



NEW YORK STATE SENATOR

Martin J. Golden

Greenfield Calls on State Legislature to Pass Life-Saving Bill Requiring ALD Testing in Newborns

MARTIN J. GOLDEN October 12, 2012

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New York – Councilman David G. Greenfield held a press conference on the steps of City Hall yesterday with Windsor Terrace residents Elisa and Bobby Seeger to call on the state Legislature to pass a life-saving bill known as Aidan’s Law during its upcoming session beginning in January. The bill is named for the Seeger’s seven-year-old son, who died earlier this year following a battle with a rare genetic condition known as adrenoleukodystrophy

(ALD). While there is no cure for ALD, which affects the brain and all neurological functioning, children with it can lead a relatively normal life with a bone-marrow transplant if it is detected early enough. Following the press conference, Councilman Greenfield introduced a City Council resolution calling on the state to make Aidan's Law a priority in the new legislative session.

Aidan's Law, sponsored by Senator Eric Adams and Assembly Member James Brennan, and co-sponsored by Senator Martin Golden, would require that ALD be added to the list of more than 40 conditions for which all newborns are tested in New York State. While the law was introduced in both chambers of the Legislature this year, no action was taken on it before the session expired. Along with Mr. and Mrs. Seeger, Councilman Greenfield was joined yesterday by Assembly Member Brennan, Jerry Kassir representing Senator Golden, Councilman Michael Nelson, Councilman Jumaane Williams and Councilwoman Sara Gonzalez

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"We must come together to sure that this live-saving legislation is passed in Albany. My heart goes out to the Seeger family, and I will stand alongside them as they fight in Aidan's memory to have all newborns tested for ALD. Our leaders in Albany have the power to help prevent other families from enduring this tragedy, but they must act as quickly as possible. My thanks to Elisa and Bobby Seeger, Assembly Member Brennan, Senator Martin Golden and Jerry Kassir, Councilman Michael Nelson, Councilman Jumaane Williams and Councilwoman Sara Gonzalez for helping spur action on this vital issue," said Councilman Greenfield.

"We have to look at the society we live in when a human life is not looked at as a priority. We need Aidan's Law to pass now, today. Every day we wait for Aidan's Law to be passed, how many children will be born with ALD and not monitored or treated to save their lives? We have the technology, the test, and the technicians to make this happen. What are we waiting for?" said Elisa Seeger.

"Since the day I met Aidan Jack Seeger's parents, I have been inspired to change New York State law so to save lives in his memory. I applaud Councilman David Greenfield for leading efforts in the New York City Council, and I know that together, we will affect change to mandate testing for ALD. This is the right thing to do for all of New York's families," said Senator Martin Golden.

"The evidence is overwhelming that mandatory screening for ALD will save lives. That's why the State government should add this simple, cost-effective test for newborns to the mandatory testing list," said Assembly Member Brennan.

"As a member of Aidan's Posse, I passionately support the passage of Aidan's law and will encourage our Assembly Members to make it a top priority on the agenda. I am moved by the Seeger family's courage and effort to honor their son, in spite of the struggle they have already endured. With the passage of Aidan's law, we will be able to screen for and treat the cruel disease of ALD for affected newborns throughout New York State," said Councilman Michael Nelson

Councilman Greenfield became involved in this issue after recently meeting with Elisa Seeger following Aidan's death on April 29, 2012. The Kennedy Krieger Institute has estimated that ALD screening would cost just \$1.50 per child, according to a recent Daily News report. About 1 in 17,000 people in the country, mostly males, are affected by ALD. Nearly one-third of people with ALD begin to display symptoms such as memory loss, hyperactivity and vision loss, between ages 4 and 8. While death typically occurs within 1 to 10 years after symptoms are detected, the childhood form of ALD can be treated if detected early enough. As a result, it is critical that all newborns are tested for ALD at the same time they are tested for HIV, sickle cell anemia, cystic fibrosis and dozens of other diseases within days of birth so that treatment can begin immediately if necessary.

"With everything we know about this debilitating disease, there is no reason to delay the adoption of Aidan's Law when the new session begins in January. I hope that our voices were heard loud and clear and will bring attention to this important issue and help prompt action in Albany," concluded Greenfield.