

Testimony of Jill Wood
Supporting the Newborn Screening Saves Lives Act
U.S. Senate Committee on Health, Education, Labor and Pensions,
Subcommittee on Children and Families
June 14, 2002

Thank you, Mr. Chairman, for inviting me to speak today. I am Jill Wood of Fairfax, Virginia. I am a mother who volunteers for the local March of Dimes Chapter. I appreciate the opportunity to testify today about my daughter, Hayley, and the importance of newborn screening immediately after birth.

When my husband and I became pregnant with Hayley, we expected to have a healthy happy baby. And, we did. However, our daughter died unexpectedly in her sleep, on our first night home, three days after her healthy hospital delivery. The autopsy found that she had extra fat from an undiagnosed metabolic birth defect that was not tested for in Virginia. On subsequent tests done at our personal expense, it was revealed that Hayley died of a disorder called CPT-II. The disorder that killed our daughter was genetically passed on so proper identification and screening was critical if we were going to consider having children in the future.

My husband, Marshall, and I converted our pain and loss into action. We found that in Virginia newborns were tested for only 8 diseases. We joined the March of Dimes in their advocacy work to get the State of Virginia to agree to test for more disorders. The March of Dimes recommends that every baby, no matter where he or she is born, receive screening for at least a "core" set of ten disorders. I won't read the names of the disorders, but have attached the list to my statement.

In February 2001, we headed to Richmond for the March of Dimes Lobby Day to talk to our legislators about expanding Virginia's newborn screening program. Prior to Lobby Day, Senator Patsy Ticer, our state senator, had introduced a Senate bill (SB 1007) to add another metabolic screening test to the list of newborn screens required for all babies born in Virginia. The test would screen newborns for a metabolic birth defect called congenital adrenal hyperplasia or CAH. CAH is when the body lacks an enzyme needed by the adrenal glands (on the top of the kidneys) to make the hormones, cortisol and aldosterone. Cortisol is needed to maintain an adequate energy supply and aldosterone is needed to maintain proper salt and water balance. If it is identified through newborn screening, CAH can be treated by giving the missing hormones to the baby.

The March of Dimes and Senator Ticer gave me the opportunity to be able to share my story and determination with legislators. In other words, we put Hayley's face on the problem we were trying to solve. This bill passed unanimously and was signed into law by Governor Gilmore. Since July 2001, Virginia has been screening for 9 of the 10 tests recommended by the March of Dimes.

This year we worked with the March of Dimes and Senator Ticer again to add that 10th test, MCAD, to the newborn screening list in Virginia. MCAD or medium chain acetyl coenzyme A dehydrogenase deficiency was missing from the screening tests in Virginia. Twenty percent of babies born with MCAD die suddenly. Many cases are confused with sudden infant death syndrome (SIDS). Actually, before we had a diagnosis on Hayley's birth defect we were seeking counseling from the SIDS Alliance. So you can see why we think adding this test is so important. Families need answers in order to make decisions on future pregnancies.

Again, I joined the March of Dimes volunteers in Richmond, talked to legislators and told my story. Again, the legislature passed the bill with a unanimous vote. However, before it can be implemented, the state needs to find the necessary funds to start the new screening tests. In order to test for MCAD, special equipment called a tandem mass spectrometer is needed. Each spectrometer costs about \$350,000 and the state needs two to serve the 95,000 birth (about 6,000 tests/day) in Virginia each year. I sincerely hope that you will help states expand their programs by providing them with the necessary financial assistance.

I want to mention that this year all of us went to Richmond to lobby for the MCAD bill. Our new baby girl, Grace, was born in August 2001. As you can imagine, we had extensive newborn screening done on her before we took her home. Again, we paid for the tests ourselves.

We will continue to work with the March of Dimes so that in the future, the Commonwealth of Virginia will be testing for 25-30 tests during a routine newborn screening. We do this for all the babies who will be born in Virginia. We do not want any family to go through a loss like ours.

Thank you very much for holding this important hearing. Families like mine, along with March of Dimes volunteers and staff in every state, including Virginia, are available to work with you to improve these critical screening programs.