

State of New York  
Legislative Resolution

Assembly No. 1825



**BY:** M. of A. Saladino, Abbate, Seminerio, K. Zebrowski, Lafayette, Burling, Alfano, Bacalles, Barclay, Barra, Bing, Boyland, Brook-Krasny, Calhoun, Clark, Colton, Crouch, Destito, Duprey, Errigo, Finch, Fitzpatrick, Gabryszak, Galef, T. Gordon, Gunther, Hayes, Jaffee, Koon, Lupardo, Maisel, McDonough, McEneny, McKeivitt, Miller, Molinaro, Oaks, Ortiz, Perry, Pheffer, Quinn, Raia, Reilly, Rosenthal, Sayward, Schimel, Scozzafava, Spano, Sweeney, Tedisco, Thiele, Townsend, Walker and Weisenberg

**MEMORIALIZING** Governor David A. Paterson to proclaim July 2008, as Tay-Sachs Awareness Month in the State of New York

**WHEREAS,** A genetic degenerative neurological condition that is classified as a lysosomal storage disease, Tay-Sachs disease is caused by the mutation of a single gene, Hex A, which is a vital enzyme needed by the brain to process waste; and

**WHEREAS,** The waste accumulates in the lysosomal storage areas of a cell and as the storage area becomes overwhelmed, the brain cells begin to swell, malfunction and ultimately die; and

**WHEREAS,** The degenerative nature of the Tay-Sachs disease often remains hidden at first as brain cells accumulate waste; there are no outward signs and children appear normal and healthy at birth; and

**WHEREAS,** Once symptoms begin so much damage has already been done that it is difficult to treat or even slow the degenerative nature of Tay-Sachs disease; and

**WHEREAS,** A child suffering from infantile Tay-Sachs has an average life expectancy of two to five years, while a juvenile patient might live to 15; the late on-set form that affects adults confines them to a wheelchair with significant impairment to motor and speech skills; and

**WHEREAS,** Tay-Sachs disease is most common in the Jewish community, specifically the Ashkenazi Jewish community, where one in 27 people carry the Tay-Sachs gene; most Jewish couples are screened before marriage to determine if one or both potential parents is a carrier; and

**WHEREAS,** The same carrier rates also exist among Louisiana Cajuns and French Canadians; the next highest carrier group is Irish-Americans, where one in 50 is a carrier; and

**WHEREAS,** Finally, one in every 250 people carries the Tay-Sachs gene, which means that over 77,000 residents in the State of New York carry the deadly gene mutation; most have no knowledge of the disease and the death sentence it can carry for their children; and

**WHEREAS,** Scientific research in the Gene Therapy field has advanced to the point where an international consortium of researchers believe a treatment or cure is possible in the next three years; this group called the Tay-Sachs Gene Therapy Consortium has launched a three year project leading to clinical trials; and

**WHEREAS,** The oldest disease advocacy organization in the nation, the National Tay-Sachs and Allied Diseases Association has been advocating for Tay-Sachs awareness for over 50 years and represents hundreds of families with affected children and/or adults, as well as the thousands of families that have lost loved ones to this horrible disease; and

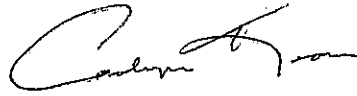
**WHEREAS,** It is imperative that there must be greater public awareness of this serious health issue, and more must be done to increase activity at the State, local and national levels to find a cure for Tay-Sachs disease; now, therefore, be it

**RESOLVED,** That this Legislative Body pause in its deliberations to memorialize Governor David A. Paterson to proclaim July 2008, as Tay-Sachs Awareness Month in the State of New York; and be it further

**RESOLVED,** That a copy of this Resolution, suitably engrossed, be transmitted to The Honorable David A. Paterson, New York State Governor.

**ADOPTED IN ASSEMBLY ON**  
May 27, 2008

By order of the Assembly,



Carolyn Kearns, *Acting Clerk*

