CHARLOTTE LOZIER INSTITUTE

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To the Distinguished Chair and Honored Members of the Committee.

Thank you for the opportunity to testify IN SUPPORT of SB 334, the bill to prohibit prenatal discrimination, by prohibiting abortion based on sex selection or genetic abnormality.

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 an adjunct professor 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 was almost 20 years a 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.

This bill deals with preventing discrimination based on gender, or based on genetic differences, in pre-born human beings. While it might seem to some people that this is a straightforward and logical protection that is unnecessary, there is ample evidence for the need of such protection.

Gender in humans is determined by the sex chromosomes, X and Y, within an individual's cells. If you have two X chromosomes (XX) you are female, if XY you are male. This genetic composition is determined at the moment of conception. Likewise many genetic abnormalities, such as Down syndrome in which an individual has an additional chromosome 21, Edwards syndrome which is trisomy 18, Patau syndrome which is trisomy 13, and numerous other single-gene and multi-gene problems, are determined at conception when the sperm and egg fuse to form the zygote, the single-celled human organism.

Eugenics is the term given to attempts to control human heredity. In the past, 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 at what some have termed "gendercide," usually selecting for boys and against girls, in the womb or as embryos in the laboratory.

There is ample evidence to show that gender selection abortion occurs in countries such as China and India.[1] One group even claims that the three deadliest words in the world are "It's a girl."[2] Globally it is estimated that there are between 160 million and 200 million missing girls, due to sex-selection abortion.[3]

But this problem also occurs in the United States, Canada, and other Western nations. The lack of proper records or mandated reports makes it more difficult to accumulate data on prenatal gender discrimination in North America, but there are now a number of studies that document similar sex-selection abortions taking place in the U.S. and in Canada,[4] and evidence as well for the U.K.[5] As in other countries, the targets are primarily girls, selected against for birth. Some opponents of prohibitions against sex-selection abortions state that such abortions are rare, but that is a tacit admission that some sex-selection abortions occur. Even one gender discrimination abortion is too many.

Chapman and Benn note that the availability of a "non-invasive prenatal test" (NIPT) that analyzes DNA fragments in the mother's blood plasma may lead to greater sex selection in developed countries.[6] Some centers now even advertise the ability to determine fetal gender as early as 10 weeks post-fertilization,[7] and published papers are pushing this determination even earlier, to 7 weeks[8] or even 6 weeks[9] after conception.

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[1] **Sachan D**. India's problem with girls, *BMJ* 347, f4149, August 2013; **Kay M**. Five Tamil Nadu doctors banned from practice for violating prenatal sex selection law of an unborn child, *BMJ* 346, f3788, June 2013; **Jha P *et al*.**, Trends in selective abortions of girls in India: analysis of nationally representative birth histories from 1990 to 2005 and census data from 1991 to 2011, *Lancet* 377, 1921, 2011; **Xu WX *et al*.,** China's excess males, sex-selective abortion, and one child policy: analysis of data from 2005 national intercensus survey, *British Medical Journal* 338, b1211, 2009; **Hesketh T *et al***., The consequences of son preference and sex-selective abortion in China and other Asian countries, CMAJ 183, 1374, 2011

[2] It's a girl, http://www.itsagirlmovie.com/

[3] **Mara Hvistendahl**, *Unnatural Selection: Choosing Boys over Girls, and the Consequences of a World Full of Men*, Public Affairs Publishing, p. 5-6 (2011). Hvistendahl writes that an estimated 163 million females were demographically `missing' from Asia alone, as early as 2005; ***United Nations Fact Sheet**: International Women's Day 2007, available at* http://www.un.org/events/women/iwd/2007/factsfigures.shtml.]

[4] **Kale R**, "It's a girl!"--could be a death sentence, *CMAJ* 184, 387, 2012; **Almond D and Edlund L**, Son-biased sex ratios in the 2000 United States Census, *Proceedings of the National Academy of Sciences USA*, 105, 5681, 2008; **Abrevaya J**, Are there missing girls in the United States? Evidence from birth data, *American Economic Journal: Applied Economics* 1, 1, 2009; **Puri S and Nachtigall R**, The ethics of sex selection: a comparison of the attitudes and experiences of primary care physicians and physician providers of clinical sex selection services, *Fertility and Sterility* 93, 2107, 2010; **Puri P *et al*.**, 'There is such a thing as too many daughters, but not too many sons': A qualitative study of son preference and fetal sex selection among Indian immigrants in the United States, *Social Science and Medicine* 72, 1169, 2011; **Egan JFX *et al*.**, Distortions of sex ratios at birth in the United States; evidence for prenatal gender selection, *Prenatal Diagnosis* 31, 560, 2011.

[5] **Adamou A *et al.*** Missing women in the United Kingdom, *IZA Journal of Migration* 2, 10, 2013

[6] **Chapman AR and Benn PA.** Noninvasive Prenatal Testing for Early Sex Identification: A Few Benefits and Many Concerns, *Perspectives in Biology and Medicine* 56, 530-547, 2013

[7] See, *e.g.*, Prenatal Genetics Center, accessed at: http://www.prenatalgeneticscenter.com/

[8] **Devaney SA *et al.*** Noninvasive Fetal Sex Determination Using Cell-Free Fetal DNA, *JAMA* 306, 627, August 2011

[9] **Fernández-Martínez FJ *et al*.** Noninvasive fetal sex determination in maternal plasma: a prospective feasibility study, *Genet Med* 14, 101, 2012

Genetic discrimination abortions, in terms of those against genetic abnormality, show well-documented evidence involving discrimination 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, who 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.[10] In the U.K., an earlier study found a 92% abortion rate for children diagnosed in the womb with Down syndrome,[11] while a 2012 study found that 100% of those babies diagnosed in the womb with Down syndrome were aborted.[12]

In the U.S., a 1999 study found almost 87% of those diagnosed with Down syndrome in the womb were aborted.[13] 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.[14]

Similar rates of selection against life are seen for babies diagnosed in the womb with other genetic conditions, or even 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 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."[15] She tells the story of Tracy Harkin, a spokeswoman for the group Every Life Counts, and the mother of 8-year-old Kathleen Rose who was born with Trisomy 13. Harkin points out that 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.[16]

Moreover, while older texts say that around 90% of children born with Trisomy 18 don't live as long as a year, this is simply outdated information. For example, Bella Santorum, daughter of former Sen. Rick

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[10] **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/

[11] **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

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

[13] **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

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

[15] **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/

[16] **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

Santorum, will be 7 years old this May. Mrs. Santorum says that "Bella's a little girl with a big message, that every person matters. She's here for a reason."[17]

Indeed, more and more children with genetic conditions like Bella and Kathleen Rose are surviving, and thriving.[18] A recent study by doctors at the Children's Hospital of Philadelphia, published in the journal *Pediatrics*, points out the improvements, noting: "Despite the conventional understanding of these syndromes as lethal, a substantial number of children are living longer than 1 year and undergoing medical and surgical procedures as part of their treatment."[19]

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.[20]

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.[21]

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.[22] Another group has shown a laboratory mechanism to remove the third (extra) chromosome from cells in culture,[23] and a different team has provided laboratory evidence for possibly silencing the extra chromosome in a trisomy.[24] A recent 2014 paper used a 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.[25]

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[17] **Dan Majors**. "Rick and Karen Santorum's book shares daughter's struggle with rare disease," Pittsburgh Post-Gazette, Feb 13, 2015; accessed Feb 16, 2015 at http://www.post-gazette.com/news/state/2015/02/13/Rick-Santorum-s-book-shares-daughter-s-struggle-with-rare-disease/stories/201502130105

[18] **Gann C.** "Trisomy 18 and 13: More Children Like Bella Santorum Survive," ABC News, April 2012, accessed at: http://abcnews.go.com/Health/trisomy-18-kids-bella-santorum-rick-santorums-daughter/story?id=16090571

[19] **Nelson KE *et al.*** Inpatient Hospital Care of Children With Trisomy 13 and Trisomy 18 in the United States, *Pediatrics* 129, 869, 2012

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

[21] **Bradford M.** Ibid

[22] **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

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

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

[25] **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

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 but for an increasing list of genetic disorders and traits.[26] 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."[27] 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.[28] We are also starting to see some conditions, including genetic abnormalities such as severe immune deficiencies[29] and osteogenesis imperfecta,[30] 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.[31] 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."

It is often claimed that late-term abortions in particular are largely due to discovery of fetal abnormalities or health of the expectant mother. However, Dr. Priscilla Coleman reported in 2010 (citing the Guttmacher Institute) that "the vast majority of late-term abortions are performed for socio-economic reasons, on a healthy and potentially viable fetus." Her report also states that "Fetal abnormalities or woman's health considerations are rarely the reason for undergoing a late-term abortion."[32] Similar results were reported by Dr. Elizabeth Johnson in 2015, analyzing a paper published in a journal of the Guttmacher Institute.[33] Dr. Johnson points out that rather than the usually-cited reasons of fetal abnormalities or health considerations, women seek abortion because of the stress

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[26] **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

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

[28] 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

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

[30] **Chan JKY and Götherström C.** Prenatal transplantation of mesenchymal stem cells to treat osteogenesis imperfecta, *Frontiers in Pharmacology* 5, 1, October 201.

[31] **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/.

[32] **Coleman PK.** Late-term Abortion: Antecedent Conditions and Consequences to Women's Health, The Human Family Research Center, October 2010. Accessed at: http://humanfamilyresearch.org/HFRC%20womens%20health%20and%20late-term%20abortion.pdf

[33] **Johnson E.** The Reality of Late-Term Abortion Procedures, Charlotte Lozier Institute On Point Series 9, January 2015; accessed at: https://www.lozierinstitute.org/the-reality-of-late-term-abortion-procedures/

of “unprepared pregnancy, single-motherhood, financial pressure and relationship discord.” She also notes that these stresses “are not fundamentally alleviated or ameliorated by late-term abortion. Indeed, late-term abortion places these women at greater risk of surgical complications, subsequent preterm birth, and mental health problems, while simultaneously ending the life of an unborn child.”

SB 334 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.