

Bill pushes for more newborn testing

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Friday, January 21, 2005

Jana Monaco fought back the tears.

She traveled with her husband Tom, daughter Caroline and son Stephen from their Woodbridge home Thursday to testify at the House of Delegates Health, Welfare and Institutions Committee.

Her voice trembled for a moment as she told the committee the story of how her 7-year-old son Stephen became severely disabled at age 3.

Stephen inherited his parents' recessive traits for a rare genetic disease called Isovaleric Acidemia, or IVA. Stephen's body lacked the enzyme to break down the amino acid leucine, a byproduct of protein.

Stephen Monaco went to bed one night with what seemed like a normal stomach virus, and by the next morning his body had gone into shock. He will never recover. These days, cracking a smile or a laugh is major progress for Stephen, who was lucky to have left the hospital alive.

But he could have lived a normal life if he had been born in another state, like North Carolina. Stephen's disease could have been detected at birth. He could have been given medications and a restricted diet to prevent his body going into shock. Instead he faces a lifetime of physical disability and his family faces a lifetime of emotional and financial suffering.

Virginia only tests for nine genetic diseases at birth, not including IVA. North Carolina tests for 36, Jana Monaco told the committee.

After the birth of their daughter Caroline Monaco a year and a half ago, the Monacos became advocates for expanded newborn screening in Virginia. Caroline also has IVA, but she lives a normal, healthy life because of early detection. Caroline Monaco has become the example of what a simple test costing approximately \$30 per child can do, her parents say.

While doctors' groups support expanding Virginia's newborn screening, some anticipate that insurance companies may oppose the extra cost. But these tests will save the companies money, said Dumfries Delegate Jeffrey M. Frederick, R-52nd District.

"If you save one doctor visit, you've paid for it," said Frederick, who sponsored a bill that would expand Virginia's newborn screening program to 30 diseases.

Jana Monaco told the committee Stephen's medical bills are approaching \$1 million, and she spends many hours dealing with insurance companies.

The committee combined Frederick's bill with others that had emerged from the General Assembly Joint Commission on Health Care. The committee did not vote on the bill Thursday because of absent members, and will likely vote Tuesday.

A federal health commission is expected to release a report suggesting states screen for 30 diseases. March of Dimes representatives told the committee Virginia already has the technology in place to expand testing.

"We can not accept the risk of failing to identify a child when the consequences are so extreme," said Doris Clements, March of Dimes chair of public affairs.

During their mother's testimony, Stephen Monaco sat quietly in the corner of the room in his new wheelchair as Caroline Monaco wandered playfully.