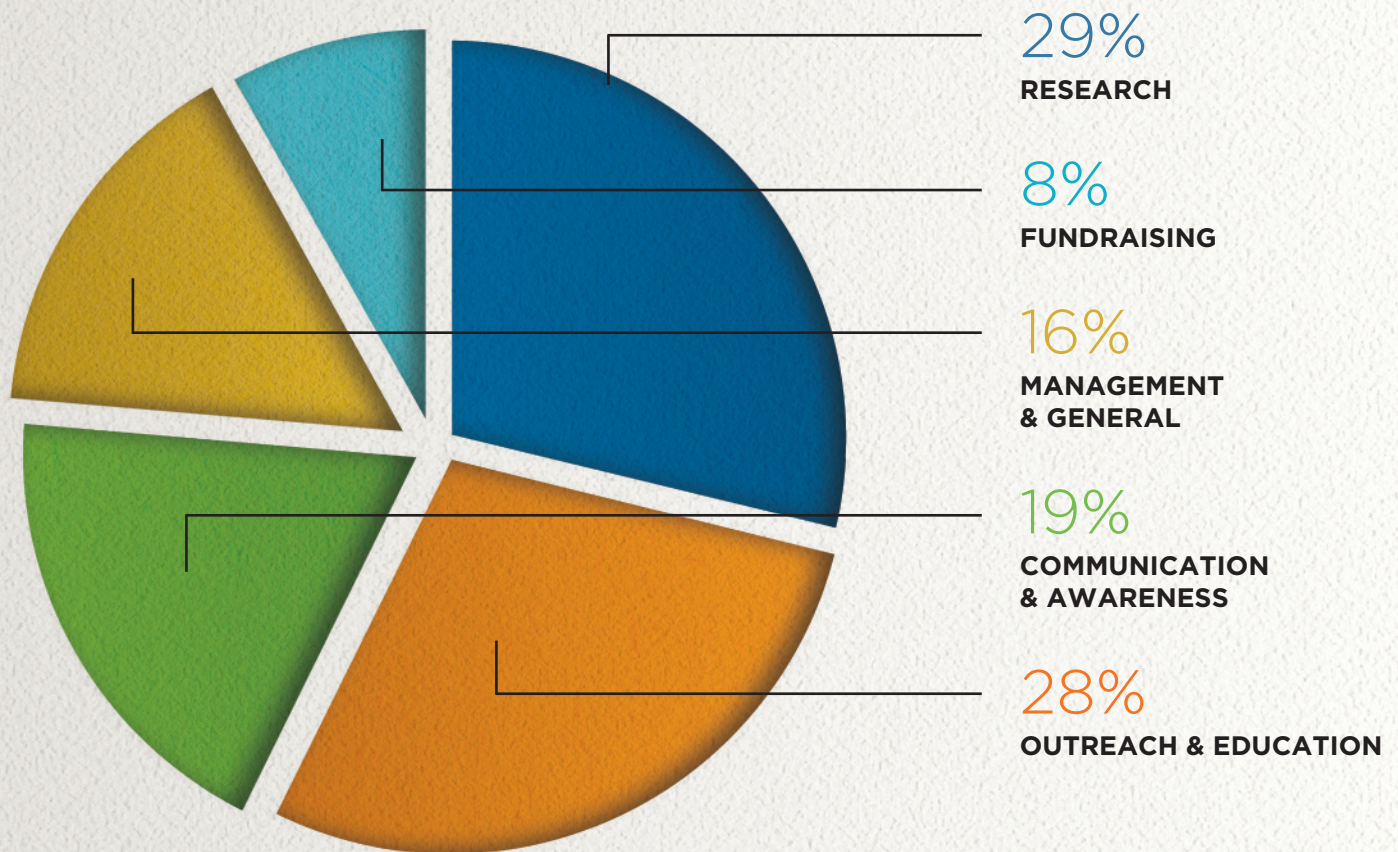
Kristophe



Kristophe Diaz, PhD

How Your Gifts Were Used

FY 2020 Functional Expenses



Thank you for your support.

Consolidated Statements of Financial Position

June 30, 2020 and 2019

ASSETS

	2020	2019
Cash and cash equivalents	\$3,069,409	\$1,876,041
Investments	1,598,135	2,001,195
Pledges receivable	108,000	25,500
Prepaid expenses and other assets	132,506	75,742
Inventory	116,476	5,745
Security deposit	7,000	7,000
Investments held for endowment	316,620	332,916
Fixed assets, net	10,055	23,325

TOTAL ASSETS

\$5,358,201

\$4,347,464

LIABILITIES AND NET ASSETS

LIABILITIES:

Accounts payable and accrued expenses	\$114,914	\$94,812
Deferred revenue	178,807	184,091
Paycheck Protection Program loan	134,035	0
Grants payable	356,532	458,113

Total liabilities

784,288

737,016

NET ASSETS:

Without donor restrictions	3,326,160	2,538,372
With donor restrictions	1,247,753	1,072,076

Total net assets

4,573,913

3,610,448

TOTAL LIABILITIES AND NET ASSETS

\$5,358,201

\$4,347,464

Consolidated Statement of Activities

YEAR ENDED JUNE 30, 2020	Without Donor Restrictions	With Donor Restrictions	Total 2020	Total 2019
PUBLIC SUPPORT AND REVENUE:				
Contributions	\$2,977,962	\$329,709	\$3,307,671	\$2,704,623
Fundraising event income, net	68,071	43,426	111,497	140,621
Sponsorships			0	129,798
Research Roundtable revenue			0	75,569
Investment income	59,725	(1,296)	58,429	32,224
Other revenue	22,737		22,737	16,637
Net assets released from restriction	196,162	(196,162)	0	0
Total public support and revenue	3,324,657	175,677	3,500,334	3,099,472
EXPENSES:				
Program services	2,004,847		2,004,847	1,804,897
Supporting services:				
Management and general	414,673		414,673	395,203
Fundraising	213,221		213,221	194,017
Total supporting services	627,894	0	627,894	589,220
Total expenses	2,632,741	0	2,632,741	2,394,117
Change in net assets from operations	691,916	175,677	867,593	705,355
Non-operating activities:				
Grants refunded to CurePSP	95,872	0	95,872	0
CHANGE IN NET ASSETS	787,788	175,677	963,465	705,355
NET ASSETS – BEGINNING OF YEAR	2,538,372	1,072,076	3,610,448	2,905,093
NET ASSETS – END OF YEAR	\$3,326,160	\$1,247,753	\$4,573,913	\$3,610,448

Venture Grants Funded in FY2020



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

Dr. Edward A. Burton

*University of Pittsburgh
Pittsburgh, PA (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)*



Connecting GWAS signal in tau locus to effector variant in tauopathies

Dr. Rueben Das

*University of Pennsylvania
Philadelphia, PA (USA)*



The role of post-translational modifications on tau transmission in PSP

Dr. Chao Peng

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



Do distinct 4R-tau seeding strains cause disease heterogeneity in PSP and CBD?

Dr. Rohan de Silva

University College London (UK)



Genotyping familial progressive supranuclear palsy

Dr. John M. Ringman

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



MicroRNA profile of isolated brain cell populations in PSP

Dr. Franziska Hopfner

Hannover Medical School (Germany)



Single-whole-cell characterization in PSP

Dr. Geidy E. Serrano

*Banner Sun Health Research Institute
Sun City, AZ (USA)*



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

Dr. Tsuneya Ikezu

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



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

Dr. John Steele

*Humboldt State University
Arcata, CA (USA)*



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

Dr. Thomas Koeglspenger

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



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

Dr. Michelle S. Troche

*Columbia University
New York, NY (USA)*



Low-dose efavirenz as a disease-modifying intervention for primary tauopathies

Dr. Rik van der Kant

*Vrije Universiteit
Amsterdam (The Netherlands)*



Quantification of PERK/EIF2AK3 in tau-vulnerable brain regions in PSP

Kyle Kim

*Stanford University
Palo Alto, CA (USA)*



Investigating PSP and CBD tau strain biology to support novel diagnostic development

Dr. Amanda L. Woerman

*University of Massachusetts
Amherst, MA (USA)*



Mouse model to replicate aspects of pathology of PSP

Gabriella King

*University at Buffalo (SUNY)
Buffalo, NY (USA)*



Using *C. elegans* as a model system to study the genetics of “freeze” phenotypes after dopamine depletion

Katherine Perks

*University of Texas at Austin
Austin, TX (USA)*



Using neural sphere culture to study clearance mechanisms of tau protein accumulation in a PSP stem cell model

Kyle Anthony

*Humboldt State University
Arcata, CA (USA)*



Diagnostic metabolites in CSF of PSP patients

Keelin Riepe

*Arizona State University Foundation
Phoenix, AZ (USA)*



Can microRNA-132 promote the breakdown of abnormal tau protein by autophagosomes in brain cells

Dixie Blumenshine

*Humboldt State University
Arcata, CA (USA)*



Analysis of MRI images from PSP and normal pressure hydrocephalus

Kathryn Cooper

*Stony Brook University (SUNY)
Stony Brook, NY (USA)*

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 Steve & Tamara Wobschall
 Mr. Malcolm Wooley
 Mrs. Denise Wozencraft
 Mrs. Liljana Xheka
 Mr. Michael R. Zaccardo

Volunteer Events

With special thanks to the organizers of our volunteer events held in FY2020

80s Ski Night
 Bonelli Music Bash
 Dick Moyers Open
 Exodus Art Exhibit
 Golf Tournament
 Karaoke for a Cure
 Lut Putt 2020
 Marathon Runner
 Marco Island Walk
 Michelle's Mixer
 Potluck for PSP
 Slot Tournament
 Strikeout PSP
 Sue's Day Beach Walk
 Sushruti Vasireddy's Bake Sale
 Szczerba Golf Tournament
 Theresa Twellman 5K Walk/Run
 to Cure PSP/CBD/MSA

Eryn Henderson
 Lois Bonelli
 Associated General Contractors of Virginia
 Carly Aguilera
 Christine M. Ferguson
 Joy Courtright
 Emily Ulrich
 Allison Forhan
 SW Florida Support Group
 Shannon Heacock
 Jordan Reisner
 Brian Trocha | Eldorado Scioto Downs
 Amanda McKendree
 Michael Studley
 Sushruti Vasireddy
 Kelly Szczerba
 Anita Barni

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UNLOCKING THE SECRETS OF BRAIN DISEASE®

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