



October 2024

NNPDF Executive Director Search

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 in a group of lysosomal storage disorders that affect metabolism and are caused by genetic mutations. The most commonly recognized forms of Niemann-Pick 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).

Now, in 2024, 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) works in partnership with the board of directors and staff to provide 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 partners, including pharmaceutical companies, advocacy organizations, and 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 staff of 1 full-time and 2 part-time employees who work remotely.

Key Responsibilities of the Executive Director

Organizational Leadership and Vision:

- Provide strategic leadership and planning to ensure the organization's sustainability and growth, especially around treatment development and gaining access to treatment.
- Inspire, unite, and guide staff, board members, scientific advisory board members, and the Niemann-Pick disease community with professionalism, poise, and presence.
- Establish and align stakeholders around a shared set of priorities and lead the organization in accomplishing those priorities.

Community Engagement:

- Build strong relationships with families and patients affected by Niemann-Pick disease, and ensure the organization amplifies 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, and support for patients and families.
- 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.
- 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.

Communications, Outreach, and Advocacy:

- Develop and implement an annual outreach plan and communications calendar for advocacy, marketing, and fundraising.
- Ensure transparent, two-way communication with all stakeholders, especially the board, staff, and community members.
- Represent the organization at events to increase visibility of the NNPDF, and actively engage with families and other key stakeholders.

Operations:

- 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.
- Develop a robust fundraising strategy to maintain support from pharmaceutical partners, to increase support from individuals and family foundations, and to expand other revenue sources.
- Work closely with a small board and committees that provide oversight and strategic direction, as well as help implement the strategic plan and supplement staff resources.

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, and the development, commercialization, and access/reimbursement aspects of prescription products.
- 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 and cover letter to connect@nnpdf.org. A search committee has been established to oversee the process and looks forward to reviewing your application.

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