

Dodd pushes for law to increase testing for birth disorders

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STAMFORD -- Soon after Jonathan Sweeney's birth three years ago, he developed a near-fatal metabolic disorder. As he clung to life in a coma, his parents, Pam and Tom Sweeney, discovered some shocking news: His condition was preventable.

The Sweeneys are among a growing number of parents who were not informed of additional newborn screenings.

Along with Jonathan, now 4, the Sweeneys joined U.S. Sen. Christopher Dodd, D-Conn., yesterday during a tour of the neonatal unit at Stamford Hospital.

Dodd, who was invited by the March of Dimes, is hoping to put \$2 million toward a law requiring screenings for up to 30 disorders for all newborns.

Connecticut enacted legislation last year expanding the screening of newborns for a series of metabolic and digestive disorders. The bill was sponsored by state Sen. David Capiello, R-Danbury, after the birth of his nephew, Jonathan.

"If we had known the tests were available to us, we would have done them," Pam Sweeney said.

Before the law, Connecticut screened for nine out of 10 disorders, including hearing defects. Dodd has included \$2 million in a bill that would provide funding to the federal Health Resources and Services Administration to support grants to improve newborn screenings. If the funding is appropriated, grants would be available to states for enhancing, improving or expanding screening.

"Awareness is the second-best thing to have next to the state enacting a law to mandate the additional testing," Capiello said.

The March of Dimes endorsed the state legislation and is lobbying Congress to pass a federal version. The nonprofit health organization recommends every baby born in the United States have access to screening for a minimum of nine metabolic disorders as well as defects.

"The good news is that we are able to make such an impact in peoples' lives by preventing these disorders," Dodd said. "The bad news is we need to do a better job. There is an awful lot more we can do."

Capiello said he was inspired by his sister's plight to keep her son healthy. Though he doesn't suffer much from the disorder today, Jonathan has been hospitalized several times with high fevers and ear infections.

"The biggest drawback to the bill was funding it," Capiello said. "But the cost to support the law will result in a substantial cost savings to treat those with lifelong defects that go undetected. It also helps save lives."

Dr. Gerald Raikos, director of pediatrics at Stamford Hospital, said when the tests are done

immediately after birth, it can mean the difference between a healthy life and a severe disability for a baby.

"The more disorders that we can detect and treat to prevent long-term disability, the better," Raikos said.

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