

National Tay-Sachs & Allied Diseases Association Announces Leadership Transition

BOSTON, MA, UNITED STATES, June 3, 2021 /EINPresswire.com/ -- National [Tay-Sachs](#) and Allied Diseases Association (NTSAD), a leader in the worldwide fight to treat and cure Tay-Sachs, Canavan, GM1 gangliosidosis and Sandhoff diseases, today announced that Susan Kahn will be stepping down as executive director at the end of October 2021. Ms. Kahn has served as executive director of NTSAD since 2007, and she will help facilitate a smooth transition in leadership. The NTSAD board of directors has initiated a search for Ms. Kahn's successor.

"It has been my great honor to lead NTSAD during a period of so many historic advances. I am proud of the extraordinary progress in research as well as our ongoing efforts to put the needs of patients and their families first by supporting them with more resources, programs, and services than ever before. With more than 14 active drug development programs and clinical trials currently underway, NTSAD is helping to bring new levels of hope to families around the world," said Ms. Kahn.

In 2020 under the direction of Ms. Kahn, NTSAD initiated a new five-year strategic plan to expand services for families and advance research priorities in areas including early diagnosis, newborn screening, and clinical trial readiness. In addition, NTSAD's Annual Family Conference has grown significantly with participation by more than 500 people from 26 countries. During the last two decades, NTSAD invested in much of the early research that has led to today's drug development programs and clinical trials. Since 2002, NTSAD has awarded more than \$4 million in research grants that have been leveraged to more than \$30 million in additional grants from the National Institutes of Health and other institutions.

"Sue has provided us with the outstanding leadership we needed to expand NTSAD's reach and impact, and she has helped to position NTSAD to achieve new levels of sustainability that will be essential for our community in the years ahead," said Staci Kallish, president of the NTSAD board of directors. "She also has spearheaded many efforts to grow the NTSAD team, foster community among families, and create a broad network of researchers, clinicians, and members of industry to collaborate in the search for effective treatments."

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 750

individuals and families through a worldwide, compassionate community, and raising awareness of the importance of carrier screening, genetic testing, and early diagnosis. NTSAD convenes families, industry members, academia, and other partners to advocate 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. For more information, visit [NTSAD.org](https://www.ntsad.org).

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