



HJ0013

LRB097 10564 RPM 50912 r

1 HOUSE JOINT RESOLUTION

2 WHEREAS, Krabbe disease, also known as Globoid Cell  
3 Leukodystrophy, is an inherited neurodegenerative lysosomal  
4 enzyme disorder affecting the central and peripheral nervous  
5 systems caused by a defect in the GALC gene; persons with this  
6 gene defect do not make enough of an enzyme called  
7 galactosylceramidase; the body needs this enzyme to make  
8 myelin, the material that surrounds and protects nerve fibers;  
9 without the enzyme, myelin breaks down and as a result, brain  
10 cells die and nerves in the brain and other body areas cannot  
11 function properly; and

12 WHEREAS, The symptoms of the infantile form of Krabbe  
13 disease usually begin before the age of one year; initial signs  
14 and symptoms typically include irritability, muscle weakness,  
15 feeding difficulties, episodes of fever without any sign of  
16 infection, stiff posture, and slowed mental and physical  
17 development; with disease progression, muscles continue to  
18 weaken, affecting the infant's ability to move, chew, swallow,  
19 and breathe; affected infants also experience vision loss and  
20 seizures; death usually occurs before the age of 2 years; and

21 WHEREAS, Though the condition is considered very rare (1 in  
22 100,000 births in the United States) it is estimated that the  
23 carrier rate in the general population is estimated to be 1 in

1 125 births; the genesis for this resolution is the late Liam  
2 Hammonds who succumbed from Krabbe disease in 2001 before his  
3 first birthday; his parents, Scott and Terry established a  
4 memorial foundation in his behalf to educate the public about  
5 Krabbe disease and provide monetary and other support to  
6 affected families; therefore, be it

7       RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE  
8 NINETY-SEVENTH GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, THE  
9 SENATE CONCURRING HEREIN, that the Department of Public Health  
10 shall study Krabbe disease and related leukodystrophies and  
11 report to the General Assembly by December 31, 2012 salient  
12 information, including, but not limited to, disease incidence  
13 in this State, available treatment options, State or federal  
14 research projects, available disease registries and biobanks,  
15 diagnostic tests and their usage, access and availability of  
16 drugs, economic impact of the disease on families, and any  
17 other relevant information that the General Assembly should  
18 consider in addressing the diseases; and be it further

19       RESOLVED, That a suitable copy of this resolution be  
20 delivered to the Director of Public Health.