



To: Members of the Joint Committee on Public Health

From: Maureen Gallagher, Executive Director and Sarah Cullen, Family Support Director, Massachusetts Down Syndrome Congress

RE: Testimony for H.B. 1528: “An Act Relative to Down syndrome genetic test results”

Date: May 10, 2011

Bill Sponsor: Representative Tom Sannicandro

We are here today to testify on behalf of H.B. 1528 - An Act Relative to Down syndrome genetic test results.

Being pregnant is about to change dramatically this fall. According to biotech companies, there will be a new blood test that promises to detect Down syndrome during the first trimester with, perhaps, no need for invasive procedures such as amniocentesis. This change has a lot of benefits: more women will have access to safer tests that are less expensive on the healthcare system. However, these new tests will also be coming at a time when there is a critical absence of information for expectant parents.

This bill will ensure that accurate, updated information and resources are available to expectant couples in order for them to make informed decisions about their pregnancy.

The Massachusetts Down Syndrome Congress is a statewide organization dedicated to providing information, networking and advocacy for and about Down syndrome. We represent over 5,000 individuals with Down syndrome and their families in the Commonwealth. We are not a pro-life or a pro-choice organization, we are a pro-information organization.

Each year, the MDSC serves more than 125 parents through a nationally acclaimed program called Parents' First Call. The goal of the program is to provide accurate, up-to-date, balanced information to both new and expectant families who have received the

diagnosis of Down syndrome. The First Call program also offers the opportunity to speak with a trained parent mentor.

Receiving the diagnosis of Down syndrome is a life-changing moment. Parents have described their reaction to this diagnosis with words such as: shocked, scared, alone, overwhelmed, blindsided.

MDSC and our First Call Program respect the very personal, very private choice that expectant parents must make. However, we believe strongly that expectant parents must be presented with accurate, up-to-date, balanced information in order to make a well-informed decision.

We have a new prenatal booklet “Understanding a Down Syndrome Diagnosis”, by Lettercase, which was created with input and consensus from both the medical and Down syndrome communities that we have available to share with expectant parents. The booklet covers common medical conditions for babies with Down syndrome, information about all pregnancy options and helpful resources. The booklet also includes a Spanish translation and has been optimized for different reading levels. The MDSC provides this booklet to all prenatal families who contact us, as well as to medical professionals who are in the position of delivering this diagnosis prenatally. Should this legislation be passed, we could work in partnership with the Department of Public Health to ensure that all expectant parents have access to this new booklet.

In addition, the MDSC provides all expectant families the opportunity to speak with a trained First Call parent who also found out prenatally and who struggled with the decision. This connection allows an expectant family to ask questions about the realities of raising a baby with Down syndrome in a confidential, non-judgmental, supportive conversation.

Our experience in working with over 500 new or expectant parents over the past five years has shown that many parents who receive the diagnosis of Down syndrome either receive inaccurate or outdated information or no information at all. They are left to their own resources to seek out information and support.

The Center for Disease Control has updated the national birth statistics which state that 1 in every 691 births is a baby with Down syndrome. Given Massachusetts birth statistics, those numbers would then support that there are approximately 112 babies with Down syndrome born in MA each year. There are many more who are receiving a prenatal diagnosis of Down syndrome, and who unfortunately are receiving inaccurate or incomplete information.

The scenario that the MDSC would like to see as the standard is similar to this recent story that an expectant couple shared with us. Upon learning the diagnosis of Down syndrome, the couple was counseled by a geneticist on the three potential options, given accurate written information, including the booklet “Understanding a Down

Syndrome Diagnosis”, and was given information on the MDSC Parents’ First Call program, which then connected them with a number of other families upon their request. They were encouraged to speak with a couple who had chosen to terminate as well. This expectant couple was offered balanced, timely, up-to-date information so that they could make the personal decision that was right for them.

A recent study in an OB/GYN journal shows that 45% of obstetric fellows say that their training in how to deliver a diagnosis of Down syndrome is “barely adequate” to “nonexistent.”

We are saying that a knowledgeable base of information, referral and support services is already in place in this state. MDSC currently outreaches to health care professionals in a variety of ways, to share information on best practices of delivering the diagnosis of Down syndrome, as well as to share local resources, including information about our First Call program and local support groups. MDSC has presented to Grand Rounds at hospitals, genetic counseling groups, medical professional students, maternity nurses, NICU staff and more.

However, we strive for stronger collaboration with health care professionals to share best practices for delivering a diagnosis of Down syndrome and supporting new and expectant families. We can provide a variety of resources for their use, including balanced, accurate information such as the “Understanding a Down Syndrome Diagnosis” booklet. Last year we reached over 350 health care professionals, however, there are still many more health care professionals that have not been reached.

Summary

Our experience in working with over 500 new or expectant parents over the past five years has shown that many parents who receive the diagnosis of Down syndrome receive inaccurate or outdated information or no information at all. They are left to their own resources to seek out information and support.

We ask that you vote favorably in support of H.B. 1528 so that every parent receiving a prenatal diagnosis of Down syndrome will receive immediate, accurate, up-to-date information so that they can make a well-informed decision that is the best decision for them. They deserve nothing less.

We appreciate your support of this bill.