

SENATE HEALTH, HUMAN SERVICES AND SENIOR
CITIZENS COMMITTEE

STATEMENT TO

SENATE JOINT RESOLUTION No. 31

with committee amendments

STATE OF NEW JERSEY

DATED: MAY 27, 2010

The Senate Health, Human Services and Senior Citizens Committee reports favorably and with amendments Senate Joint Resolution No. 31.

As amended, this joint resolution designates July 20 of each year as “Emma’s Day” in the State of New Jersey. Emma Daniels was born in New Jersey in 2009 and diagnosed with Krabbe disease, a lysosomal storage disorder. Lysosomal storage disorders are inherited, and affect primarily children, many of whom die within a few months or years of birth after much suffering. There are more than 40 of these disorders, including Krabbe disease, Tay-Sachs disease, Gaucher disease, and Pompe disease. Currently no cure or reliable treatments exist.

This resolution urges the Department of Health and Senior Services and all other public and private entities entrusted with the health of the citizens of this State to observe “Emma’s Day” with appropriate activities to increase public awareness of lysosomal storage disorders.

The committee amended the bill to acknowledge the importance of newborn screening in diagnosing lysosomal storage disorders.

As amended, this resolution is similar to Assembly Joint Resolution No. 45 (Diegnan/Rible/Bucco), which is pending before the Assembly Health and Senior Services Committee.