Testimony in support of Senate Bill 2137

Good afternoon Mr. Chairman and Committee members. My name is Taylor Kane. I am 14 years old and I live in Mount Laurel.

When I was three years old, my dad, Jack Kane, was diagnosed with Adrenoleukodystrophy (ALD for short). From what I remember, and from what everyone tells me, my dad was a man with a great personality. He loved to talk and make people laugh. He grew up in Philadelphia and worked as a longshoreman when he was young, but eventually, he worked his way through college, and then law school. My dad was always helping other people. My mom says what she liked most about my dad was that he liked everyone for who they were as a person. It didn't matter how they dressed or how much money they made. Everyone was equal in his eyes. He never had a bad word to say about anyone. People loved my dad too.

I remember my dad playing with me all the time when I was really young. He was a perfect dad. But he suddenly started acting very strange. He was sleeping a lot and some days he couldn't get out of bed to go to work until lunchtime. Other times, he wouldn't come home for dinner, and he would say he didn't remember where he had been. It was scary. My dad went to the doctor and got a CAT Scan of his brain. That's when he found out he had ALD.

Within a few months, my dad began getting very confused. He lost his job. Then he lost his ability to walk, talk and swallow. He had to have surgery so the doctors could put a feeding tube in his stomach. My dad lived in a hospital bed in our dining room. Most of the time, he didn't seem to know who we were. Sometimes, he tried to talk by using his fingers. One finger for "yes," and two for "no." After a while, he didn't understand the difference and would hold up three fingers, or just put the covers over his head. It was sad to see him suffering. My dad stayed in this condition, on hospice, for two more years. He died on December 20, 2003, just after I started kindergarten. That was the saddest day of my life. My dad will always be my hero.

Now, a little bit about ALD. ALD is a disease that attacks the spinal cord and white matter of the brain. It is best known as the disease portrayed in the 1993 movie, Lorenzo's Oil. ALD affects 1 out of every 17,000 people. It is found in all races and nationalities. The disease is hereditary. Males get the most severe symptoms of

the disease and females are carriers. Forty percent of the time ALD shows up in childhood, and affects boys between 4 and 10 years old. The rest of the time, it comes on in adulthood, like it did with my dad. Once the symptoms begin, there is no effective treatment or cure. Boys usually lose their ability to walk, talk, swallow and understand, and then they go into a coma or die within a few years.

But, if a boy finds out he has ALD before symptoms begin, ALD can be cured by a bone marrow transplant. In fact, 90% of boys who get a bone marrow transplant before they develop symptoms survive. The problem is that very few boys find out they have ALD until it is too late. Newborn screening would solve this.

For example, newborn screening could have saved Matthew Gagliardi. Matthew is a twelve year old boy who lives near me in Stratford, New Jersey. When he was young, he loved riding his bike and playing baseball. Matthew began having problems in school when he was seven, but like many boys with ALD, he was misdiagnosed with Attention Deficit Disorder. His symptoms got worse and he began having vision problems, but by the time he was finally diagnosed with ALD, it was too late for a bone marrow transplant. When I visit Matthew now, he reminds me of my dad – he can't walk or talk anymore and he has lost most of his cognitive abilities. But Matthew is still fighting, and it is also his dream to stop ALD. (Matthew's mother Jill is here in the audience to support this bill, and so is John Gentless, the Mayor of Stratford where Matthew lives).

Newborn screening for ALD would also help in another way – the test can identify more than ¾ of female carriers of the disease. Since my dad had ALD, I know I am an ALD carrier. My mom began explaining to me what it meant to be a carrier when she thought I was old enough to understand.

I now know that 50% of female carriers eventually develop physical symptoms, such as numbness in the legs, difficulty walking and bladder problems. But I'm glad I know this now, so I that can I take care of myself and get plenty of exercise to try to stay strong and healthy.

But even more importantly, I understand that when I get older, if I were to have children, there is a 50% chance that each of my children would inherit the ALD gene from me. But I also know that this doesn't have to happen. There are medical procedures that can be done before I have children so that they are not born with the ALD gene. Or, I could adopt. But trust me, I am so happy that I know

I am a carrier so I will have this choice.

Most women don't know they are carriers. They unknowingly pass the ALD gene to their babies. No woman should have to find out that she is a carrier by having a baby who gets sick or dies from ALD! Newborn screening would identify most of these women so that they would be able to make informed choices about having children.

The newborn screening test which has developed to test for ALD has been shown to be safe and reliable in several pilot studies, and there is a large study going on at the Mayo Clinic which is nearly complete. Since New Jersey already tests newborns for 54 diseases, it would just be a matter of adding the ALD test to the others.

This August, a bill requiring ALD screening was introduced in the state of New York. And just last week, I testified before an Advisory Committee of the Secretary of Health and Human Services in Washington, D.C. Although the Committee is still waiting for the final information from the Mayo Clinic, it is only a matter of time before the Secretary formally recommends that all states screen newborns for ALD.

Mr. Chairman and Committee members, I've been working to raise awareness of ALD in my dad's memory ever since third grade. I've also done everything I can to raise money for ALD research, from selling lemonade to volunteering at the annual 5K Run for ALD in Pennsauken. Now, there is finally a way to save boys and men from this horrible disease. Please – for the sake of my dad, boys like Matthew Gagliardi, and all of the other families in New Jersey who are or may be affected by ALD – approve this bill so that ALD will be added to New Jersey's current newborn screening panel.

Thank you.

Taylor Kane
114 Preakness Drive
Mount Laurel, NJ 08054
(856) 222-0580