



## Associate Director of Public Policy and Advocacy

### About us:

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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:

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CurePSP seeks an Associate Director of Public Policy 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 manages CurePSP's initiatives that include: direct interaction with people affected by PSP, CBD and MSA, a network of prestigious medical centers, educational resources and events for both community members and healthcare professionals, the Quality of Life Respite Grant, support groups and peer supporters, engagement with volunteers, brain donation assistance and raising awareness. The goals of these initiatives are to lead to earlier diagnosis, assessment and addressing of unmet needs, outreach and support for historically underrepresented communities, improved access to comprehensive clinical care and support for people with PSP, CBD and MSA and increased coordination, funding and research around these diseases.

CurePSP has expanded its advocacy arm in recent years and is now looking to add a full-time team member to guide and lead its public policy agenda and community engagement. This key role presents the opportunity to work alongside, and on behalf of, diagnosed individuals, family care partners, medical professionals, policymakers, organizational partners and other stakeholders to achieve the above-described efforts.

The Patient & Care Partner Advocacy Team closely partners with the Marketing Team, Development-Events Team, Scientific Affairs Team, Chief Executive Officer, volunteer committees and Board of Directors to carry out responsibilities and priorities.

### Primary Functions

- Development and execution of:
  - A public policy and legislative advocacy agenda that centers the voices of people with PSP, CBD and MSA and aligns with the mission and strategic priorities of CurePSP.
  - Roadmap of federal-level advocacy opportunities through mobilization of community members and relationship-building with key policymakers and federal agencies.
  - Regular engagement with the Advocacy Steering Committee to pressure-test policy priorities, amplify their input in the policymaking process and maintain their connection to CurePSP's advocacy priorities and programs.
- Monitor and evaluate legislative and regulatory developments, assess potential impacts and provide insights to guide policy priorities and strategies.

- Maintain close working relationship and regular communication with CurePSP's DC-based lobbying and advocacy consultant firm.
- Create informational content and advocacy toolkits for CurePSP's website, email and social media as well as resources, public-facing statements, presentations, events and programs.
- Recruit, train and track CurePSP community advocates (volunteers) to carry out advocacy agenda.
- Organize meetings between community members/advocates and Congressional offices around key legislation, appropriations requests and policy issues.
- Articulate and advance the Foundation's policy positions to diverse stakeholders; represent the organization at forums, meetings and conferences; and develop reports, briefs, testimony and other policy communications to support advocacy and public policy goals.
- Represent the organization in coalitions to align PSP, CBD and MSA priorities with broader patient access efforts.
- Other advocacy-related initiatives as needed.

#### **Required Skills:**

- Proficiency in legislative advocacy, public policy, government relations/affairs and grassroots organizing, ideally related to neurological diagnoses, chronic illness, disability and/or end of life.
- Strong networking and rapport-building skills needed for direct, empathetic and strategic communication with people diagnosed, families, medical professionals, non-profit organizations, community leaders and policymakers.
- Outstanding written and oral communication and interpersonal skills.
- The strategic and creative planning and leadership skills necessary to take the initiative to design and implement effective solutions, and the ability to measure impact.
- 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, Muster, Survey Monkey, Zoom and social media platforms.

#### **Education and Experience:**

- Bachelor's degree in Social Work, Public Health, Public Policy or related field; Master's preferred
- 3-5 years experience in healthcare policy, advocacy or government relations

#### **Location and Travel:**

- 100% remote role
- Preference for candidates in the Washington DC area or who are easily able to travel to Washington DC multiple times per year
- Travel approximately 15% of the year for team meetings, Congressional Hill and federal agency meetings, networking opportunities and community events

#### **Salary and Benefits:**

- This position offers a salary range of \$75,000-90,000, commensurate with experience
- CurePSP offers a comprehensive benefits package that includes retirement, medical, dental and vision

#### **How to apply:**

Please send resume and cover letter to: Jessica Shurer, MSW, LCSW, Director of Clinical Affairs and Advocacy, at [shurer@curepsp.org](mailto: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.*