Panel OKs infant health screenings

Sari Krieger Potomac News Wednesday, February 2, 2005

Newborns in Virginia may soon have 21 new health protections.

The House of Delegates Health, Welfare and Institutions Committee approved HB 1824 Tuesday. Delegate Jeffrey M. Frederick, R-Woodbridge; Delegate Kenneth R. Plum, D-Fairfax; and Delegate John J. Welch III, R-Virginia Beach, sponsored different versions of the bill, which the committee rolled into one.

The bill would expand the number of genetic diseases screened for at birth in Virginia hospitals from nine to approximately 30.

Woodbridge resident Jana Monaco has been an advocate on the state and national level for this expansion. She and her family testified for this committee two weeks ago. The committee heard her emotional statement, and saw her 7-year-old son Stephen, whose genetic disease caused his body to go into shock at age 3, severely disabling him for life.

If the Monacos had known he suffered from isovaleric acidemia, a disease detectable with equipment Virginia hospitals already use, they could have simply altered his diet. He would have lived a normal life. Now a good day for Stephen Monaco includes cracking a smile or a laugh.

Plum has been an advocate for newborn screening for 20 years, said Committee Chairman Delegate Phillip A. Hamilton, R-Newport News. Frederick submitted the bill after talking with residents during the past year, including Jana Monaco.

Stephen Monaco's body lacks the enzyme to break down the amino acid leucine, a byproduct of protein. His body couldn't handle a regular diet.

His younger sister Caroline Monaco will live a healthy life because her parents learned from Stephen's experience and had her tested early. She tested positive for the disease, but with an altered diet and medication, she continues to grow as a healthy, outgoing child.

The General Assembly Joint Commission on Health Care recommended Virginia expand its testing program to adhere to federal guidelines, which should recommend testing for approximately 30 diseases. The federal government does not require states to test for any specific number of diseases, so they vary.

Although insurance companies may shoulder the burden of these extra tests, the Virginia Association of Health Plans supports this bill, said executive director Doug Gray.

The committee reported the bill to the House Appropriations Committee to determine whether the \$570,000, or approximately \$30 per child, needed for this measure could come from state coffers. If the state passed the cost on to residents through

insurance companies, the companies would pay approximately \$56 per child, Hamilton said.

Stephen's medical bills are approaching the \$1 million mark.

"This will save a ton of money," Frederick said.

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