



Legislation Text

File #: Res 1537-2012, **Version:** *

Res. No. 1537

Resolution calling upon the New York State Legislature to pass and the Governor to sign Aidan's Law, A.10813/S.7837, legislation requiring adrenoleukodystrophy screening of newborns.

By Council Members Greenfield, Williams, Arroyo, Brewer, Chin, Fidler, Gonzalez, Koo, Koppell, Koslowitz, Nelson, Palma, Wills, Dromm and Halloran

Whereas, Adrenoleukodystrophy (ALD) is a rare metabolic disease, which affects the brain and all neurological functioning; and

Whereas, Symptoms can include aggression, memory loss, hyperactivity and vision loss; and

Whereas, This disease affects approximately 1 out of 17,000 people in the United States, primarily males; and

Whereas, Death usually occurs within 1 to 10 years after symptoms appear, yet if detected early, the childhood cerebral form of the disease can be treated with a bone marrow transplant; and

Whereas, Senator Eric Adams (D-Brooklyn) and Assembly Member James Brennan (D-Brooklyn) introduced Aidan's Law, S.7837/ A.10813; and

Whereas, Aidan Jack Seeger, the namesake of this legislation, was diagnosed with ALD on June 2, 2011, at the age of 6 years old; and

Whereas, Aidan's battle with ALD began innocently enough as he was in first grade, performing above grade level, and playing with other children; and

Whereas, He started to experience vision problems in April of 2011 and it was assumed that he simply required glasses; and

Whereas, After testing, including an MRI and a very long chain fatty acid blood test, Aidan was

diagnosed with ALD, and the only option to stop the progression of this disease was through a bone marrow transplant; and

Whereas, Aidan received this transplant on his seventh birthday, however the following months were difficult for Aidan, because although the transplant was successful he had already experienced symptoms and had to undergo chemotherapy; and

Whereas, As the disease further progressed, Aidan lost his sight, hearing, and the ability to eat, walk, and communicate; and

Whereas, After ten months in the hospital, Aidan succumbed to ALD on April 29, 2012; and

Whereas, Aidan's parents, Elisa and Bobby Seeger, have advocated for the passage of Aidan's Law and have taken their fight to Albany and Washington, D.C.; and

Whereas, In New York, Aidan's law would require that all newborns in New York State be screened for ALD; and

Whereas, According to the New York Daily News, if passed, Aidan's Law would add ALD to the list of more than 40 conditions that newborns are screened for in New York hospitals; and

Whereas, Newborns would be screened at the same time and in the same way they are currently screened for more than 40 conditions, by extracting blood from the infant's heel; and

Whereas, It has been estimated that the cost of screening a newborn for ALD is \$1.50 per child or \$375,000 per year for all New York newborns; and

Whereas, The Seegers have generated an abundance of support from more than 20,000 members of Aidan's Facebook page and a group called "Aidan Has A Posse"; and

Whereas, With routine screening for ALD, New York State can ensure that other families do not experience the same tragedy as the Seeger family, and that newborns receive prompt treatment and care; now, therefore, be it

Resolved, That the Council of the City of New York calls upon the New York State Legislature to pass

and the Governor to sign Aidan's Law, A.10813/S.7837, legislation requiring adrenoleukodystrophy screening of newborns.

JM
LS# 4069
9/28/12