National Tay-Sachs &
Allied Diseases Association

2023 NTSAD Research Initiative Program
Request for Proposals (RFP)

About Us
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 more than $30 million of investments in additional research, leading to new therapies in Tay-Sachs, Canavan, GM1, and Sandhoff diseases.

In addition to funds from NTSAD, the Cure Tay-Sachs Foundation (CTSF) and the Blu Genes Foundation (BGF) are partnering with NTSAD in this funding round and may support selected projects that align with the foundations' missions and grant-making priorities. Please note CTSF and Blu Genes' funding priorities are limited to research relating to Tay-Sachs and Sandhoff disease (GM2 gangliosidoses) and gene therapy research for rare disease, with a priority for Tay-Sachs, respectively.

Award Description
Funding will be awarded up to $70,000 for one year or up to $140,000 for two years, inclusive of indirect costs not to exceed 5%. Two-year grants will be reviewed after the first year to assess sufficient progress before a second year of funding is provided.

Research Initiative Program Objective

NTSAD's Research Initiative Program is soliciting proposals for innovative research projects studying the following diseases: Tay- Sachs, Canavan, GM1, and Sandhoff diseases. The focus of this grant cycle is on translational and clinical studies, with special interest in the following areas:

1. Clinical research on symptomatic treatment and research to improve quality of life.
2. Clinical tools that support future trials across the severity spectrum of any given indication. This may include developing severity scales for disease staging, translational biomarkers with clinical utility, or measurable and clinically meaningful efficacy endpoints for clinical trials.
3. IND- enabling studies for new therapeutic approaches for Tay- Sachs, Canavan, GM1, and Sandhoff diseases.

Application Process and Grant Review

There is a two-step application process. First, a one-page letter of intent (pre-application) must be submitted. The letter of intent will be reviewed by a sub-committee of NTSAD's scientific advisors. A select group of applicants will be invited to submit full applications for further review and funding consideration. An invitation to submit a full application should not be interpreted as a commitment to fund.

Pre-application

The pre-application should include**:**

1. Title of project, names of Principal Investigator (PI), co-PIs, and associated institutions.
2. Overall goal of the project.
3. Three to five bullet points outlining how the application meets the RFP criteria.
4. Statement of translation describing how the proposed study can be translated into therapeutic development.
5. Specific aims.
6. Requested resources.

Additional pages: Please submit a bio-sketch for the PI in NIH bio-sketch format (no more than five pages).

Pre-applications must be submitted as a PDF document to vgreger@ntsad.org by 5 p.m. EDT January 8, 2023.

Schedule:

Pre-application deadline	January 8, 2023
Invitation to submit a full application	February 1, 2023
Full application deadline	March 12, 2023
Award announcement	May 2023
Executed grant agreement due	June 15, 2023
Earliest anticipated start date	July 2023