



June 2025

NNPDF Family Services Manager

The [National Niemann-Pick Disease Foundation, Inc.](#) (NNPDF) is a non-profit organization dedicated to supporting and empowering patients and families affected by Niemann-Pick disease through community education, collaboration, and research. Niemann-Pick diseases are a group of lysosomal storage disorders that affect metabolism and are caused by genetic mutations. The most commonly recognized forms of Niemann-Pick Disease are ASMD (Acid Sphingomyelinase Deficiency types A and B) and Niemann-Pick type C (NPC). These diseases have a severe impact on quality of life and life expectancy, especially for children. Our vision is a world where Niemann-Pick Disease is no longer a threat to a full and productive life for patients and their families.

Founded in 1993, the NNPDF serves patients and families at all stages of their Niemann-Pick journey. The NNPDF has grown mightily in the past 30 years and currently has over 450 Niemann-Pick families as members. The NNPDF is the largest Niemann-Pick Disease family support organization in the world and is the US member organization of the International Niemann-Pick Disease Alliance (INPDA).

Through incredible perseverance and steadfast collaboration among patients and families, pharmaceutical partners, researchers, clinicians, and regulatory authorities, the NNPDF is in the extraordinary position of having multiple therapies newly approved by the FDA, as well as several more in development and clinical trial.

The NNPDF is seeking an experienced and compassionate Family Services Manager to serve and guide families through the Niemann-Pick journey. This is a unique opportunity to make a meaningful difference for individuals and families affected by Niemann-Pick disease.

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 voice is amplified and meaningfully represented in all organizational initiatives.

NNPDF operates as a virtual office, and the Family Services Manager is a full-time, fully remote position, with some travel required approximately 4 - 6 times per year.

Responsibilities include (but are not limited to):

Family & Patient Support:

- Serve as the main point of contact for families facing the Niemann-Pick Journey: to inform them about disease journey, including offering resources related to education about the disease, its management, available treatments, support, and guidance.
- Connect families to each other in the Niemann-Pick Disease community as appropriate.
- Assess patient needs, challenges, strengths, and support networks to assist the family in determining personalized goals.
- Refer patients and families to medical specialists, community and foundation resources, clinical trials and FDA approved treatments, as appropriate.
- Stay up to date on new information and changes in the Niemann-Pick Disease and rare disease communities that may impact patients and their families.
- Establish regular follow-up contact with patients and their families to ensure continuous support and connection with the foundation.
- Oversee and enhance 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.
- Develop and implement comprehensive communication and outreach strategies to support family services.
- Gather patient and caregiver input through direct communications, surveys, and other forums, gaining knowledge to meet the needs of the NNPDF community.
- Act as a liaison between the patient community and pharmaceutical industry partners.
- Assist with family outreach tools and other informational resources.
- Promote and support engagement within the NNPDF community.
- Work collaboratively with the NNPDF team and board of directors to support the foundation's mission.

Organizational Support:

- Collaborate with the Executive Director, staff, and board of directors on special initiatives and community engagement.
- Contribute to planning of NNPDF events, including annual conference and family gathering events throughout the year.
- Participate in meetings, training, webinars, and cross-functional opportunities.
- Perform other duties as assigned.

Qualifications:

- Bachelor's or master's degree in genetic counseling, social work, nursing or related field with work experience in health care case management preferred.
- Minimum 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.
- Strong communication, listening, and writing skills to understand the needs of families, 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.
- High level of self-awareness, empathy, and sensitivity to others.
- Ability to provide compassionate support during emotionally challenging situations, including grief and loss, and provide bereavement support when appropriate.
- Embody the Foundation's values and mission.
- Proficient in Microsoft programs and comfortable using remote work technologies, including scheduling across time zones and conducting virtual meetings.
- Strong interpersonal skills with the ability to collaborate effectively with remote teams and across diverse communication platforms.
- 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:

NNPDF is committed to offering a competitive salary and benefits.

Please email your resume, cover letter, and 3 professional references to connect@nnpdf.org.

The National Niemann-Pick Disease Foundation is an equal opportunity employer.