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National Tay-Sachs & Allied Diseases Association Welcomes Kathleen M. Flynn as Chief Executive Officer

Boston, Mass., October 6, 2021— The National Tay-Sachs & Allied Diseases Association (NTSAD), leader in the worldwide fight to treat and cure Tay-Sachs, Canavan, GM1 and Sandhoff diseases, is pleased to announce the appointment of Kathleen M. Flynn to the newly created role of Chief Executive Officer. The non-profit organization selected Flynn through an extensive national search to succeed Executive Director Sue Kahn, who has led the patient advocacy organization for the past 14 years.

Flynn's organizational management expertise spans non-profit, corporate, and academic environments. Prior to joining NTSAD, she served in leadership roles at the American Liver Foundation, The Arthritis Foundation, Yale Law School, and Mercy Learning Center.

"Kathy is a dynamic and compassionate leader who has positively impacted people's lives through collaboration with patients, caregivers, healthcare professionals, industry members and donors to identify common goals," said Staci Kallish, DO, NTSAD Board President. "We are confident that with Kathy's stewardship and her broad non-profit leadership experience, NTSAD will continue to thrive in the years to come."

"NTSAD plays a critical role in so many people's lives, and it is a true privilege to lead such a purposeful organization," says Flynn. "There's never been a time of greater hope for families faced with rare diseases, and yet people need more than promise. They need support, comfort and an organization that they know stands up for them. That's what NTSAD is all about, and I'm thrilled to join this talented team."

Flynn will join NTSAD effective November 1 and will work closely with Kahn through the end of 2021 to ensure a smooth transition.

"The NTSAD community thanks Sue Kahn for more than a decade of dedication and extraordinary leadership," said Blyth Lord, NTSAD Board past president. "During her tenure, NTSAD was transformed into a modern organization that has continued to provide unparalleled support for families while solidifying its financial foundation and building relationships with industry that set the stage for the first clinical trials for those impacted by this family of tragic diseases."

About NTSAD

NTSAD is among the first and most respected patient advocacy groups and was a pioneer in advancing carrier screening to prevent rare genetic diseases. The organization supports families and individuals around the world through one-on-one professional support, mentoring and peer groups, information and resources, and its Annual Family Conference. As part of its mission, NTSAD also advances research. Since 2002, the organization has awarded more than \$4 million in grants that have been leveraged to more than \$30 million of investments in research. These initiatives have led to the development of potential therapies for Tay-Sachs, Canavan, GM1, and Sandhoff diseases. For more information, please visit NTSAD.org.