

## About CurePSP

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CurePSP is a nonprofit advocacy and research organization fighting “prime-of-life” neurodegenerative disorders with a strong focus on progressive supranuclear palsy and corticobasal degeneration. The “prime-of-life” disorders, so called because they typically strike during a person’s most productive and rewarding years, are presently incurable and together have been diagnosed in nearly 50,000 people living in the U.S.

Since 1990, CurePSP has funded more than 190 research studies and is the leading source of information and support for patients and their families, caregivers, researchers, physicians and allied healthcare professionals in this disease area. CurePSP has a motivated team of professionals dedicated to improving awareness, educating and supporting patients and families and funding research to end the challenge of these neurodegeneration disorders.

CurePSP is a New York City based foundation that currently employs eight. Our mission-specific budget of \$1.9 million and revenues of \$2.9 million strategically position us to focus on our core missions. Please visit [www.curepsp.org](http://www.curepsp.org) for additional information.

### **CurePSP has three mission areas:**

- Patient and family support and advocacy
- Education and awareness of laypersons and clinicians
- Research funding and dissemination of scientific knowledge among scientists

## Research at CurePSP

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CurePSP seeks to accelerate meaningful therapeutic advances toward prevention or cure for disorders like PSP and CBD. Since inception of its research program in 1997, CurePSP has become one of the largest global funders of PSP and CBD research in the world. An aspirational goal is for the scientific insights that we bring to these protein aggregation disorders to impact other major neurodegenerative disorders beyond our core mission, including Alzheimer’s and Parkinson’s diseases.

### **CurePSP supports research primarily through three programs:**

- **Venture Grants** – up to \$100,000, with a preference for studies submitted by early career investigators; that evaluate new ideas; and that may lead to funding from larger agencies such as the NIH. Applications from the private sector are also considered
- **The Prime of Life Brain Initiative** – research jointly funded with the Rainwater Charitable Foundation and implemented by members of its Tau Consortium
- **Urso Student grants** – \$3,000 to fund summer student projects under the mentorship of established faculty investigators

### Other research-related activities of CurePSP include:

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- Facilitating pharmaceutical companies' clinical trials through subject recruitment, retention, and marketing
- Reimbursing families' expenses related to brain donation to the Mayo Clinic Brain Bank in Jacksonville, Florida
- Organizing and sponsoring an annual international scientific symposium, where our grantees, invited speakers and free poster submitters present the latest advances
- Co-leading, with the Rainwater Charitable Foundation, the PSP Research Roundtable. The RRT is a group meeting once or twice a year, comprising representatives from academia, pharma, nonprofits, government regulators and payors. It attempts, in a precompetitive environment, to facilitate the development and approval of treatments for PSP

### The Opportunity

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This key role presents the opportunity to work alongside those diagnosed, families and their carepartners affected by the spectrum of incurable and mostly untreatable prime of life brain diseases supported by a team of dedicated professionals fighting the great healthcare challenge of the 21st century.

### Objectives

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- Develop innovative and effective programs to ease the burden of those diagnosed, families, and caregivers struck by incurable neurodegenerative diseases
- Expand and support the CurePSP volunteer network of support group leaders and peer group supporters through presentations and training
- Assist in program improvement through coordination with the Patient & Carepartner Advocacy Committee & Chair
- Educate patients and families and healthcare professionals through speaking engagements and participation at conferences, health fairs, and support group meetings
- Through the Vice President –Events, coordinate programming for family conferences, professional education days, carepartner retreats, and related events

### Responsibilities

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- Develop partnerships with key players in academia, biotech, pharma, government, foundations and the philanthropic community to accelerate research and therapeutic developments
- Coordinate closely with CurePSP VP of Scientific Affairs, shaping qualifications and programs for the Centers of Care
- Collaborate with families, CurePSP VP of Scientific Affairs, Community Outreach and Resource Manager, Chair, PCA Committee, and the Mayo Clinic Brain Bank Coordinator for Brain donations, verifying and keeping a current list of Pathologists and Protocols to assist families with requests for donations, as well as end-of-life support

- Serve on the Cherie Levien Quality of Life Fund grant committee with CurePSP VP of Scientific Affairs, Community Outreach and Resource Manager, and Chair PCA Committee to:
  - Promote the grant program and select grantee applications for quarterly awards
  - Coordinate grant “next steps” with families and homecare agencies
  - Monitor and track usage of grant awards per family
  - Monitor and acquire feedback from grantees for committee use
- Work as part of a fundraising team to cultivate and solicit prospective donors
- Manage departmental expenses per an approved budget with assistance from the CurePSP Office Manager

### **Key Skills and Expertise**

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- Strategic planner and effective leader who takes the initiative to design and implement effective solutions
- Self-Starter and team member who readily offers ideas
- Innovative, Creative, and Organized with a focus on careful planning
- Interpersonal Skills that facilitate a positive experience for those who interact and interface with CurePSP
- Outstanding written and oral communication skills, including public speaking
- Competency with software and other CurePSP utilized productivity tools

### **Required Qualifications**

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- Master’s or PhD degree in Social Work or related field, including Human Services, Community Health, or Counseling
- Minimum of 5 years of experience working closely with those diagnosed and their families affected by chronic illness or disability, in a healthcare setting or related non-profit foundation
- Familiarity with neurodegenerative diseases program development designed to maintain and improve the quality of life for those diagnosed
- Outstanding written and oral communication skills, inclusive of grant writing and appeals
- 25% Travel Required

### **Supervision**

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Reports to President of CurePSP

## Contact

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Kiwi Partners has been retained for this search on behalf of CurePSP. Interested candidates should send their CV or resume, and a cover letter to:

Diana Gallardo, VP of HR Services

Kiwi Partners

237 West 35th Street

New York, NY 10001

212-532-7171 ext. 169

*dgallardo@kiwipartners.com*

CurePSP, Inc. is an equal opportunity employer. We respect and seek to empower each individual and support the diverse cultures, perspectives, skills and experiences within our workforce.

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