



Employment Opportunity

NNPDF Family Services Manager

The National Niemann-Pick Disease Foundation, Inc. (NNPDF) is a leading non-profit patient advocacy and family support organization dedicated to empowering individuals and families affected by all types of Niemann-Pick disease. Since 1993, NNPDF has served as a trusted resource for education, collaboration, and research, fostering a strong community of hope and resilience. Our mission is grounded in transparency, ethical governance, and respect for diversity, ensuring that every patient and family receives compassionate support throughout their Niemann-Pick journey. Please see the full job description below for more details on this exciting role.

About the Position:

NNPDF is seeking a compassionate, organized, and mission-driven professional to serve as Family Services Manager and lead our family services programs. This role will support patients and families, expand engagement efforts, and strengthen NNPDF's communications and advocacy presence. The successful candidate will work closely with the Executive Director and collaborate across departments to ensure the patient's voice is amplified and meaningfully represented in all organizational initiatives.

NNPDF operates as a virtual office, and the Family Services Manager is a US-based full-time, fully remote position, with some travel required approximately four-to-six times per year depending on the need in the NNPDF community.

Key Responsibilities:

Case Management & Family Support:

- Serve as the primary contact for families, providing education on the Niemann-Pick disease journey and connecting them with resources for treatment, disease management, and ongoing support.
- Assess patient needs to assist the family in determining personalized goals.
- Regularly update the patient and family database (CRM).
- Refer patients and families to medical specialists, community, foundation resources, clinical trials, and FDA approved treatments, as appropriate.
- Establish regular follow-up contact with patients and their families to ensure continuous support and connection with the foundation, as needed.

Program Management

- Gather and record patient and caregiver input through direct communications, surveys, and other forums, gaining knowledge to meet the needs of the NNPDF community.
- Collaborate with Foundation staff to inform the community of new information and changes in the Niemann-Pick Disease and rare disease communities that may impact patients and their families.
- Manager and continue to develop family service programs to ensure they effectively support the evolving needs of the NNPDF community.
- Continue outreach efforts to engage new families and grow the NNPDF community.
- Collaborate with staff to develop and implement comprehensive communication and outreach strategies to support family services.
- Serve as staff to the Family Services committee and be prepared to provide updates on programs, gather knowledge, and community needs.
- Connect as needed with the NNPDF pharmaceutical liaison committee and other patient advocacy groups.
- Assist with the creation, implementation, and distribution of family outreach tools and other informational resources.

Organizational & Event Support:

- Collaborate with the Executive Director, staff, and board of directors (through the Family Services Committee) on special initiatives and community engagement.
- Contribute to planning NNPDF events, including annual conferences, regional family events, and other special events throughout the year.
- Facilitate and/or participate in meetings, training, webinars, and cross-functional opportunities.
- Perform other duties as assigned.

Qualifications:

Education & Experience:

- Bachelor's or master's degree in genetic counseling, social work, nursing or related field with work experience in healthcare case management preferred.
- A minimum of 2 years' professional level experience working with individuals and/or families in health care case management is required. Five years preferred. Rare disease experience a plus.

Skills & Competencies:

- Excellent communication, conflict resolution, and interpersonal skills
- The ability to empathize with families, understand their needs, provide clear and accurate education, answer questions, and communicate within ethical and legal boundaries without offering advice. Strong organizational and time management skills to balance new patient visits and required follow-up contacts with previous patients.
- Must be able to take complex scientific concepts and break them down into simple, easy-to-understand ideas.
- Effective at managing complex individual case needs.
- Proficient in Microsoft programs and comfortable using remote work technologies, including scheduling across time zones and conducting virtual meetings.
- Flexibility for occasional evening and weekend commitments.
- Based in the U.S. with the ability to travel as required.
- Bilingual (Spanish) skills preferred.

Compensation & Benefits:

- Competitive salary commensurate with experience.
- Medical Expense Reimbursement Program
- Paid time off, including holidays, personal, vacation, and sick leave.
- Professional development opportunities.
- Flexible work environment supportive of work life balance.

To Apply:

Please email your resume, cover letter, 3 professional references, and a writing sample to connect@nnpdf.org by March 10, 2026.

Equal Opportunity Statement

NNPDF is an equal opportunity employer. We celebrate diversity and are committed to creating an inclusive environment for all employees. All qualified applicants will receive consideration without regard to race, color, religion, gender, gender identity or expression, sexual orientation, national origin, disability, age, or veteran status.

Disclaimer

This job description is not intended to cover every activity, duty, or responsibility required of the employee. Duties may change or be assigned at any time with or without notice to meet the evolving needs of the organization.