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To the Distinguished Chair and Honored Members of the Committee.

Thank you for the opportunity to testify IN SUPPORT of HB 135, the Down Syndrome Non-Discrimination Act.

I am a cell biologist, currently working for the Charlotte Lozier Institute in Washington, D.C. as Vice President and Research Director; I also serve as adjunct professor of molecular genetics at a Washington, D.C. university, and as an Advisory Board Member for the Midwest Stem Cell Therapy Center, a unique comprehensive stem cell center in Kansas. Previously I spent 10 years as Senior Fellow for Life Sciences at another policy think tank in Washington, D.C., and prior to that almost 20 years as Professor of Life Sciences at Indiana State University, and Adjunct Professor of Medical and Molecular Genetics, Indiana University School of Medicine. Before that I was a faculty member in the Department of Obstetrics, Gynecology and Reproductive Sciences, University of Texas Medical School at Houston. I have done federally-funded laboratory research, lectured, and advised on these subjects extensively in the U.S. and internationally. I've taught embryology, developmental biology, molecular biology and biochemistry for over 30 years to medical and nursing students, as well as undergraduate and graduate students. I am testifying in my capacity as a scientist and on behalf of the Charlotte Lozier Institute.

Our genetic composition is determined at the moment of conception. That includes many genetic differences considered to be abnormalities, such as Down syndrome in which an individual has an additional, third copy of chromosome 21 (a "trisomy"); this is also determined at conception when the sperm and egg fuse to form the zygote, the single-celled human organism, a new human being.

Eugenics is the term given to attempts to control human heredity. In the past, including here in the United States, extensively documented in the archives at Cold Spring Harbor, such attempts have included efforts at selective breeding of "high-quality" individuals, selective sterilization of others to prevent offspring, and even infanticide. Today we see eugenic attempts based on specific genetic traits.

This bill, HB 135, deals with preventing discrimination based on genetic differences. While it might seem that this is a straightforward and logical protection that is unnecessary, there is ample evidence for the need of such protection.

Genetic discrimination abortions, in terms of those against genetic abnormality, show well-documented evidence involving bias against babies diagnosed *in utero* with Down syndrome. Studies show that such pre-born children are aborted at an extremely high rate. Documentation from other countries, which keep better records than the United States, tells a chilling tale.

In France, which keeps excellent records on prenatal screening as a matter of public policy, Bradford cites a 96% rate of abortion for those diagnosed in the womb with Down's.¹

In the U.K., an earlier study found a 92% abortion rate for children diagnosed in the womb with Down syndrome,² while a 2012 study found that 100% of those prenatally diagnosed with Down syndrome were aborted.³

In the U.S., a 1999 study found almost 87% of those diagnosed with Down syndrome in the womb were aborted.⁴ A 2012 review of the literature on this topic, looking only at U.S. data, found a weighted mean from 61% up to 93% of those diagnosed who were aborted.⁵ A new report just published in the *American Journal of Medical Genetics*, using rigorous statistical modeling of the sparse U.S. data from 2006-2010, finds that abortion after prenatal diagnosis has reduced the population of individuals living with Down syndrome in the U.S. by approximately 30%.⁶ Bradford's analysis cautions that this is not the percentage of women who abort following a prenatal diagnosis of Down syndrome, as that number would certainly be higher.⁷ Rather, this analysis illuminates the overall reduction in the Down syndrome population, considering total number of Down syndrome pregnancies, whether prenatally diagnosed or not. If prenatal screening using the newer non-invasive blood tests becomes more widely available, as seems likely, then the expectation is that the number of terminations will certainly increase.^{8,9}

Similar rates of selection against life are seen for babies diagnosed in the womb with other genetic conditions, or with physical abnormalities. Again, this is simply a modern version of eugenic selection.

Sometimes regarding these prenatal diagnoses, we hear the term "incompatible with life." Nora Sullivan points out that this label "portrays as a medical diagnosis what is really a judgment call about a profoundly disabled child's quality of life. The term is not only offensive to parents who object to the

¹ **Bradford M.** Improving Joyful Lives: Society's Response to Difference and Disability, American Reports Series Issue 8, June 2014, accessed at: <https://www.lozierinstitute.org/improving-joyful-lives-societys-response-to-difference-and-disability/>

² **Mansfield C et al.** Termination rates after prenatal diagnosis of Down syndrome, spina bifida, anencephaly, and Turner and Klinefelter syndromes: a systematic literature review, *Prenatal Diagnosis* 19, 808, 1999

³ **Nicolaidis KH et al.** Noninvasive prenatal testing for fetal trisomies in a routinely screened first-trimester population. *Am J Obstet Gynecol* 207, 374.e1, 2012

⁴ **Britt DW et al.**, Determinants of parental decisions after the prenatal diagnosis of Down syndrome: Bringing in context, *American Journal of Medical Genetics* 93, 410, 1999

⁵ **Natoli JL et al.** Prenatal diagnosis of Down syndrome: a systematic review of termination rates (1995-2011), *Prenatal Diagnosis* 32, 142, 2012

⁶ **de Graaf G et al.** Estimates of the live births, natural losses, and elective terminations with down syndrome in the United States. *Am J Med Genet Part A* 167A, 756, 2015

⁷ **Bradford M.** New Study: Abortion after Prenatal Diagnosis of Down Syndrome Reduces Down Syndrome Community by Thirty Percent, April 21, 2015, Accessed at: <https://www.lozierinstitute.org/new-study-abortion-after-prenatal-diagnosis-of-down-syndrome-reduces-down-syndrome-community-by-thirty-percent/>

⁸ **Chitty LS.** Use of Cell-free DNA to Screen for Down's Syndrome. *New Engl J Med* 372, 1666, April 2015

⁹ **Norton ME et al.** Cell-free DNA Analysis for Noninvasive Examination of Trisomy. *New Engl J Med* 372, 1589, April 2015

implication that their children's lives hold less value due to their potential brevity but also has serious implications as to how families perceive these disabilities and their decision-making process."¹⁰ The term is "medically meaningless, incorrect, and enormously hurtful." Indeed, a study in *Critical Care Medicine* noted that what doctors tell parents about their child's prognosis is often influenced by the doctor's own attitude toward neurological impairment.¹¹

Contrast the prevalent attitude about Down syndrome that leads to a lethal diagnosis, with the recent facts about increased life span, health, learning, and especially satisfaction for those with Down syndrome and their families. A recent study by Skotko *et al.* found that 99% of people with Down syndrome are happy with their lives, 99% of parents said they love their child with Down syndrome, and 97% of brothers/sisters, ages 9-11, said they love their sibling.¹²

Medical science has also improved significantly not only in terms of surgeries to alleviate some of the physical problems associated with Down syndrome, but also in potential pharmaceutical treatments. Bradford notes several clinical trials, all begun within the last five years, with drugs that are hoped will improve cognition for individuals affected by this condition.¹³

Other work has helped elucidate some of the genetic and cellular mechanisms that lead to tissue characteristics associated with Down syndrome. Work with a mouse model has shown that treatment of newborns with a genetic activator has therapeutic potential to improve cognitive function.¹⁴ Another group has shown a laboratory mechanism to remove the third (extra) chromosome from cells in culture,¹⁵ and a different team has provided laboratory evidence for possibly silencing the extra chromosome in a trisomy.¹⁶ A recent 2014 paper used an induced pluripotent stem cell model, with cells from Down syndrome patients, to show that certain neural cells called astroglia behave aberrantly in Down syndrome, but that an FDA-approved antibiotic drug, minocycline, can partially correct problems with these cells.¹⁷ Another study reported in April 2015 the discovery of a potential mechanism to explain some of the cognitive deficits seen with Down syndrome, and found that use of an FDA-approved drug, bumetanide, enhanced behavioral performance in learning and memory tests in a mouse model of Down syndrome.^{18,19}

¹⁰ Sullivan N. The Term "Incompatible with Life" is Incompatible with the Best Care, December 2014, Accessed at: <https://www.lozierinstitute.org/the-term-incompatible-with-life-is-incompatible-with-the-best-care/>

¹¹ Randolph AG *et al.* Factors explaining variability among caregivers in the intent to restrict life-support interventions in a pediatric intensive care unit, *Crit. Care Med.* 25, 435, 1997

¹² Skotko BG *et al.* Self Perceptions from People with Down Syndrome, *American Journal of Medical Genetics Part A* 155, 2360, 2011

¹³ Bradford M. *Ibid*

¹⁴ Das I *et al.* Hedgehog Agonist Therapy Corrects Structural and Cognitive Deficits in a Down Syndrome Mouse Model, *Science Translational Medicine* 5, 201ra120, September 2013

¹⁵ Li LB *et al.* Trisomy Correction in Down Syndrome Induced Pluripotent Stem Cells, *Cell Stem Cell* 11, 615, 2012

¹⁶ Jiang J *et al.* Translating dosage compensation to trisomy 21, *Nature* 500, 296, August 2013

¹⁷ Chen C *et al.* Role of astroglia in Down's syndrome revealed by patient-derived human-induced pluripotent stem cells. *Nature Communications* 5:4430, doi:10.1038/ncomms5430, July 2014

¹⁸ Deidda G *et al.* Reversing excitatory GABAAR signaling restores synaptic plasticity and memory in a mouse model of Down syndrome. *Nature Medicine* 21, 318, April 2015

¹⁹ Costa AC. Intracellular chloride accumulation: a possible mechanism for cognitive deficits in Down syndrome. *Nature Medicine* 21, 312, April 2015

The commercialized non-invasive prenatal tests have made screening much easier and earlier, but have also presented greater opportunities for selecting against individuals with genetic abnormalities, and not just for chromosome trisomies such as Down syndrome, but for an increasing list of genetic disorders and traits.²⁰ This should not be the case, but rather these tests should be used, as Dr. Diana Bianchi of Tufts Medical Center has noted, to “develop new approaches to fetal treatment.”²¹ For example, fetal surgery is undergoing a rapid expansion as more doctors and parents realize the possibility, and even advantage, of surgery while the child is still within the womb.²² We are also starting to see some conditions, including genetic abnormalities such as severe immune deficiencies²³ and osteogenesis imperfecta,²⁴ treated in the womb using adult stem cells or gene therapy. These are very young patients, and should be treated as such.

Donovan and Messner summarized arguments against disability discrimination abortions, provided by disability rights groups in an amicus curiae brief filed with the Supreme Court.²⁵ These disability rights groups point out: “Though some abortions of children with disabilities involve diagnoses that are likely to be fatal, many involve non-fatal conditions such as Down syndrome, cystic fibrosis, and spina bifida.” Even in these non-fatal cases, the statistics are alarming; they note “recent evidence suggests that as many as 95 percent of parents receiving a prenatal diagnosis of cystic fibrosis elect to terminate the child.” According to those disability rights groups, the Supreme Court “has never endorsed a right to abort children only because they have been detected to have a disability.”

HB 135 would provide necessary, distinct protections for developing human beings, preventing discrimination based on genetics or disability. Thank you for the opportunity to contribute to the discussion on this important issue.

²⁰ **Wong AIC and Lo YMD.** Noninvasive fetal genomic, methylomic, and transcriptomic analyses using maternal plasma and clinical implications, *Trends in Molecular Medicine* 21, 98, February 2015

²¹ **Bianchi DW.** From prenatal genomic diagnosis to fetal personalized medicine: progress and challenges, *Nature Medicine* 18, 1041, July 2012

²² See, e.g., the **Center for Fetal Diagnosis and Treatment**, Children’s Hospital of Philadelphia, accessed at: <http://www.chop.edu/centers-programs/center-fetal-diagnosis-and-treatment>

²³ **Loukogeorgakis SP and Flake AW.** In utero stem cell and gene therapy: Current status and future perspectives, *Eur J Pediatr Surg* 24, 237, 2014

²⁴ **Chan JKY and Götherström C.** Prenatal transplantation of mesenchymal stem cells to treat osteogenesis imperfecta, *Frontiers in Pharmacology* 5, 1, October 2014.

²⁵ **Donovan CA and Messner T.** Twenty-Week Bans Raise Issue of Disability Discrimination Abortion, Charlotte Lozier Institute On Point Series 4; November 2013. Accessed at: <https://www.lozierinstitute.org/twenty-week-bans-raise-issue-of-disability-discrimination-abortion-2/>. Original brief accessed at: <http://sblog.s3.amazonaws.com/wp-content/uploads/2013/11/FILED-AmicusLeJeuneSDiDSC-BDF.pdf>, filed by the Bioethics Defense Fund, Scottsdale, Arizona, <http://www.bdfund.org/>.