

Associate Director of Clinical Affairs and Advocacy

About us:

Founded in 1990, CurePSP is the leading non-profit organization dedicated to the awareness, care, and cure of 3 neurodegenerative diseases: progressive supranuclear palsy (PSP), corticobasal degeneration (CBD) and multiple system atrophy (MSA). As a catalyst for new treatments and a cure, we establish important partnerships and fund critical research. Through our advocacy and support efforts, we enhance education, care delivery, and quality of life for people living with PSP, CBD, and MSA and their families. Science, community and hope are at the heart of CurePSP's mission and all of our services. CurePSP is a registered 501(c)(3) charity within the United States (Federal Employer ID Number: 52-1704978).

Our mission is to raise awareness, build community, improve care and find a cure for PSP, CBD and MSA. We accomplish this through our three pillars: Care, Consciousness and Cure.

About the role:

CurePSP seeks an Associate Director of Clinical Affairs and Advocacy to work as part of the Patient & Care Partner Advocacy Team, reporting to the Director of Clinical Affairs and Advocacy. This team primarily focuses on CurePSP's care and consciousness pillars and oversees programs and strategies that include direct interaction and support of people affected by PSP, CBD and MSA, a network of 33 Centers of Care across the U.S. and Canada, the Quality of Life Respite Grant, printed and digital collections of informational resources, online and regional support groups, family conferences, bereavement support, educational programs for community members and healthcare professionals, engagement with volunteers, brain donation assistance and raising awareness among the general community, healthcare providers and policy makers. The goals of these initiatives are to lead to earlier diagnosis, assessment and addressing of unmet needs, better outreach and support for historically underrepresented communities, and improved access to high quality and patient-centered clinical care and resources for people with PSP, CBD and MSA. This key role presents the opportunity to work alongside, and on behalf of, diagnosed individuals, family care partners, medical professionals and other stakeholders to achieve these efforts. The Patient & Care Partner Advocacy Team closely partners with the Marketing Team, Events Team, Executive Director, foundational/volunteer committees and other organizations to carry out responsibilities and priorities.

Primary Functions:

- Management of CurePSP's educational efforts including:
 - New and updated printed resources and website content designed to offer tools for education and self-advocacy for patients, families and healthcare professionals
 - In-person and virtual programs and events, including family conferences and webinars
- Direct interaction with community members through phone calls and emails, offering support, education and connection to resources
- Growth of programs and campaigns aimed at outreach and awareness across the medical community, underserved populations and the general community
- Involvement with other initiatives if needed and of interest, including patient engagement for clinical research, support groups, volunteer support, legislative advocacy and CurePSP Centers of Care

Required Skills:

- Experience working closely with those diagnosed and their families affected by neurological diagnoses (preferred), chronic illness, disability or at end of life, either in a healthcare setting or related non-profit foundation.
- Experience and proficiency in the development and coordination of educational programs and resources.
- Strong interpersonal, clinical and rapport-building skills needed for direct and empathetic communication with patients and families.
- An ability to network and establish relationships with stakeholders and community leaders.
- Outstanding written and oral communication and interpersonal skills, including public speaking.
- The strategic and creative planning and leadership skills necessary to take the initiative to design and implement effective solutions.
- Highly organized and excellent at planning and follow-through on tasks.
- Ability to work within a collaborative team environment as well as the organizational skills and drive to operate independently.
- Competency with software and other productivity tools that are part of the CurePSP toolkit, such as Microsoft Office products, Slack and social media platforms.

Education and Experience:

- Master of Social Work, Public Health or related field
- Minimum of 3 years of post-graduate, relevant work experience

Location and Travel:

- 100% remote role with a preference for candidates on the east coast of the U.S.
- Travel approximately 15% of the year for in-person meetings, networking opportunities and community events

Salary and Benefits:

- This position offers a salary range of \$70,000-85,000, commensurate with experience.
- CurePSP offers a comprehensive benefits package that includes retirement, medical, dental and vision.

How to apply:

Please send resume/CV and cover letter to: Jessica Shurer, MSW, LCSW, Director of Clinical Affairs and Advocacy, at shurer@curepsp.org

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.

