

Annual Report

For the fiscal year ended June 30, 2019



Report of the Board Chair 2019

It is my pleasure to report, on behalf of the Board, that CurePSP has made significant progress over the past six months.

We are strategically and financially positioned for ongoing success in 2020 and beyond. Our mission is laser-focused: To fight, cure, and eradicate the devastation of PSP while we support patients, families, and carepartners through the most challenging circumstances imaginable. Our progress is the result of an extraordinary team effort under the excellent leadership of David Kemp—and the passionate commitment of our staff, volunteers, donors, and Board.

A critical aspect of strengthening CurePSP is the ongoing development of a top-tier Board. To that end, the Board has elected three new members who add a wealth of knowledge and know-how in fulfilling our purpose-driven mission. Joining us is Brent Bluett, DO, clinical assistant professor of neurology and neurological sciences at the Stanford Medical School.

Dr. Bluett is a practicing neurologist with expertise in PSP and a heartfelt passion for patient care. Andy Maus, a senior human resources executive with a Fortune 500 company primarily serving the healthcare industry, has been elected to our Board. Like so many of our Board members, Andy has family members with PSP. Jessica Shurer, MSW, LCSW, is a practicing licensed clinical social worker who serves at the Movement Disorders Center at the University of North Carolina, Chapel Hill, CurePSP Center of Care. Jessica's passion for patients and families has led her to facilitate multiple community support groups for Parkinson's and atypical Parkinsonism diagnoses. Jessica coordinates specialty interdisciplinary clinics, organizes educational programs and focus groups, and provides training for allied health clinicians such as physical therapists, occupational therapists, and speech language therapists.



William R. McFarland

Bringing on the best and brightest talent is foundational in moving our mission forward. In addition to our three new Board members, we have recently added two new staff members. Gregg Felice, LCSW-R, a practicing licensed clinical social worker, was appointed as Director-Patient & Carepartner Advocacy. Gregg's knowledge and ability will strengthen, train, and expand the foundation's support network leaders, patients, and health professionals. Mr. Felice will work with CurePSP's Centers of Care and develop and cultivate partnerships with industry, academia, foundations, and other nonprofits in the neuroscience space.

I am thrilled to announce that CurePSP has appointed Kristophe J. Diaz, PhD, as Vice President-Scientific Affairs. Dr. Diaz will direct the foundation's Venture Grants program, which provides research grants for frontotemporal disorders, including PSP. Dr. Diaz will also assist in identifying new and promising research funding opportunities, expand our growing international partnerships with pharmaceutical and biotech leaders at the frontiers of neurological research, and help to coordinate our activities with government agencies and foundations.

Many heartfelt thanks go to Dr. Larry Golbe, who served as our interim Vice President-Scientific Affairs and whose world-class PSP expertise provided a strong bridge until the role was filled.

As always, efficiency and financial stability are hallmarks of all our endeavors. We are very proud to report that our financial statements have just been audited (as happens every year), and we received a clean, unmodified opinion from our audit firm—a first-class rating. Our program spending ratio is a superior 75%, meaning that for every dollar spent, 75 cents went toward programs and services. Our liquidity is very strong, with adequate financial reserves to continue funding our all-important Venture Grants and genomic research. We will continue to take steps to maximize efficiency, act frugally, and streamline operations.

The Board's vision is crystal clear: To win the battle against all prime of life diseases, bringing hope and support to all those who suffer with them.

With great appreciation for your support,

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

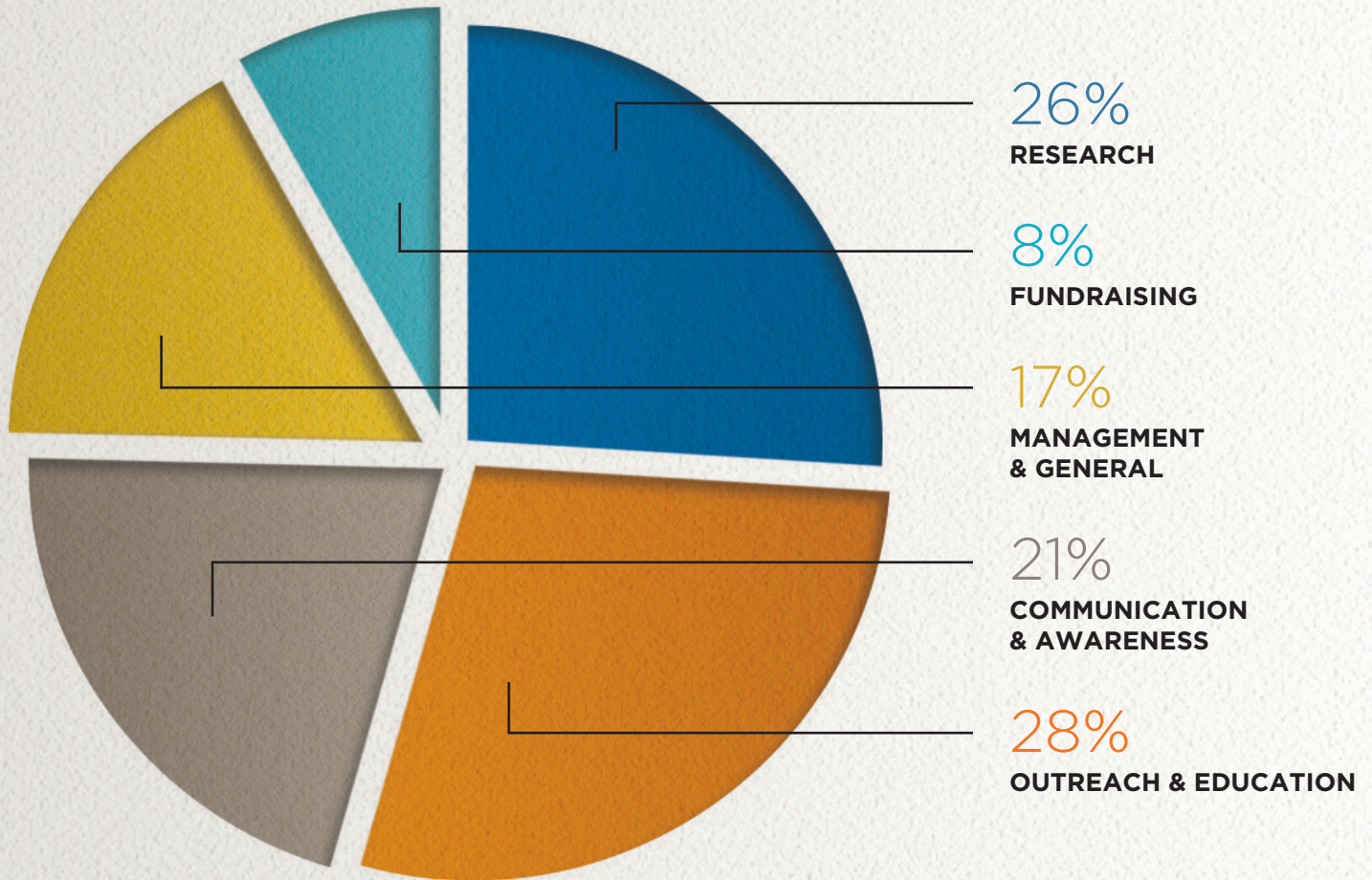
Bill McFarland

Board Chair

How Your Gifts Were Used

(FY 2019)

FY 2019 Functional Expenses



Thank you for your support.

Consolidated Statements of Financial Position

June 30, 2019 and 2018

ASSETS

| | 2019 | 2018 |
|-----------------------------------|--------------------|--------------------|
| CURRENT ASSETS: | | |
| Cash and cash equivalents | \$1,876,041 | \$3,038,100 |
| Investments | 2,001,195 | 0 |
| Pledges receivable | 25,500 | 1,650 |
| Prepaid expenses and other assets | 81,487 | 120,200 |
| Security deposit | 7,000 | 13,482 |
| Investments held for endowment | 332,916 | 452,650 |
| Fixed assets, net | 23,325 | 90,243 |
| TOTAL ASSETS | \$4,347,464 | \$3,716,325 |

LIABILITIES AND NET ASSETS

| | 2019 | 2018 |
|---|--------------------|--------------------|
| LIABILITIES: | | |
| Accounts payable and accrued expenses | \$94,812 | \$119,986 |
| Deferred revenue | 184,091 | 159,659 |
| Grants payable | 458,113 | 531,587 |
| Total liabilities | 737,016 | 811,232 |
| NET ASSETS: | | |
| Without donor restrictions | 2,538,372 | 2,062,060 |
| With donor restrictions | 1,072,076 | 843,033 |
| Total net assets | 3,610,448 | 2,905,093 |
| TOTAL LIABILITIES AND NET ASSETS | \$4,347,464 | \$3,716,325 |

Consolidated Statement of Activities

YEAR ENDED JUNE 30, 2019

PUBLIC SUPPORT AND REVENUE:

| | Without Donor Restrictions | With Donor Restrictions | Total |
|--------------------------------------|----------------------------|-------------------------|-------------|
| Contributions | \$2,171,601 | \$533,022 | \$2,704,623 |
| Fundraising event income, net | 140,621 | — | 140,621 |
| Sponsorships | 129,798 | — | 129,798 |
| Research roundtable revenue | 75,569 | — | 75,569 |
| Investment income | 9,369 | 22,855 | 32,224 |
| Other revenue | 16,637 | — | 16,637 |
| Net assets released from restriction | 326,834 | (326,834) | 0 |

Total public support and revenue

2,870,429 **229,043** **3,099,472**

EXPENSES:

| | | | |
|---------------------------|-----------|---|-----------|
| Program services | 1,804,897 | — | 1,804,897 |
| Supporting services: | | | |
| Management and general | 395,203 | — | 395,203 |
| Fundraising | 194,017 | — | 194,017 |
| Total supporting services | 589,220 | 0 | 589,220 |
| Total expenses | 2,394,117 | 0 | 2,394,117 |

CHANGE IN NET ASSETS

476,312 **229,043** **705,355**

NET ASSETS - BEGINNING OF YEAR

2,062,060 **843,033** **2,905,093**

NET ASSETS - END OF YEAR

\$2,538,372 **\$1,072,076** **\$3,610,448**

YEAR ENDED JUNE 30, 2018

REVENUE AND SUPPORT:

| | Unrestricted | Temporarily Restricted | Permanently Restricted | Total |
|---|--------------|------------------------|------------------------|-------------|
| 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**

Venture Grants Funded in FY2019



Dissecting neuronal dysfunction under 3R:4R isoform imbalance

Dr. Maria-Elena Avale

Instituto de Investigaciones en Ingeniería Genética y Biología Molecular (Argentina)



Small-molecule modulation of tau clearance and aggregation

Dr. Gal Bitan

University of California, Los Angeles, CA (USA)



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

Dr. Edward A. Burton

University of Pittsburgh, PA (USA)



Bifunctional intrabodies to lower tau

Dr. David C. Butler

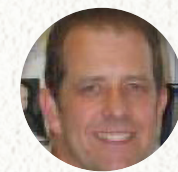
The Neural Stem Cell Institute, Rensselaer, NY (USA)



Uncovering unique tau profiles that distinguish PSP from other tauopathies

Dr. Todd J. Cohen

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



The Influence of TRIM11 on tau aggregation, release, and propagation

Dr. Jonathan Mark Cooper

University College London (UK)



Care where it counts: support to reduce isolation and ensure well-being for patients and caregivers

Dr. Jori Fleisher

Rush University, Chicago, IL (USA)



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

Dr. Jeffrey S. Friedman

Managing Director, PSP Genetics Consortium (USA)



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

Dr. Tsuneya Ikezu

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



Structural basis for tau strain conformation in CBD and PSP

Dr. Lukasz Joachimiak

UT Southwestern Medical Center, Dallas, TX (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)



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)



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)



Small molecule regulation of a protein quality control E3 to treat PSP

Dr. Kenneth Matthew Scaglione
Duke University, Durham, NC (USA)



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

Dr. John Steele
Humboldt State University, Arcata, 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)

URSO STUDENT GRANTS

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)

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)

Role of oligodendroglial and astrocytic tau pathology in a PSP model

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

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For the Period July 1, 2018, through June 30, 2019

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 FY2019

15k Bike Ride
 1st Annual CurePSP Event in Memory
 of Jane Weiner Schatz
 Annual Szczerba Memorial Golf Outing
 Bonelli Music Bash in Honor of John Bonelli
 Bowling for Pop Pop
 Chicago Half Marathon Runner
 Hope Squared Art Show and Auction

 Karaoke For A Cure
 Ken's Ride
 Magic the Gathering
 Marathon Runner
 Marilyn's Spring Stroll
 Mini Golf Classic
 Run For CBD
 Strikeout PSP
 Sue's Day Beach Walk
 Sundaes to Stop PSP
 Sykes and Cooper Corn Maze
 The CurePSP Awareness and Memorial Walk

Mike Freeman
 Audrey Locorondo and Ira Weiner

 Kelly Szczerba
 Lois Bonelli and Family
 Dawn Leach
 David Rosenbrock
 Ileen McFarland, Catrina Nieser,
 and the Dallas Support Group
 Joy Courtright
 Jan Appel
 Rick Stout
 Amanda Melillo
 Donna Etergineoso
 Light of Day Foundation
 Abby Sayre and Team Dosie
 Amanda McKendree
 Michael Studley
 Chicagoland Support Group
 Jaime Losco and Brittanie Sykes
 Marco Island Support Group

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