Landmark Prenatal Testing Bill Signed Into Law

Expectant parents to get latest, culturally-appropriate information on Down syndrome

Boston, MA - It was an historic day for people with Down syndrome, their families and those who love them in Massachusetts. Just after noon, in the Governor's chambers of the State House, surrounded by more than a dozen legislative leaders, parents of people with Down syndrome and self-advocates, Governor Patrick signed landmark legislation that promises to bolster a bright future for the Down syndrome community in the Bay State.

An Act Relative to Down Syndrome Genetic Test Results (H3825), modeled on the national Kennedy-Brownback bill, will have a huge impact for decades to come. The new law mandates that new or expectant parents of children with Down syndrome are given the latest, culturally-appropriate information about what it means to have a child with Down syndrome and contact information for services to ensure they have access to the supports that every family in their position needs. The legislation specifically identifies the MDSC's Parent's First Call Program as a key resource for these families, formally recognizing our signature outreach program, which is a national model in the field.

The bill, the first state legislation of its kind in the nation, was sponsored by Rep. Tom Sannicandro of Ashland, whose son David has Down syndrome and Senator Katherine Clark of Melrose. Both have
been tireless champions of good disability policy. Given recent scientific developments around prenatal diagnosis, it was critical to get a bill like this on the books. The future is indeed bright for the Down syndrome community in Massachusetts.

MDSC Executive Director Maureen Gallagher commented that Massachusetts “will now have a mandate to provide accurate, up-to-date, balanced information about Down syndrome to people receiving a diagnosis of Down syndrome prenatally or postnatally. We'll have the ability to make a profound difference in the way people receive the diagnosis along with appropriate information, resources and supports,” she said.

In his remarks, the Governor said that the legislation “gives parents additional resources to make informed decisions for their families.” Lt. Governor Tim Murray added: “We strongly support the sharing of useful and timely health information with all patients. This bill will provide expecting families with critical information reviewed by medical experts and also takes an extra step to ensure expecting parents have the appropriate support and resources.” According to Rep. Sannicandro, “This bill is about providing the most accurate and up-to-date information about Down syndrome. I am proud to see it signed.”

New Science
Last fall, the San Diego-based biotech company Sequenom released the first non-invasive prenatal test for Down syndrome, piloting it in 20 cities in the United State. This advancement was not unexpected, but it was unprecedented. It signaled a not-far-off future in which expectant parents will routinely receive an accurate prenatal diagnosis for Down syndrome and other chromosomal conditions early in their pregnancy.

Today, there are two other such non-invasive prenatal tests on the market, all of which are being used in a limited fashion throughout the country and internationally. These tests are not yet routine for all pregnant moms, but we know they will be within the next decade if not sooner. At the MDSC, we understand that parents want to know as early as possible whether they are having a child with Down syndrome. In fact, it is this very respect for the right of expectant parents to have as much information as possible that underlies our position and this legislation.
The Bill
According to the new law, medical professionals are required to give parents who receive a prenatal or postnatal diagnosis "up-to-date, evidence-based, written information about Down syndrome that has been reviewed by medical experts and national Down syndrome organizations."

The written information provided must include "physical, developmental, educational, and psychosocial outcomes, life expectancy, clinical course, and intellectual and functional development and treatment options." All of this information must be culturally and linguistically appropriate.

Furthermore, the law requires that these parents are given contact information for the MDSC's Parent's First Call Program and support services, "including information hotlines specific to Down syndrome, resource centers or clearinghouses, national and local Down syndrome organizations such as the Massachusetts Down Syndrome Congress, and other education and support programs."

Courageous Leaders & Everyday Heroes
The MDSC wants to publicly thank Governor Patrick and his Administration, including Department of Developmental Services Commissioner Elin Howe and Department of Public Health Commissioner John Auerbach; Lieutenant Governor Tim Murray, Senate President Therese Murray and Speaker of the House Robert DeLeo; Rep. Sannicandro and Sen. Clark, our Board of Directors, Honorary Board of Directors, Legislative Advocacy Task Force, Management Team, and MDSC members who we reached out to for help and advocacy.

More in the Works
The MDSC welcomes media inquiries about this important bill and other issues involving the Down syndrome community. This weekend, Board members will gather at the Turner Hill Country Club for a Board retreat. Executive Director Maureen Gallagher, Board President Louise Borke (whose son Louis has Down syndrome), Dr. Brian Skotko (an internationally acclaimed expert and co-director of MGH’s new comprehensive Down Syndrome Program) will all be in attendance. We welcome the press to come conduct interviews. Visit our Facebook page and YouTube page for photos and videos of the day. Wednesday, June 27th Channel 5's news magazine show Chronicle, featured the MDSC, our First Call program and our members in a program about how the lives of people with Down syndrome has
changed. The show includes MDSC Advocacy Specialist John Anton and Melanie Perkins McLaughlin (both of whom attended the ceremonies today and are pictured above with Melanie's daughter Gracie.) As the Chronicle promo puts it: "In the last three decades, the outlook has changed dramatically for people born with Down's syndrome: they live longer, have more independence, and participate more fully in society." This couldn’t be more true, and the MDSC is thrilled that with this bill the state has formally recognized what it actually means to have Down syndrome in this day and age.

About the MDSC

In the early years, parents met in a living room to share information about their children, provide support for each other and strategize how to educate their families, schools and communities. More than 28 years later, the MDSC has over 3,000 members, an energetic Board of Directors, a dynamic management team, and a vision to ensure that every person with Down syndrome has the opportunity to reach his or her full potential. Today, the MDSC is on the cutting edge of Down syndrome advocacy at a time when an innovative, forward-thinking vision is needed.

The MDSC offers a broad array of programs to serve people with Down syndrome and their families throughout the state, including: our signature Parent’s First Call Program, a volunteer, state-wide group of trained parent mentors available 24/7 that is a national model; two major annual conferences that draw national and international experts in their fields; a Buddy Walk® Program that gives individuals, schools, community groups, and local businesses an opportunity to get involved in fundraising campaigns and events year-round; a Teacher Partnership Network that matches educators with experience teaching students with Down syndrome with teachers who have limited or no experience; Self-Advocate Programs like Advocates in Motion and our Self-Advocate Advisory Council, which provide opportunities for teens and adults with Down syndrome while making empowerment a central component.

As we have over the past nearly three decades, the MDSC continues to ensure that all individuals in Massachusetts with Down syndrome are valued, included, and given every opportunity to pursue fulfilling lives.