



**State of Connecticut**  
**HOUSE OF REPRESENTATIVES**  
STATE CAPITOL  
HARTFORD, CONNECTICUT 06106-1591

**Representative Lonnie Reed**  
Chair - Energy and Technology Committee  
102<sup>nd</sup> Assembly District  
Branford

Legislative Office Building  
Hartford, Connecticut 06106  
860-240-8585 or 800-842-8267  
Lonnie.Reed@cga.ct.gov

**Testimony of Representative Lonnie Reed**  
**In support of SB 465 Act Requiring Newborn Screening for Adrenoleukodystrophy**  
**February 27, 2013**

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Good morning to Committee Chairs, Sen. Gerratana and Representative Johnson; the Vice Chairs, Sen. Slossberg and Rep. Miller and the Ranking Members, Sen. Welch and Rep. Srinivasan, and all members of the Public Health Committee.

My name is Lonnie Reed, State Representative for Branford. I am here to support SB 465 and to talk to you about one of our town's most beloved and awe inspiring families.

Jean and John Kelly and their warrior son Brian are asking you -- asking us all -- to help other families avoid the devastating, life changing health challenge that has befallen them.

Brian Kelly appeared to be a totally healthy, rambunctious little boy until a sledding accident at the age of six revealed that he had Adrenoleukodystrophy (ADL), a gene-linked, inherited, deteriorating condition that can lead to total incapacitation and early death. It is a condition that can now be detected and often controlled with interventional therapies by adding ADL to the diseases that are easily tested for in newborns.

You will undoubtedly hear more about the human costs of ADL.

I want to talk just a bit about the financial costs that we all pay.

The Kellys asked the Branford School system to tally up the additional price paid to educate Brian, given his disabilities.

Some of the line items include special transportation costs of \$46,000 per year; Special Computer Hardware/Software and Assistive Technology Evaluation that came to \$35,000 for Brian's twelve years in school. The grand total of extra costs came to almost \$1-Million Dollars.

The human costs and the societal costs could have perhaps all been prevented if there had been the automatic testing of newborns for ADL.

I have to say that throughout his years in our Branford schools, Brian's strength, determination and refusal to give up inspired his classmates and his educators, teaching them valuable lessons they would not have learned otherwise.

Brian is still teaching us and he is asking us today to please vote for SB 465, Act Requiring Newborn Screening for Adrenoleukodystrophy, ADL. What a legacy that would be for Brian and his family and all for Connecticut families who could be spared the heartbreaking, life altering destruction caused by ADL.

I am grateful to you for hearing this bill. I ask you to please keep supporting it and to help it become law. Thank You.