NTSAD
NATIONAL TAY-SACHS &
Allied Diseases Association

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FOR IMMEDIATE RELEASE
May 28, 2020

NTSAD HOLDS LARGEST ANNUAL FAMILY CONFERENCE

42nd Annual Event Held Virtually with Focus on Families, Collaboration, and Research

Boston, Mass.– National Tay-Sachs & Allied Diseases (NTSAD) kicked off its 42nd Annual Family Conference with a record-breaking turnout of nearly 400 individuals, including individuals and families affected by Tay-Sachs, Canavan, GM1, and Sandhoff, all rare genetic diseases. The four-day event moved from an in-person gathering in Denver, Colorado to a virtual event because of the Covid 19 pandemic.

The switch to a virtual event enabled the largest turnout in the Annual Family Conference's history, including many first-time families who in the past could not afford to travel as well as broader participation from researchers, academics, industry members, and government officials. In addition to registrants from the U.S., event participants hail from Argentina, Brazil, Canada, France, Germany, Sweden as well as other countries. NTSAD families live with underlying, life-threatening health risks to their child or adult child every day and for years, and many cannot travel as a result under normal circumstances, let alone during a global pandemic.

The conference, which kicks off at noon (EDT), Thursday, May 28 and continues through Sunday, May 31, features an entire day of experts discussing the latest breakthroughs in research and clinical trials as well as offers multiple support sessions for parents of affected children, individuals with late-onset forms of the diseases, and extended family members. The event concludes with Sunday's commemoration ceremony honoring children and adults who have passed in the last year due to the rare, lethal diseases.

"NTSAD families depend on us for information, and more importantly a real lifeline—connecting with other families who share similar experiences of providing care to a terminally ill child or adult child. We quickly made the move to virtual as cancelling the event was never an option," said Sue Kahn, NTSAD's executive director. "We feel our conference theme 'Together, We Are All Rare, All Family, Always Connected,' says it all."

At the conference, Board President, Staci Kallish, DO, a medical geneticist, announced the organization's new mission statement, "NTSAD leads the worldwide fight to treat and cure Tay-Sachs, Canavan, GM1, and Sandhoff diseases by driving research, forging collaboration, and fostering community. Supporting families is the center of everything we do."

The new mission statement reflects the organization’s current focus on research, collaboration, community, and most of all, families.

The conference is made possible by lead sponsor Sanofi Genzyme and other generous sponsors, including Amicus Therapeutics, Aspa Therapeutics, Axovant Gene Therapies, Cameron and Hayden Lord Foundation, The Davis Family, Emma’s Fund for Families, Gain Therapeutics, Harry Hoffman Fund, JScreen, Laura and Simeon Schindelman, Lysogene, Matthew Forbes Romer Foundation, Passage Bio, Taysha Gene Therapies, and The Urban Family.

For more information, visit www.ntsad.org. Follow the conference on social media using #NTSADVFC2020 and #Always Connected.

About NTSAD

Founded in 1957 National Tay-Sachs & Allied Diseases Association (NTSAD) is one of the oldest patient advocacy groups in the U.S. and leads the way to end Tay-Sachs, Canavan, GM1, and Sandhoff diseases. We focus on driving research and collaboration, supporting more than 500 families and individuals through a worldwide, compassionate community, and raising awareness of the importance of carrier screening, genetic testing, and early diagnosis. NSTAD convenes families, industry members, academia, and other partners to advocate for and propel treatments, provides professional expertise and guidance, and funds and connects families with research and clinical trials. NTSAD gives help and hope to thousands of individuals and families from many backgrounds and ethnicities who have been or are affected by Tay-Sachs, Canavan, GM1, and Sandhoff diseases all over the world as we seek effective treatments and ultimately, a cure.

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