



12730 Triskett Road  
Cleveland, Ohio 44111  
(216) 812 - 5855  
Fax (216) 251 - 6728  
ken.bihn@curetay-sachs.org

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FOR IMMEDIATE RELEASE

Contact: Ken Bihn  
(216) 812-5855  
[ken.bihn@curetay-sachs.org](mailto:ken.bihn@curetay-sachs.org)

## **CURE TAY-SACHS FOUNDATION AWARDS FIVE RESEARCH GRANTS IN 2011 TOTALING \$733,044 FOR TAY-SACHS DISEASE RESEARCH**

### **Tay-Sachs families target October 2012 clinical trials to halt terminal illness**

CLEVELAND, OH (Dec. 31, 2011) - The Cure Tay-Sachs Foundation (CTSF) headquartered in Cleveland, Ohio has announced the awarding of five grants totaling \$733,044 to further Tay-Sachs and Sandhoff disease research. The grants cover a number of expenses related to the Tay-Sachs Gene Therapy Consortium's effort to conduct a gene therapy clinical trial using viral vectors by October 2012. The grants include \$114,380 to conduct a prospective study on Tay-Sachs and Sandhoff disease; \$30,000 to test viral vector manufacturing capabilities at a UC Davis facility; \$115,000 in consulting services for preparation of the application to the FDA to initiate the clinical trial; \$209,854 to test the viral vector delivery system and delivery location in primate brains; and \$263,810 for an FDA required Toxicity Study. 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 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 12) that is just not an acceptable way to confront the disease. We chose to fight this disease for all the families that have, or will be told there is no hope."

Since the CTSF creation in June of 2007 the foundation has raised \$1.9 million for Tay-Sachs research and spent \$598,709 in research grants! The CTSF currently has \$717,693 in research funding commitments and an expense to donation ratio of less than 6%. The CTSF is the largest private funder of the Tay-Sachs Gene Therapy Consortium.

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](http://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](mailto: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**