

MDSC Prenatal First Call and MA Legislation Update



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Prenatally & Postnatally Diagnosed Condition Act (P.L. 110-34)



- ▶ The Prenatally & Postnatally Diagnosed Condition Act (P.L. 110–34) was enacted into federal law in 2008 to increase the readiness of accurate, up-to-date, and balanced information about Down syndrome to women and families considering prenatal testing, and the state of Massachusetts recently followed suit and passed a similar state law. The focus on recent federal and state legislation is a result of the many ways to screen for and diagnose Down syndrome during a pregnancy, including new noninvasive prenatal tests (NIPT) available in select markets.

What Does the Federal Law Do?

- ▶ Provides accurate, up-to date info to pregnant women and physicians
- ▶ Provides accurate, up-to date info to women who get a post-natal diagnosis
- ▶ Referrals of women who get a prenatal diagnosis to community resources
- ▶ Develops and distributes accurate information



Why Advocate for State Legislation?

- ▶ The Prenatally & Postnatally Diagnosed Condition Act (P.L. 110-34) is not a mandate and funding for its implementation is limited.
- ▶ State legislation has the ability to be more closely monitored and build on the MDSC's work in educating health care professionals and supporting parents across Massachusetts.
- ▶ The MDSC has a firm pro-information position that has bi-partisan support – every couple in Massachusetts receiving a pre-natal or postnatal diagnosis should have access to up-to-date accurate information and supports.
- ▶ We need funding to disseminate balanced and accurate materials to new and expectant couples and to staff our First Call program.
- ▶ With the emergence of new prenatal blood tests it is more important than ever before to have a law like this on the books in Massachusetts.

Prenatal Bill in Massachusetts Signed into Law on June 22, 2012



What the new Massachusetts Law Says

An Act Relative to Down Syndrome Genetic Test Results

Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same as follows:

Chapter 111 of the General Laws is hereby amended by inserting after section 70G the following section:—

Section 70H. (a) For the purposes of this section, the term “Down Syndrome” shall mean a chromosomal condition caused by an error in cell division that results in the presence of an extra whole or partial copy of chromosome 21. A facility, as defined in section 70E, physician, health care provider, nurse midwife or genetic counselor who renders prenatal care, postnatal care or genetic counseling shall, upon receipt of a positive test result from a test for Down Syndrome, provide the expectant or new parent with information provided by the department under subsection (b).

(b) The department shall make available to a person who renders prenatal care, postnatal care or genetic counseling to parents who receive a prenatal or postnatal diagnosis of Down Syndrome the following: (i) up-to-date evidence-based, written information about Down Syndrome that has been reviewed by medical experts and national Down Syndrome organizations; provided, however, that the written information provided shall include physical, developmental, educational and psychosocial outcomes, life expectancy, clinical course and intellectual and functional development and treatment options; and (ii) contact information regarding first call programs and support services, including information hotlines specific to Down Syndrome, resource centers or clearinghouses, national and local Down Syndrome organizations including the Massachusetts Down Syndrome Congress, and other educational and support programs. The department may also make such information available to any other person who has received a positive test result from a test for Down Syndrome.

(c) Information provided under this section shall be culturally and linguistically appropriate for a woman receiving a positive prenatal diagnosis and for the family of a child receiving a postnatal diagnosis of Down Syndrome.

Implementing the New Bill

- ▶ The Commissioner of the MA Department of Public Health will be mailing a letter in the next couple of weeks to ob/gyns, geneticists, maternal and fetal medicine specialists and neo-natal and peri-natal practitioners to inform them about the new law.
- ▶ The memo will direct individuals who deliver a diagnosis of Down syndrome to expectant couples to a new DPH webpage www.mass.gov/dph/downsyndrome.
- ▶ The prenatal booklet “Understanding a Down Syndrome Diagnosis” will be made available free of charge through the Health Promotion Clearinghouse.

What's Happening in Other States?

- ▶ In March, North Dakota became the first state in the USA to ban abortions in the case of genetic conditions such as Down syndrome.
- ▶ Several other states, Virginia, Kentucky, and Missouri have passed laws requiring that women with a prenatal Down syndrome diagnosis receive “accurate up-to-date” information about the condition.

NDSS Toolkit

<http://www.ndss.org/en/Advocacy/Advocacy-Programs/NDSS-Government-Affairs-Committee-GAC-Program/NDSS-Prenatal-Information-State-Law-Toolkit/>

NDSS & MDSC TOOLKIT

MODEL LEGISLATION

- Sample Prenatal Testing Information Model Legislation

PRESS RELEASE

- Sample Prenatal Testing Information Press Release

TESTIMONY EXAMPLES

- Sample Down Syndrome Organization Testimony
- Sample Advocate Parent Testimony
- Sample Developmental Disabilities Council Testimony
- Sample Physician Testimony



Follow us



MDSC Parents First Call Program

- ▶ Serve families both prenatally and after delivery
- ▶ Accurate, up-to-date, balanced information
- ▶ *Opportunity* to connect with a trained First Call parent mentor

Parents First Call Program

- ▶ National gold standard program
 - Program replication in seven states
 - Down Syndrome Affiliates in Action
- ▶ Support over 140 new and expectant families each year

First Call Mentor Parents

- ▶ 40+ trained First Call parent volunteers

- Statewide
- Dads
- Cultural background
- Language
- Faith
- Medical concerns
- City/town

MDSC Prenatal Pre-Decision First Call

Goal is that all expectant couples receiving a prenatal diagnosis will receive accurate, up-to-date, balanced information and the opportunity to speak with a trained mentor so they can make an informed decision.

Prenatal Pre-Decision Parent Volunteers

- ▶ Only parents who found out their child's diagnosis prenatally and weighed all of the pregnancy options
- ▶ Understand that some families may choose not to continue the pregnancy
- ▶ Agree to outreach only ONE time

Training Collaboration

- ▶ Additional 2-hour training for prenatal pre-decision parent volunteers with Mary-Frances Garber, MS, CGC to include:
 - Non-directive skills
 - Listening skills and reflecting
 - Understanding grief and emotional processes
 - Understanding the options
 - Resource sheet for families
- ▶ Emotional support for prenatal pre-decision parent volunteers

Prenatal Resources

- ▶ Booklet Called “Understanding a Down Syndrome Diagnosis”



Prenatal Resources

- ▶ www.downsyndromepregnancy.org
 - “Diagnosis to Delivery: A Pregnant Mother’s Guide to Down Syndrome” (downloadable book) – POST DECISION (continuing pregnancy)
 - Blog
 - Discussion board

Prenatal and Postnatal Resources

- ▶ www.brightertomorrow.org
 - English and Spanish
- ▶ “Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Our Lives”
 - Edited by Kathryn Lynard Soper – collection of personal stories is a source of validation and inspiration to parents receiving the diagnosis

Postnatal Resources

- ▶ Resource folder
- ▶ Book – “Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Our Lives”
- ▶ Book – “Down Syndrome 101”
- ▶ New Parent Socials
- ▶ Support Groups

Accessing MDSC First Call Program

- ▶ 800-664-MDSC
- ▶ scullen@mdsc.org
- ▶ FAX release forms

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Questions?

