

## Executive Director – The Global Foundation for Peroxisomal Disorders

*When the GFPD was founded in 2010, the organization was a small parent support group of approximately 50 families. Fourteen years later, the GFPD is a 501(c)(3) non-profit public charity committed to supporting its mission, which includes improving the lives of individuals with peroxisomal disorders by funding research, championing scientific collaboration, and empowering families and professionals through educational programs and support services. Peroxisomal disorders are some of the estimated 10,000 rare diseases impacting nearly 30 million Americans. Today, the GFPD connects hundreds of families from over 40 countries globally. We have an esteemed group of Medical and Scientific Advisors comprised of leading researchers and physicians in the field of peroxisomal disorders. Our biennial Family and Scientific Conferences bring together families and professionals from around the world to meet and collaborate on ways to improve the lives of patients with peroxisomal disorders.*

*The Executive Director leads the GFPD's strategic vision and daily operations in alignment with our mission and values. The Executive Director serves as the primary spokesperson and representative for the organization and is responsible for its relationships with internal and external stakeholders, including the Board of Directors, GFPD staff and contractors, GFPD families, community partners, donors, local government, industry, and media.*

### **Governance**

- Cultivates a robust and transparent working relationship with the Board of Directors.
- Informs and advises the Board regarding current trends, strengths, weaknesses, opportunities, and threats to the organization's mission and operations.
- Serves as a non-voting member of the Board of Directors.
- Develops the strategic plan and annual scorecard with the Board of Directors.
- Ensures necessary staff and contractors are in place to achieve the mission and goals.
- Reviews and revises policies for approval by the Board of Directors.

### **Operations**

- Supervises staff, contractors, volunteers, and interns. Recruits and retains highly qualified personnel and administers an effective human resources system that includes position descriptions, performance standards, performance appraisals, and a fair compensation system. Ensures the necessary staff and contractors are in place to achieve the mission and goals.
- Maintains the financial, human resources, and other management and administrative policies and procedures for day-to-day operations.
- Ensures smooth day-to-day management of the organization, including execution of all contracts and agreements and the creation of a contingency/emergency plan.

### **Financial Sustainability**

- Leads efforts to ensure financial stability and efficient operations while ensuring compliance with financial policies, managing accounts, and providing regular (no less than quarterly) reporting to the Board of Directors on the organization's financial status.
- Raises funds to support organizational operations from various sources, including government, foundations, corporate and individual donors.
- Develops the annual budget, in cooperation with the Finance Committee, subject to approval by the Board of Directors.

### **Scientific Initiatives**

- Directs the Medical and Scientific Research Initiatives of the GFPD, including internal programming and research grants in alignment with our strategic plan, mission, and scorecard.
- Collaborates with various nonprofit, academic, industry, and government partners to ensure that GFPD Medical and Scientific Research Initiatives move forward.
- Builds relationships with researchers, industry partners, government partners, and other rare disease organizations.

### **Qualifications and Skills**

- A bachelor's degree is required; a master's degree is preferred.
- 5+ years' experience in management and/or leadership, showing progressively more responsibility.
- Knowledge and experience in the rare disease space or a related field.
- Creative visionary flexible enough to reprioritize and adapt to adversity with a strong work ethic.
- Experience and strong skills in leadership, management, and supervision.
- Excellent ability to liaise with government partners, academia, industry, biotech, pharma, and other patient advocacy organizations and nonprofit partners to collaborate and advance the mission of the GFPD.
- Strong experience in fundraising, fiscal management, budgeting, and forecasting skills.
- Excellent written and oral communication skills, including the ability to communicate advanced scientific concepts related to peroxisomal disorders, advocacy and policy-related information, and financial information to a broad group of stakeholders.
- Strong professional reputation and record of integrity, sound judgment, and respect for established legal and ethical standards.
- Ability to travel up to 25% and as necessary for GFPD Family and Scientific Conferences, Annual Scientific Meetings, Regional Family meetups, rare disease conferences, and fundraising events.

This position is exempt from Federal overtime laws.