



CUREPSP®  
UNLOCKING THE SECRETS OF BRAIN DISEASE®

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Care,  
Consciousness  
and Cure

Annual Report

2020

-2022



# INTRODUCTION

## **Our Mission**

To raise awareness, build community, improve care and find a cure for PSP, CBD and MSA.

## **Our Vision**

A world free of neurodegenerative disease.

## **Our Three Pillars**

### Care

CurePSP is here for our community of people diagnosed with PSP, CBD and MSA and their families through a commitment to enhancing the delivery of care, building community and providing direct support.

### Consciousness

CurePSP empowers people diagnosed with PSP, CBD and MSA and their families with tools to understand their diagnosis and advocate for themselves. Additionally, raising awareness of PSP, CBD and MSA among healthcare professionals and the public is a top priority.

### Cure

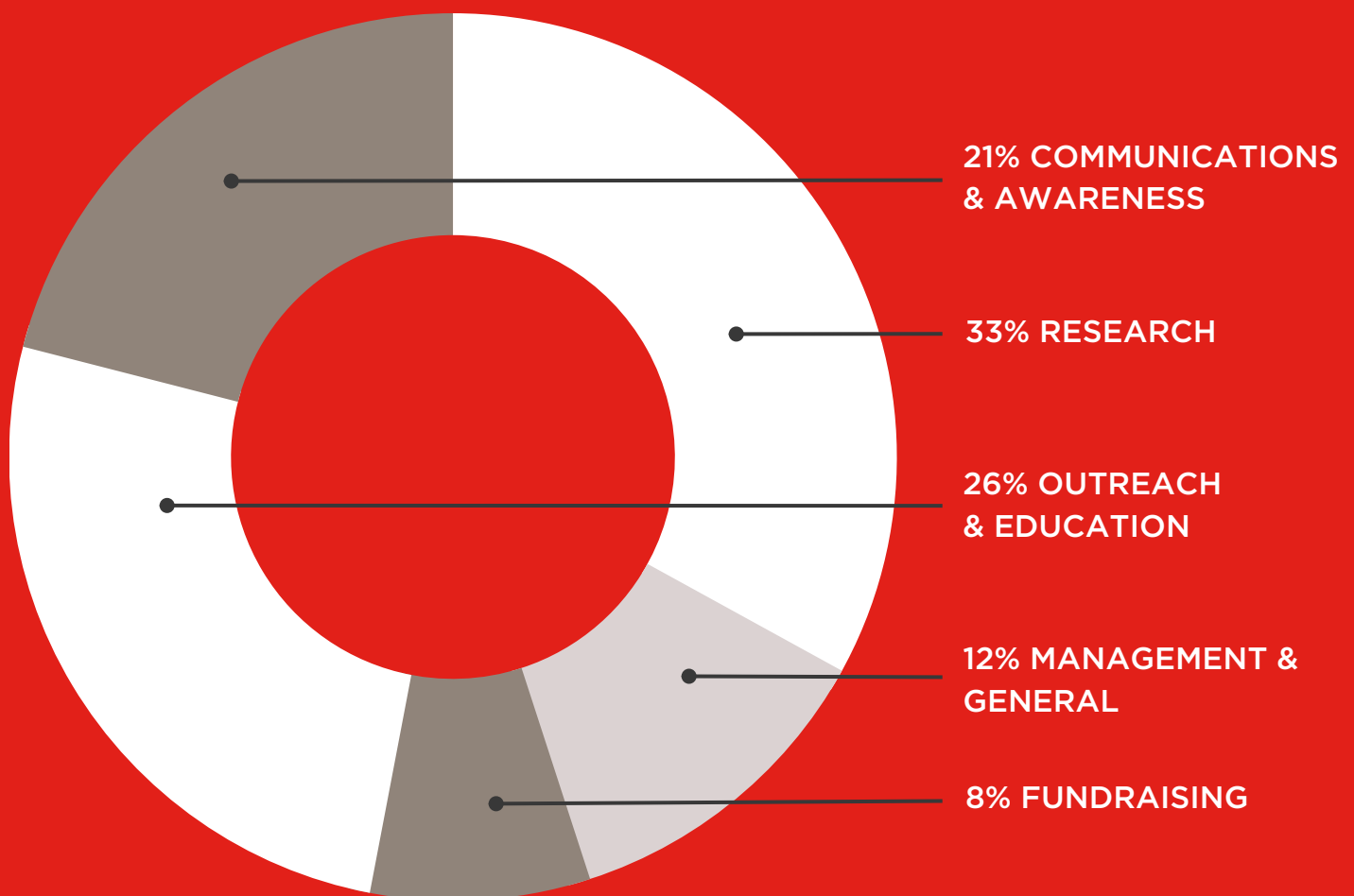
CurePSP is devoted to our goals to identify the causes of PSP, CBD and MSA; accelerate the development of diagnostic tests; and be a catalyst in treatments to prevent, slow, halt or even reverse disease progression.

# HOW YOUR GIFTS WERE USED

## 2020-2022

"We are closer to our goal of becoming more equitable across our three pillars of care, consciousness and cure."

- Kristophe Diaz, PhD  
Executive Director and Chief  
Science Officer



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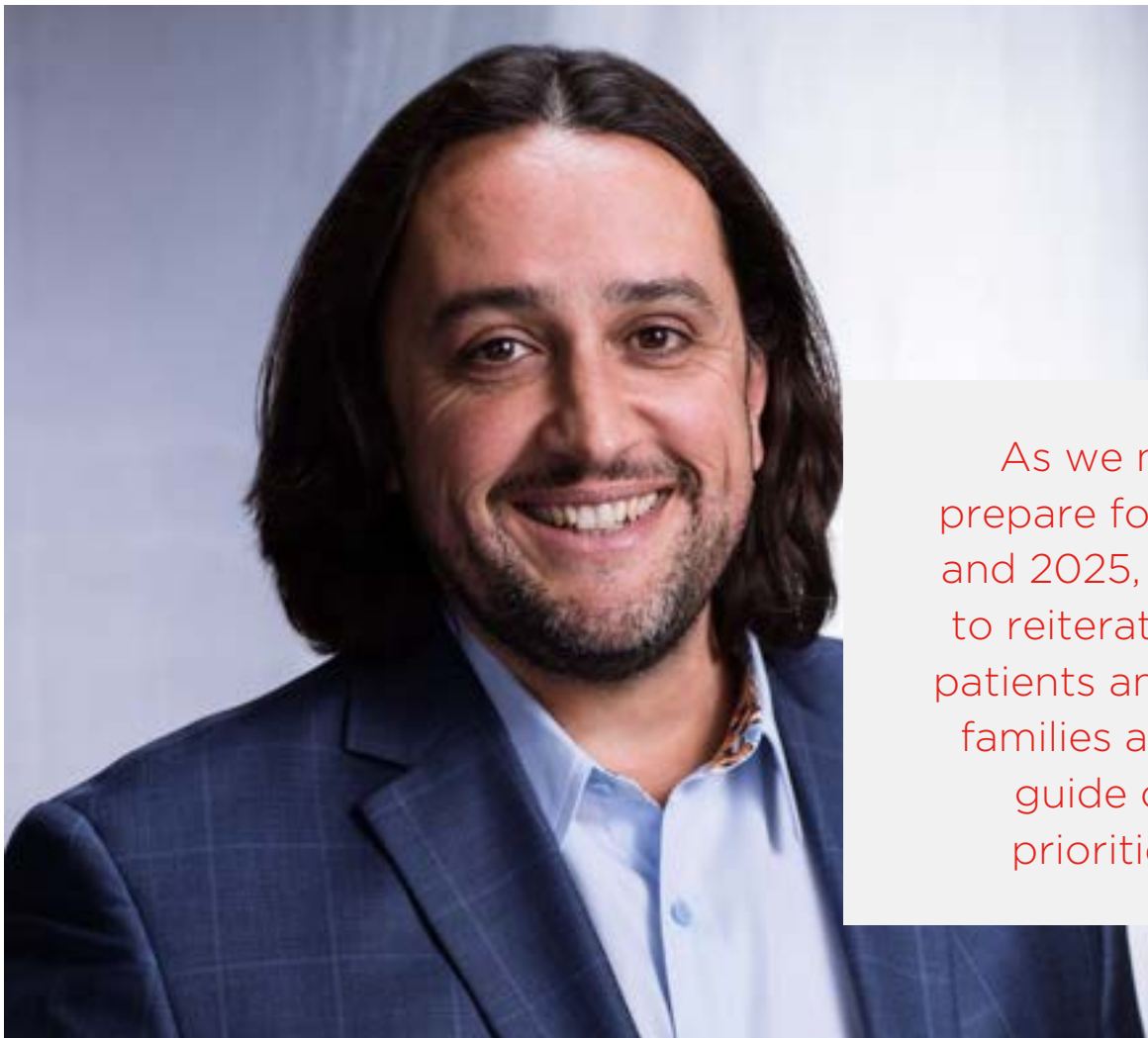
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# MESSAGE FROM THE EXECUTIVE DIRECTOR



As we now prepare for 2024 and 2025, I'd like to reiterate that patients and their families always guide our priorities.

It has been a privilege to be part of CurePSP and work alongside a dedicated team, supporting board members and many empowering volunteers across the country. I'm looking forward to making a difference in the coming years and putting actions toward this commitment: to be a catalyst for a cure.

I joined CurePSP in January 2020 and assumed its leadership in July 2021 in the middle of a world pandemic with many uncertainties and impossible questions. At CurePSP, we couldn't let this obstacle prevent us from advancing the programs and services core to our mission, especially when the families we support had to isolate even more.

These complicated times gave our team and Board of Directors no choice: we had to adapt, prioritize continuity of our services and, most importantly, innovate quickly. And we did just that with the help of our community of patients, caregivers, volunteers and healthcare professionals.

For example, we were able to maintain our support groups by fully transitioning to virtual meetings, allowing people to receive the benefit of these conversations in the comfort of their home. Also, we remained responsive to our community requests and added several regional and thematic support groups to our offerings.

As you review this annual report, I take note of the following key accomplishments:

- We updated our strategy and our guiding principles. The core message is that we are focusing on being a catalyst for a cure. This means we prioritize scientific advances that have a chance to progress to the clinic, and we build powerful partnerships with critical stakeholders. As an example, we've strengthened our collaboration and funding partnership with the Rainwater Charitable Foundation to work together on the development of biomarkers and new therapeutics for tau-based diseases (which include PSP and CBD, and could also have positive outcomes for CTE, Alzheimer's disease and other tauopathies).
- We refocused our research grants. Pipeline and Pathway grants are now our main science funding vehicles. They aim to continue supporting novel ideas and knowledge (there is still so much we don't know on the biology at the base of neurodegeneration) and support promising projects in the development of new treatments and new biomarkers.
- We reset and expanded our CurePSP Centers of Care program. We now have a network of 28 centers in the United States and two in Canada. All are driven to learn from each other and collaborate to tackle difficult but important unmet needs — for example to provide timely information when a family experiences new symptoms or a new challenge.
- We launched a new grant, called the CARES grant to further incentivize Centers of Care to work together on what will help patients and families NOW.
- Since July 2021, we added six full-time employees to our team. This growth is a critical step toward accelerating our mission. I promise you that the programs and partnerships we'll establish in the coming years will speak to the success of these additional resources.

As we now prepare to plan for 2024 and 2025, I'd like to reiterate that patients and their families always guide our priorities. And the priorities are clear: in the short term, families should have access to better care faster; in the long term, we need to make sure more clinical trials are available to our families and that industry invests more in solving neurodegeneration. These responsibilities drive my work and the work of CurePSP's team. We are proud of the work we do, and we are impatient to do more and to make a difference in the lives of those living with PSP, CBD and MSA.

Thank you,



Kristophe Diaz, PhD  
Executive Director & Chief Science Officer  
CurePSP

# CONSOLIDATED STATEMENTS OF FINANCIAL POSITION

(With comparative totals at June 30, 2021 and 2022)

<b>ASSETS</b>	<b><u>6/30/22</u></b>	<b><u>6/30/21</u></b>
Cash and cash equivalents	\$1,872,863	\$5,293,553
Investments	5,307,184	2,374,844
Pledges receivable	56,899	82,874
Prepaid expenses and other assets	144,499	130,293
Inventory	120,054	124,626
Security deposit	7,000	7,000
Fixed assets, net	3,650	4,401
Investments held for endowment	<u>351,053</u>	<u>397,078</u>
<b>Total assets</b>	<b><u>\$7,863,202</u></b>	<b><u>\$8,414,669</u></b>
<b>LIABILITIES AND NET ASSETS</b>		
<b>LIABILITIES:</b>		
Accounts payable and accrued expenses	\$205,592	\$150,591
Deferred revenue	223,513	223,513
Grants payable	<u>676,670</u>	<u>542,420</u>
<b>Total liabilities</b>	<b><u>1,105,775</u></b>	<b><u>916,524</u></b>
<b>NET ASSETS:</b>		
Without donor restrictions	5,663,353	6,394,463
With donor restrictions	<u>1,094,074</u>	<u>1,103,682</u>
<b>Total net assets</b>	<b><u>6,757,427</u></b>	<b><u>7,498,145</u></b>
<b>TOTAL LIABILITIES AND NET ASSETS</b>	<b><u>\$7,863,202</u></b>	<b><u>\$8,414,669</u></b>



# CONSOLIDATED STATEMENT OF ACTIVITIES

(With comparative totals at June 30, 2021 and 2022)

	Without Donor Restriction	With Donor Restriction	Total 6/30/22	Total 6/30/21
<b>PUBLIC SUPPORT AND REVENUE:</b>				
Contributions	\$3,114,745	\$83,367	\$3,198,112	\$5,934,036
Fundraising event income	364,956	22,477	387,433	222,837
Investment return	(838,772)	(43,025)	(881,797)	97,994
Government grant Paycheck Protection Program	0		0	134,035
Other revenue	3,984		3,984	23,693
Net assets released from restriction	72,427	(72,427)	0	0
<b>Total public support and revenue</b>	<u>2,717,340</u>	<u>(9,608)</u>	<u>2,707,732</u>	<u>6,412,595</u>
<b>EXPENSES:</b>				
Program services	2,766,372		2,766,372	2,793,292
Supporting services:				
Management and general	427,735		427,735	406,825
Fundraising	254,343		254,343	288,246
Total supporting services	<u>682,078</u>	<u>0</u>	<u>682,078</u>	<u>695,071</u>
<b>Total expenses</b>	<u>3,448,450</u>	<u>0</u>	<u>3,448,450</u>	<u>3,488,363</u>
<b>CHANGE IN NET ASSETS</b>	(731,110)	(9,608)	(740,718)	2,924,232
<b>NET ASSETS BEGINNING OF YEAR</b>	<u>6,394,463</u>	<u>1,103,682</u>	<u>7,498,145</u>	<u>4,573,913</u>
<b>NET ASSETS END OF YEAR</b>	<u>\$5,663,353</u>	<u>\$1,094,074</u>	<u>\$6,757,427</u>	<u>\$7,498,145</u>

# CUREPSP<sup>®</sup> CENTER OF CARE



# IMPACT REPORT



2,000 mailed educational resource packets to people in all 50 U.S. states and 10 other countries



Over 1,000 hours with community members answering questions about PSP, CBD and MSA and offering support and connection to resources



310 brain donations through the CurePSP Brain Donation Assistance Program

# 100%

of donations go toward our mission to raise awareness, build community, improve care and find a cure for PSP, CBD and MSA. Your gift not only brings progress, it brings hope.



Over 6,000 event registrations globally



Over 5,000 hours of professional in-home respite care



Over 1,800 registrants for the CurePSP online support groups



Peer supporters and regional support groups across 31 U.S. states and 3 other countries



Provided respite services to over 86 families through the Quality of Life Respite Grant Program



Joined the Unified Parkinson's Advocacy Council



Launched Collaborative Approaches to Resources, Education and Support (CARES) grant program, funding \$81,000 of research focused on patient-centered care delivery, outreach to underserved communities, improvement in access to care and education of the medical community.

# 29,000

Total Number of Gifts

## 67

IN-PERSON AND VIRTUAL EVENTS

## 38

REGIONAL SUPPORT GROUPS

## 25

EDUCATIONAL WEBINARS

## 16

ONLINE SUPPORT GROUPS

## 7

EDUCATIONAL AND SCIENTIFIC CONFERENCES

## 66

PEER SUPPORTERS

## 24

VOLUNTEER FUNDRAISERS

## 30

CENTERS OF CARE



20K+ Likes  
30,502 Page Visits  
900+ Posts



10K+ Likes  
10,954 Page Visits  
350+ Posts



2K+ Likes  
6,000 Page Visits  
150+ Posts

# MOMENTUM AND UPDATES IN RESEARCH

Thanks to the generosity of families living with or caring for someone with PSP, CBD or MSA, we've been able to invest more than \$20 million in scientific research.

We have helped establish a strong knowledge base and a productive network of scientists and medical professionals. Looking to the future, we are establishing new programs, strategies and partnerships to be a catalyst for a cure. The next page showcases the last 12 programs we funded, representing \$1.2 million gifts from more than 4,000 donors who decided to support research.

01

## Supporting Early-Career Scientists

We're supporting early-career scientists dedicated to understanding the underlying mechanisms relevant to neurodegeneration and elucidating what we still don't know.

02

## Supporting Established Researchers

We're supporting the established researchers and teams who are discovering or validating biomarkers and therapeutic targets for PSP and CBD.

03

## Powerful Partnerships

We're building powerful partnerships so that the scientific questions common to all neurodegenerative disease can be addressed.

# 26

Grants Funded From  
2020 to 2022

# 2000+

Grants Funded in  
20 States and  
10 Countries

# 185

Lifetime Completed  
Grants

# 35

Active Projects

# \$20,000,000

COMPLETED  
RESEARCH  
FUNDING FROM 1997  
TO PRESENT.



26 YEARS OF RESEARCH DEDICATED TO UNDERSTANDING PSP AND CBD



**Dr. Johannes Levin, LMU Hospital,  
Munich, Germany**

In Vivo Assessment of Reactive  
Astrogliosis in PSP



**Dr. Rachel Baily, UT Southwestern  
Medical Center, Dallas, TX**

Gene Replacement Therapy for  
Tauopathies



**Dr. Naomi Visanji, University of  
Toronto, Toronto, Canada**

Prioritizing the in Vivo Modeling of  
Progressive Supranuclear Palsy



**Dr. Sarah Hopp, The University of Texas  
Health Science Center, San Antonio, TX**

Harnessing Microglia to Internalize and  
Degrade Tau



**Dr. Shu Chen, University of Alabama,  
Birmingham, AL**

Development of RT-QuIC Assays of  
Skin Biopsy for Early Diagnosis of  
PSP



**Dr. Mikael Simons, German Center for  
Neurodegenerative Diseases (DZNE),  
Munich, Germany**

Evaluation of Fluid-Based and Imaging  
Biomarkers for Interventional Trials in  
PSP



**Dr. Hong Xu, University of Pennsylvania, Philadelphia, PA**

Understanding the Diversity of Tau Pathogenesis in PSP



**Dr. Franziska Hopfner, Hannover Medical School, Hannover, Germany**

MicroRNA Profile of Isolated Brain Cell Populations in PSP



**Dr. Marta Olah, Columbia University, New York, NY**

Identification of Microglia Phenotypes Associated with Tau Pathology in PSP and CBD



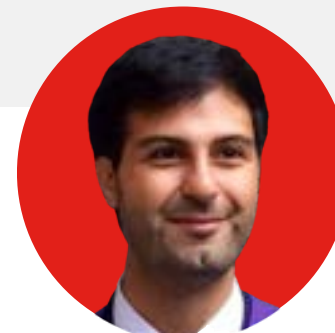
**Dr. Maria Catarina Lima da Silva, Massachusetts General Hospital, Harvard Medical School, Boston, MA**

Investigation of ULK1-Based Autophagy Activators as Therapeutics for Tauopathies



**Dr. Rueben Das, University of Pennsylvania, Philadelphia, PA**

Connecting GWAS Signal in Tau Locus to Effector Variant in Tauopathies



**Dr. Edwin Jabbari, University College London Queen Square Institute of Neurology, London, UK**

Fluid Markers of LRRK2 as a Determinant of PSP Risk and Disease Progression



#becausehopematters >>>



2020





2022

# DONOR LISTING

CurePSP extends its sincere appreciation to our supporters for their unwavering commitment to our mission of raising awareness, building community, improving care and finding a cure for PSP, CBD and MSA. Their dedication and contributions have been instrumental in driving our efforts forward, and we are deeply grateful for their support. We look forward to continuing to work together toward our common goal.

## **\$100K and Above**

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Benevity  
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Light of Day Foundation, Inc.  
Peebler PSP Research Foundation, Inc.  
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Members of the Board of Directors of CurePSP accept the major responsibility of implementing the mission of the foundation. Board members are actively involved in continually defining and redefining the mission and participating in strategic planning to review purposes, programs, priorities, funding needs and levels of achievement.

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We're grateful to have some of the most innovative and committed team members pushing our mission and organization forward.

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Joined 2015  
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# MEET OUR TEAM

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Library of educational resources available for download or order, including Some Answers booklets, fact sheets and medical wallet cards



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## **SUPPORT GROUPS**

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## **EDUCATIONAL EVENTS**

Regularly scheduled webinars and family conferences (archived content is available on our YouTube channel)



## **RESEARCH AND CLINICAL TRIALS**

Tracking, supporting and sharing updates on current research on PSP, CBD and MSA



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