



## **Director of Development Job Description**

National Tay-Sachs & Allied Diseases Association (NTSAD), a family-focused patient advocacy organization, seeks a Director of Development to lead its efforts to raise funds to support affected families and to find a cure for rare genetic diseases (Tay-Sachs, Sandhoff, Canavan and GM1 gangliosidosis), with an annual goal of \$1.2 million, growing to an annual goal of \$2 million by 2024. This is a unique time in NTSAD's history as we have just completed a new five-year strategic plan outlining plans for growth as clinical trials begin for the first time ever for our diseases.

### **Qualities and Experience Required**

The ideal candidate will have a successful track record meeting or exceeding annual fundraising goals utilizing various fundraising strategies, including Annual Fund giving, events, major gifts program, and grants. They should be able to demonstrate a track record of fund growth over their career. Candidates will have the capability to build, develop, and retain strong, positive relationships with donors and NTSAD family members. They will be a creative thinker with the ability to inspire and communicate effectively, both in person and through written communications, with individuals, foundations, and board members, and be comfortable asking for money. They will work well in a small collaborative environment, be sensitive and be flexible. The position reports to the Executive Director. A flexible schedule may be arranged.

### **Responsibilities include:**

- Collaborate with Executive Director and Development Committee Chair to create and implement both an annual and 5-year Development Plan to meet or exceed annual revenue goals including an annual income and expense budget for Development. The plan includes appeals, personal solicitations, events and grants.
- Monitor and evaluate all fundraising activities to ensure that the fundraising goals are being achieved.
- Develop and implement Major Gifts program including evaluating relationships with current prospect/donors; creating 3-5 year individual plans for each prospect/donor; recommending gift level; identifying those to be involved in cultivation and solicitation; assuring that solicitations are carried out; revising plans annually
- Develop and maintain strong relationships with donors who have restricted family funds, many of whom are Major Donors. Oversee record keeping for these funds.
- Develop and implement Planned Giving program with select donors
- Work with staff and volunteers to plan and execute fundraising events, including annual gala and family events.

- Work with the Executive Director to maintain and build strong, positive relationships with existing and prospective individual, corporate, and foundation funding sources and prepare and submit grant applications.
- Supervise Development Associate and oversee data entry, gift processing, and reporting
- Participate with staff to develop an annual communications plan to promote the organization to its donors and prospects

#### **Position Requirements:**

- Bachelor's degree
- 7-9 years progressively responsible fundraising experience
- Experience in successfully managing multiple projects and competing priorities
- Proven experience in solicitation and sponsorship requests
- Familiarity with Donor Perfect or another donor database
- Excellent organizational and interpersonal skills
- Strong verbal communication skills; proven ability to write clearly and persuasively
- Success working in a fast-paced, mission-focused nonprofit environment
- Demonstrated ability to work independently as well as part of a collaborative team, showing strong initiative to reach individual goals while supporting team goals
- Personal connection or experience with the rare disease community is not required but is preferred.

#### **About NTSAD**

National Tay-Sachs & Allied Diseases Association (NTSAD) is the nation's longest-standing rare disease advocacy organization, founded in 1957. NTSAD works toward ensuring that all families affected by Canavan, GM1, Sandhoff, and Tay-Sachs are diagnosed early, can participate in cutting-edge research, access effective treatment, to live full and healthy lives. Families are at the center of everything that we do. We work toward supporting them through three strategic priorities:

- We build community for all affected families, so that families have access to a strong peer community.
- We mobilize patients, families, industry, academia, and other partners to advance research and treatments, resulting in families having treatment and supportive care options.
- And, we provide families with resources and expertise to help them navigate a rapidly evolving landscape—meaning that families have access to professional expertise and guidance.

More information about NTSAD and Tay-Sachs, GM-1, Canavan, Sandhoff is available at <https://www.ntsad.org>.

#### **To apply**

Please submit a cover letter and resume to Merle Adelman, Development Committee Chair, merle.adelman@adelmanassociates.com