



NTSAD's 45th Annual Family Conference

Industry Focus Group Opportunity – June 1, 2023

National Tay-Sachs & Allied Diseases Association (NTSAD) is one of the oldest patient advocacy organizations in the country serving families and individuals coping with a diagnosis of Tay-Sachs, Canavan, GM1 gangliosidosis, and Sandhoff diseases.

Since 1978, NTSAD has hosted the Annual Family Conference to provide families a safe space to support and learn from one another, to gain knowledge directly from researchers and industry members working on potential therapies, and to contribute and share their experiences to further enhance the development of clinical trials.

Prior to the start of this year's conference, NTSAD is offering the opportunity for industry partners to convene a focus group of affected families and/or individuals. Industry Focus Groups are an optional "add-on" to an existing sponsorship.

When? Thursday, June 1, 2023 – 10am -12pm ET

Where? Hyatt Regency Hotel – Reston, VA (dedicated private space)

Who? Up to 8 participants

The topic and content of the focus group will be designed by the industry partner, with input from NTSAD's Director of Family Services.

NTSAD will coordinate outreach to affected families and individuals and provide a host for the focus group.

Cost? \$9,000 (includes hotel accommodations for families who will need to arrive early to the conference, focus group meeting space with snacks and beverages, childcare for families who need it, and staff coordination and outreach)