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FOR IMMEDIATE RELEASE

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CURE TAY-SACHS FOUNDATION AWARDS THREE GRANTS TOTALING \$208,358 FOR TAY-SACHS DISEASE RESEARCH

Tay-Sachs families and friends continue their grassroots effort to cure a terminal disease.

CLEVELAND, OH (Apr. 19, 2010) - The Cure Tay-Sachs Foundation (CTSF) headquartered in Cleveland, Ohio has announced that it has award three grants totaling \$208,358 to further Tay-Sachs and Sandhoff disease research. The grants will cover research on Jacobs sheep that have been identified as Tay-Sachs affected, stem cell research in Sandhoff mouse models, and better understanding the role inflammation plays in the brains of Sandhoff affected mice. Tay-Sachs is a genetic, degenerative neurological condition resulting from a single gene mutation (Hex A). There is currently no treatment or cure for the disease, and it is ALWAYS fatal in children. This 100% mortality rate in children and the desperate lack of funding for research to find a treatment or cure for Tay-Sachs was the catalyst for the formation of the CTSF and continues to drive the grassroots efforts to raise awareness and provide the funds needed for research.

The Tay-Sachs gene mutation is found most frequently in Ashkenazi Jews, French Canadians, Louisiana Cajuns, and Irish Americans. The carrier rates are 1 in 27 in the highest risk populations and 1 in 50 in the Irish American population. Nationwide, 1.5 million people carry a Tay-Sachs gene mutation.

The CTSF makes the grants in collaboration with the National Tay-Sachs and Allied Disease Association's (NTSAD) Research Initiative and their Scientific Advisory Board. Since the CTSF creation in June of 2007 the foundation has raised \$1.2 million for Tay-Sachs research and issued \$533,358 in research grants! The CTSF also played a pivotal role in the Tay-Sachs Gene Therapy Consortium winning a four year \$3.5 million grant from the National Institute of Health in August 2009.

The President of the Cure Tay-Sachs Foundation, Ken Bihn, said "The prescribed treatment for Tay-Sachs today is to take your child home, make them as comfortable as possible as the disease runs its course – ending in death. As the parent of a Tay-Sachs child (Dakota, age 10) that is just not an acceptable way to confront the disease. We chose to fight this disease for Dakota and for all the families that have, or will be told there is no hope."

"We are battling to raise funds for research and raising public awareness of the disease. We will continue our mission until we have eradicated Tay-Sachs disease," said Mr. Bihn. The research is making significant progress towards slowing and even stopping the disease progression. The CTSF mission is to stop the disease from damaging the brain and then find a way to repair the damage so children born affected can live a long and healthy life.

To support The Cure Tay-Sachs Foundation, an IRS-approved 501(c)(3) non-profit entity, tax-deductible donations can be made on-line at www.CureTay-Sachs.org or checks can be made payable To the Cure Tay-Sachs Foundation and mailed to 12730 Triskett Road in Cleveland, OH 44111. Please e-mail any requests to ken.bihn@curetay-sachs.org.

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Tay-Sachs Disease Gene Carrier Statistics

1 in 27 Ashkenazi Jews

1 in 50 Irish Americans

1 in every 250 people