

NTSAD Seeks an Executive Director

National Tay-Sachs & Allied Diseases Association (NTSAD) is looking to hire a passionate, experienced, and inspiring Executive Director to lead the organization in this unprecedented time of progress and hope. The landscape for the patient community is rapidly evolving with increased and promising drug development activity. NTSAD's next Executive Director will have the opportunity to navigate this exciting chapter, as clinical trials are underway for the first time, providing the tremendous potential to modify the course of these life-threatening and debilitating diseases.



**National Tay-Sachs &
Allied Diseases Association**

Supporting families is the center of everything we do

About NTSAD

Founded in 1957, NTSAD was one of the first patient advocacy organizations in the USA and has played a pivotal role in reducing incidence of Tay-Sachs, Canavan, GM1, and Sandhoff diseases in at-risk populations. Supporting families is at the center of its mission. NTSAD leads the worldwide fight to treat and cure these rare diseases by driving research, building community for all affected families, and providing families with resources and expertise to help them navigate a rapidly evolving clinical landscape. NTSAD's work has contributed to carrier screening science, community education, laboratory quality control programs, and rigorous community carrier screening. It continues to support patients and affected families in profoundly important ways and represents their voice in the science, research, and drug development process.

The NTSAD office is located in Boston, MA. It is staffed by a talented and versatile internal team of five employees. Its 20-member board of directors is national, collaborative, and diverse and is comprised of families from the rare disease community and professionals from the biotechnology industry. The annual operating budget of approximately \$1M is supported by net assets of \$2M. NTSAD has a strong cash position and healthy fundraising strategy. To learn more about NTSAD: <https://www.ntsad.org/>

The Opportunity Going Forward

The Executive Director will have overall strategic and operational responsibility for NTSAD's staff, programs, expansion, and execution of its mission. As the organization begins its new chapter, this Executive Director will embrace this multifaceted role and further define the vision and growth opportunities for NTSAD, leveraging the recently completed 5-year strategic plan. This is a meaningful time for NTSAD. Notable opportunities and expectations for this position are to:

- Provide enthusiastic leadership, inspiration, strategic direction, and vision for the organization and its strong staff; further define and develop the new Research Director staff position.
- Help the organization navigate the new frontier of drug development, continually understanding and anticipating the needs of patients and affected families and representing their voice with the rare disease research and academic communities
- Engage with families, funders, industry and other stakeholders to strengthen existing relationships and develop new relationships to further the mission
- Maintain and expand connections to leading groups in the rare disease community and identify and pursue opportunities to maintain and elevate NTSAD as a rare disease community leader
- Collaboratively enhance the fundraising strategy to increase existing sources and establish new sources of revenue and funding for NTSAD
- Initiate, maintain, and adapt programs (family support, conferences, research) to ensure excellence aligned with the strategic plan and changing environment
- Assess and define an organizational infrastructure that leverages staff talent and efficiency

The Ideal Candidate

While no one candidate will possess every quality outlined for this position, successful applicants will bring many of the following professional qualifications and personal attributes:

- Passion for and experience in rare diseases preferred; scientific acumen
- Experience crafting strategy for a mission-focused, growth-oriented organization
- Skilled at communicating, building rapport, and navigating across stakeholder groups, such as patients, families, industry, non-profits, academic institutions, government groups, and funding agencies
- Emotionally intelligent, a good listener, and has empathy for the challenges faced by people served by the organization
- Track record of successful fundraising
- Proven understanding of the operational needs of a nonprofit or similar enterprise, including fiscal experience
- People management experience inclusive of developing, leading, and inspiring teams and leveraging individuals' strengths to meet goals
- Ability to set priorities decisively, delegate responsibilities, assure accountability and allocate resources to ensure results
- BS/BA degree required with an advance degree preferred, and seven plus years of for-profit or non-profit leadership experience
- The Board prefers Boston/Northeast-based leadership yet is open to a remote work arrangement

Application Guidelines

Candidates must include a resume and a cover letter that describes how their qualifications and experience match the needs and mission of NTSAD, along with salary requirements. Applications will be accepted until the position has been filled. Send required documents to: <https://eostransitions.applicantpool.com/jobs/>

Salary is commensurate with experience and within the framework of the organization's annual operating budget.

EEOC Statement: NTSADs believes in a diverse environment and is committed to equal employment opportunity. We do not discriminate in recruitment, hiring, any other employment practices for reasons of race, color, gender, religion, national origin, gender identity, age, sexual orientation, marital or veteran status, disability, or any other legally protected status.

This executive search is being conducted by Eos Transition Partners consultant Nancy Jackson. All submissions will be acknowledged and are confidential, and any questions must be submitted to Nancy Jackson at: njackson@eostransitions.com.



www.eostransitions.com