



Employment Opportunity NNPDF Executive Director

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. Niemann-Pick diseases include ASMD (Acid Sphingomyelinase Deficiency types A, A/B, 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 500 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).

In 2026, 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 passionate leader to serve as its next Executive Director and guide the community through this new post-approval landscape of commercially available treatments. This is a unique opportunity to lead a small, capable, and dedicated team that is making 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:

The Executive Director (ED) provides strategic vision and planning, financial oversight and fundraising, and management of day-to-day operations. The ED engages deeply with the community, and champions the needs of patients and families in a wide variety of settings, including family services programming, treatment development, federal regulation and legislation, and drug access. The ED is responsible for developing and maintaining strong relationships with strategic and global partners, including pharmaceutical companies, advocacy organizations, research organizations and foundations focused on Niemann-Pick disease.

The NNPDF has a virtual office, and the ED is a remote position, with travel as required (~1x per month). The ED reports to the board of directors and oversees a small staff who work remotely.

Key Responsibilities:

Organizational Leadership and Vision:

- Partner with board of directors to set the strategic vision, goals, and priorities.
- Establish and align all stakeholders around a shared set of priorities and lead the organization in accomplishing those priorities.
- Provide strategic leadership and planning to ensure sustainability and growth, especially in family services, treatment access, and development.

Community Engagement:

- Build strong relationships with families and patients affected by Niemann-Pick disease, and ensure the organization centers the voices of patients and families.
- Actively engage the community in programs and committees that meet the needs of patients and families through all stages of the Niemann-Pick journey.

Strategic Partnerships:

- Nurture existing relationships and forge new partnerships with pharmaceutical companies to facilitate therapy development, access to treatment, education initiatives, and support for patients, families, and caregivers.
- Collaborate with research organizations and foundations focused on Niemann-Pick disease to promote education about the disease and research related to treatment options and real-world data generation.
- Strengthen relationships with advocacy organizations related to Niemann-Pick disease and other rare diseases to raise awareness about the needs of patients and families and to educate the community about legislative and regulatory initiatives.

Communications, Outreach, and Advocacy:

- Partner with staff to develop and implement an annual outreach plan and communications calendar for advocacy, marketing, and fundraising.
- Represent the organization at events to increase visibility of the NNPDF and actively engage with families and other key stakeholders.
- Effectively communicate with professionalism, poise, and presence to all stakeholders, including staff, board members, scientific advisory board members, and the entire Niemann-Pick disease community.

Operations, Human Resources, and Financial Management:

- Manage and implement day-to-day operations, including planning, budgeting, and staffing.
- Oversee family services programs, annual family support and medical conference, and regional events, including contracting with and managing external vendors.
- Lead and implement the strategic plan, in partnership with the board of directors and contracted partners.

- Collaborate with and maintain support from pharmaceutical partners.
- Develop a robust fundraising strategy to increase support from individuals and family foundations and to diversify other revenue sources.
- Seek out, apply, implement, and manage corporate and other foundation grant partnerships.
- Strengthen internal controls and policies to ensure financial stewardship and sustainability.
- Ensure compliance with legal, regulatory, and reporting requirements.
- Lead a small staff, contracted employees, and volunteers.

Qualifications:

- Minimum of 7 years experience in a non-profit executive management position, preferably in the rare disease community.
- Knowledge of the US healthcare system, including legislative and regulatory environment, as well as the development, commercialization, and access/reimbursement aspects of prescription products is a plus.
- Ability to articulate a clear vision, develop a strategic plan, and execute it within budget.
- Proven experience with financial planning, budgeting, and reporting.
- Demonstrated success in fundraising, grant writing, and securing major gifts.
- Strong track record of building and maintaining relationships, especially with pharmaceutical partners and peer organizations.
- Adept at listening and collaborating with diverse stakeholders to coalesce around common goals.
- Excellent communication skills, both oral and written; comfortable with public speaking.

To Apply:

NNPDF is committed to offering a competitive salary and benefits. Please email your resume, cover letter, 3 professional references, and a writing sample to connect@nnpdf.org by April 15, 2026. A search committee has been established to oversee the process and looks forward to reviewing your application.

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.