



National Tay-Sachs & Allied Diseases Association

65th Anniversary

Research Associate

(Part-time)

ABOUT NTSAD:

National Tay-Sachs & Allied Diseases Association (NTSAD) is one of the oldest patient advocacy organizations in the country. NTSAD's mission is to lead the fight to treat and cure Tay-Sachs, Canavan, GM-1, and Sandhoff diseases by driving research, forging collaboration, and fostering community. Supporting families is the center of everything we do. NTSAD remains committed to advancing and funding research, and first launched its Research Initiative in 2002, which to date has made direct investments of more than \$4 million in grants that have been leveraged to attract more than \$30 million in funding for additional research, leading to new therapies in Tay-Sachs, Canavan, GM1, and Sandhoff diseases.

In 2021, NTSAD hired its first Research Director, who drives the organization's research efforts and is responsible for the Research Initiative Program and Research Committee. NTSAD is looking to hire a part-time Research Associate to support the Research Director.

POSITION SUMMARY AND RESPONSIBILITIES:

The Research Associate will play an important role in coordinating NTSAD's Research Initiative. He/she will support scientific work groups and manage an international network of researchers, clinicians, and industry partners. This role may include the following responsibilities:

- Expand and maintain internal resources including a scientific literature database and a clinical trial database
- Track grant applications and progress of awarded grants
- Organize and attend meetings with working groups, task forces, and advisory councils
- Support NTSAD's effort to initiate a patient registry
- Summarize research in a manner that is approachable for lay audiences
- Other responsibilities, as needed

QUALIFICATIONS:

- MS or PhD in the Life Sciences, PhD candidates welcome
- Experience in rare disease and/or genetic disorders desirable
- Passion and appreciation for the patient voice and prioritization of patient needs in research
- Highly organized with good project management skills
- Ability to read, interpret, and communicate key findings from scientific articles
- Ability to engage various, diverse stakeholders
- Able to work independently as part of a virtual team with opportunities to connect in-person in the Boston area

Exempt part-time position – 20 hours per week

Reports to the Research Director

Interested candidates are asked to send a cover letter, including salary requirements, and resume to Valerie Greger, PhD, Research Director, at vgreger@ntsad.org.

NTSAD is an Equal Opportunity Employer and does not discriminate against any employee or applicant for employment because of race, color, sex, age, national origin, religion, sexual orientation, gender identity, status as a veteran, and basis of disability or any other federal, state, or local protected class.