

Position description – Program Manager/ Family Services Specialist, CJD Foundation

The CJD Foundation seeks a **Program Manager/Family Services Specialist** to work with patient families and other constituents who contact the Foundation's Helpline. This individual would respond to questions, provide referrals and resources, introduce families to the Foundation's programs and would:

Support patient families by:

- Providing short-term crisis intervention services including help in understanding and finding palliative care and hospice care
- Providing information about resources and how to access them, such as state respite care policy and SSDI benefits
- Referring to Genetic Counselors when appropriate and helping families and professionals to:
 - Understand process of genetic testing
 - Find options for blood draw for genetic testing if needed

Follow-up regularly with families and professionals who contact the HelpLine.

- Touch base with families during caregiving process and following patient's passing.
- Work with professionals to develop opportunities for medical education.

Host support groups including current caregivers group, regional support groups, and bereavement groups.

Develop resources for families, including:

- Identify sources of referrals (e.g., where to find a list of nursing homes or hospice providers in your state or how to apply for respite care)
- Build list of providers in various areas and families to serve as references (when someone on Helpline recommends the hospice program or neurologist they used)
- Build bank of peer advisors in various scenarios (for different forms of the disease)

Contribute to related web content and written materials for families

Assist with annual family conference, family workshops, and other programs

Preferred background

- Social work or related degree or training
- Experience with non-profit helpline or patient family support programs
- Professional or personal experience with dementia caregiving, geriatrics, and related areas
- Experience with programs in caregiving as well as bereavement and ambiguous loss

Position details: Work remotely day-to-day, some travel expected (when in-person programs resume), flexible hours (emphasis on afternoon and early evening), full-time or near-full-time. Proof of vaccination required. Candidates able to work in Mountain or Pacific Time Zone preferred.

Salary and Benefits: Salary \$50,000 and up, depending on qualifications and regional cost of living rates. Health benefits not included. Long-term disability insurance and employee assistance program are provided. Paid time off and paid holidays are provided.

Apply to: HumanResources@CJDFoundation.org

Please note that only those individuals whose qualifications match the current needs of the organization will be considered and will receive responses.

About the CJD Foundation: The CJD Foundation supports families affected by Creutzfeldt-Jakob Disease and other Prion Diseases, a set of neurodegenerative conditions with symptoms that may include dementia, cognitive impairment, and motor impairment. CJD is rapidly progressive and currently has no treatment. The CJD Foundation offers a 7-day Helpline, medical education, advocacy, conferences and support groups, and a research grant program. The Foundation has offices in Akron, Ohio and a team of resources and volunteers across the country.