



## **Director of Development Job Description National Tay-Sachs & Allied Diseases Association (NTSAD)**

National Tay-Sachs & Allied Diseases Association (NTSAD), a family-focused patient advocacy organization, supports individuals and families affected by rare neurodegenerative genetic diseases. NTSAD's mission is to "lead the worldwide fight to treat and cure Tay-Sachs, Canavan, GM1, and Sandhoff diseases by driving research, forging collaboration, and fostering community. Supporting families is the center of everything we do."

### **Position Overview**

NTSAD's **Director of Development** is responsible for the fundraising efforts of the organization. This role reports to the Chief Executive Officer, and collaboratively interacts with NTSAD's major donors, staff, Board of Directors, committee members, and members of the rare disease community. The Director's primary responsibility is oversight of all fundraising operations that follow best practices to meet or exceed the organization's annual revenue budget while adhering to (or reducing) the expense budget. Striving to identify and secure new revenue sources and expand existing sources that position NTSAD for mission success and growth is paramount to this position. The Director of Development works cross-functionally with other staff members to align fundraising efforts with organizational objectives and provides guidance to the Administrative Assistant related to fundraising and special event assistance. To articulate the need for organizational support, the Director of Development stays apprised of all current NTSAD research projects, advocacy initiatives, and family services programs and activities.

The Director of Development position is a full-time, exempt position based in our Boston office. Benefits include vacation, personal, and sick time as well as optional health and dental insurance and a retirement savings plan.

### **Responsibilities**

- Fundraising - exceed the organization's annual revenue budget through grant writing, sponsorship solicitation for NTSAD's Annual Family Conference and *Imagine & Believe*, annual appeal donations, restricted funds, Day of Hope and Rare Disease Day campaigns, planned gifts/bequests, and major gifts, while adhering to (or reducing) the expense budget.
- Build, develop, and retain strong, positive relationships with donors, Board members, restricted fund holders, and the NTSAD community at large.
- Update and implement the organization's Development Plan to complement its strategic plan and annual fundraising budget, with the intent to increase revenue goals year after year.
- Stay apprised of all NTSAD initiatives to aid in effectively fundraising for the organization.
- Continuously and proactively identify and secure new sources of revenue (individual donors, companies, foundations, etc.), while engaging and expanding opportunities for existing donors. developing moves management strategies for existing donors.
- Enter all development-related interactions in donor database and produce revenue reports, as needed.
- Participate in the annual budget-planning process and strategic planning led by the Board of Directors.
- Further develop and implement a major gift plan, including initiating and cultivating relationships with prospects/donors, researching and recommending gift level, deploying solicitation strategies, and ensuring that solicitations are well executed.
- Provide Administrative Assistant with support and guidance related to processing donations, producing acknowledgement letters, updating the donor database and website, and assisting with special events and volunteer engagement.

- Work in partnership with staff to create two annual appeal campaign letters and coordinate mailings to be scheduled no later than May 1<sup>st</sup> and the Friday after Thanksgiving in November each year.
- Provide support and resources for individuals and families who conduct third-party fundraisers for Day of Hope, Rare Disease Month/Day, or other initiatives.
- Collaborate with staff to create NTSAD's annual Impact Report.
- Manage the planning, internal and external promotion, execution, vendor relations, auction procurement, volunteer engagement, and revenue sourcing for NTSAD's annual signature fundraising event, *Imagine & Believe*, and additional fundraising campaigns or events.
- Serve as the staff liaison to the Development Committee to help the Board carry out its due diligence function related to assuring fiscal health through philanthropy and fund development, which includes regular interaction with the Development Committee Chair (or interim Chair) who serves on the Board of Directors and attendance at quarterly committee meetings.
- Recruit non-Board members to serve on the Development Committee and ad hoc events committee, when appropriate.
- Submit written progress reports summarizing development activities for all Board meetings and participate in Board meetings, upon request.
- Periodically conduct a comprehensive evaluation of development initiatives' success against established goals.
- Participate in an annual end-of-year virtual meeting in early December for the greater NTSAD community.

### **Key Skills**

- Proven, successful fundraiser
- Driven and self-motivated to reach/exceed fundraising goals
- Implement advanced planning strategies to meet internal and external deadlines
- Demonstrate success working independently or cross-functionally with other team members, Board, and committee members
- Efficiently manage multiple projects with competing priorities
- Prioritize increasing net revenue and growing fundraising portfolio
- Exemplary organizational and interpersonal skills
- Strong verbal communication skills with a proven ability to write clearly and persuasively
- Consistently provide high-quality deliverables
- Thrives in a fast-paced, dynamic environment
- Ability to recruit and manage volunteer committee members
- Familiarity with the rare disease philanthropic ecosystem preferred
- Proficient in Microsoft Office Suite and Donor Perfect

### **Other Duties**

Please note this job description is not designed to contain a comprehensive listing of activities, duties, or responsibilities that are required of the employee for this job. Activities, duties, or responsibilities may change at any time with or without notice.

### **To Apply**

Please submit a resume and cover letter outlining your qualifications and interest in the role and salary requirements to [jobs@ntsad.org](mailto:jobs@ntsad.org).

### **Why Work for NTSAD**

National Tay-Sachs & Allied Diseases Association (NTSAD) offers a rewarding career working for one of the nation's oldest patient advocacy organizations supporting individuals and families affected by ultra-rare neurodegenerative genetic diseases. Our staff members like working at NTSAD because of our mission, work-life balance, benefits, and culture:

- Competitive base pay determined by several factors including, but not limited to, relevant work experience, education, etc.
- Generous paid time off, including holidays and vacation days
- Retirement savings plan (optional)
- Joining our dedicated team affords the gratification of knowing beyond a doubt that you will impact the lives of individuals and families affected by rare neurodegenerative genetic diseases.