

Information to improve for parents of babies diagnosed with Down syndrome

By Maria Wiering

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UPDATED 9 a.m. May 6, 2014: Twenty-two years ago, Nicol Hudson found out that her unborn son, two months from his due date, showed signs of Down syndrome in an ultrasound.

The Essex mom didn't know what that meant for her son, she said, but the materials her doctor provided did not help. The document was outdated and used words like "retarded" and "Mongoloid." Her doctor's attitude made things worse – she asked if Hudson and her husband wanted to consider putting their baby up for adoption. The Hudsons didn't.

Accompanied by Alex, her son with Down syndrome, Hudson, 45, shared her experience with Maryland legislators in February to support a bill requiring the Maryland Department of Health and Mental Hygiene to provide up-to-date, evidence-based, written information about Down syndrome to health care facilities for parents of children diagnosed with Down syndrome.

The General Assembly passed the bill April 7, just minutes before its 2014 session adjourned. The information is designed for prenatal and postnatal diagnoses and would cover development, health care expectations, quality of life issues and resources for support. Gov. Martin J. O'Malley signed the bill into law May 5.

The negative experience Hudson had years ago is similar to what some parents of babies with Down syndrome face now, she said.

"We hear stories where women have a prenatal or postnatal diagnosis that they either receive no information, or the information they receive is very out-of-date and does not reflect what people with Down syndrome are doing today," said Sara Weir, National Down Syndrome Society (NDSS) vice president of advocacy and affiliate relations.

The video below gained worldwide attention for its heartwarming message about the type of life a child with Down Syndrome can live.

The Maryland Catholic Conference in Annapolis worked with the Washington-based NDSS and Maryland Down syndrome coalitions to push for the bill's passage.

"The church got involved because of the Archdiocese of Washington, which supports

a huge disability community, brought the issue to us,” said Andrea Garvey, MCC associate director for respect for life.

“This is trying to raise the standard of health care for parents and children,” she said. “Down syndrome is the most tested for condition in prenatal testing.”

According to the NDSS, Down syndrome occurs in one of every 691 babies born in the United States. It is the most commonly occurring chromosomal condition.

The Maryland bill was inspired by a 2008 federal law co-sponsored by then-Senators Sam Brownback (R-Kan.) and Edward Kennedy (D-Mass). The Prenatal and Postnatal Conditions Awareness Act required the U.S. Department of Health and Human Services to expand and develop national resources for parents of children with disabilities, as well as expand peer-support programs.

The Maryland bill sought to build from the federal legislation by improving the information and resources available through the DHMH, and by raising doctors’ awareness about the spread of inaccurate information, Weir said.

Similar legislation has passed in Kentucky, Massachusetts and Missouri.

An early version of Maryland’s bill would have compelled doctors to provide updated information, but it was amended to say that doctors “may provide” the information to parents.

The MCC and coalition partners said they plan to continue to work with the DHMH and health care providers to ensure parents receive the information at the time of diagnosis.

The NDSS provides information about Down syndrome, including a “New and Expectant Parent Guide,” on its website. Other resources are available through the National Center for Prenatal and Postnatal Down Syndrome Resources at the University of Kentucky’s Human Development Institute.

The Internet has improved access to information about Down syndrome, but it also perpetuates misinformation, said Hudson, a systems analyst in development for the Archdiocese of Baltimore.

Maryland’s legislation is an opportunity to standardize the information parents receive and provide resources for support, Hudson said.

“These materials are out there,” she said. “They’re readily available, they’re written by medical professionals. Why not have that for parents?”

She added: “There is so much potential out there for people with disabilities, not only (those) with Down syndrome. I want for them to be able to see that their lives are valuable and that their future is bright.”

This article was originally published April 26, 2014.

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