Written Testimony in Support of HB 135

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I. Greetings

Good afternoon, Mr. Chairman and members of this distinguished committee. My name is Dr. Ashley Fernandes. I reside in Hilliard OH. I am pleased to give my expert opinion before this committee in support of HB 135, and I intend to briefly address four principal areas: medicine, ethics, the law, and history.

II. Qualifications

I am a pediatric physician, and have been licensed to practice medicine in the state of Ohio since 2006. I grew up in Toledo, OH and completed two undergraduate degrees at The University of Toledo—one in Biology and one in Philosophy, in 1994. I received a Masters degree in Philosophy from Johns Hopkins University in 1999;

my MD degree from The Ohio State University in 2003; and a PhD in Philosophy with a concentration in Bioethics from Georgetown University in 2008. I completed pediatric residency training at St. Louis University in 2006, and then taught and practiced pediatric medicine and ethics at Wright State University School of Medicine. In 2014, I returned to The Ohio State University where I am now the Associate Director of the Center for Bioethics and Medical Humanities and an Associate Professor of Pediatrics at The Ohio State University and Nationwide Children's Hospital.

III. Medical and Clinical Aspects: Quality of Life:

Ladies and gentleman, Down Syndrome, or Trisomy 21, is a chromosomal disorder where an effected person has a genotype with an extra 21st chromosome, in whole or in part, and leads to a phenotypic spectrum with certain typical features such as small stature, epicanthal folds of the eyes, and usually mild developmental disabilities—although the phenotype varies widely. These special people are also more likely to be born with congenital heart defects, have endocrine problems such as low thyroid and diabetes, and are at higher risk of leukemia in childhood.

I am aware that the committee has heard medical testimony already, and so I intend to briefly speak from my expertise as a board certified pediatrician and address the issue of quality of life, which looms large in this debate. Opponents of this bill argue that the worries about the burden of having a child with Down Syndrome are too great, and that a woman with a prenatal diagnosis ought to be able to abort that unborn child if she chooses. Testimony from Jaime Miracle of NARAL Ohio to this committee on June 2, 2015 makes this clear. Ms. Miracle rhetorically asks a series of questions that she speculates go through the mind of those faced with such a choice, first of which is "Can I raise a child with disabilities?"

Both my personal experience as a pediatrician and the medical literature are quite clear on this question. Yes, women can, and do. The more our state affirms and values the lives of these individuals from conception, the greater the impetus to refine and improve the support structures which are so crucial to the quality of life of these children and their families.

The medical literature, for example, supports the notion that the quality of life of families is dependent on the psychological support and social support they receive more than medical or socio-economic factors.[1] Women choose to terminate after a prenatal diagnosis of Down Syndrome because of psychosocial factors such as the *perceived* parenting burden and *perceived* quality of life of children with Down Syndrome, their familiarity and attitudes toward persons with disabilities, and their support from others.[2] These are mutable, reversible factors that are dependent upon our efforts and us and do not involve killing anyone. Abortion—which takes

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[1] Hatzmann J, Valstar MJ, Bosch AM, Wijburg FA, Heymans HS, Grootenhuis MA. Predicting health-related quality of life of parents of children with inherited metabolic diseases. Acta Paediatr. 2009 Jul;98(7):1205-10.

[2] Choi, H., Riper MV, Thoyre S. Decision making following a prenatal diagnosis of Down Syndrome: an integrative review. J of Midwifery and Women's Health 2012; 57: 156-164.

place in more than 90% of those with a prenatal diagnosis of Down Syndrome—is irreversible. In short, stigma—or lack of it—is critical to women who under the current system must make these decisions. Those decisions about societal support for children with Down Syndrome will consistently be undermined if women and their doctors are allowed to make a "choice"—in absolute value—which says that such life is disposable.

Two recent, large studies in the *American Journal of Medical Genetics* examined the impact of having a child with Down Syndrome on both parents and siblings.[3,4] Both studies demonstrate startling findings. In a study of 822 siblings, "More than 96% of brothers/sisters that responded to the survey indicated that they had affection toward their sibling with DS; and 94% of older siblings expressed feelings of pride. Less than 10% felt embarrassed, and less than 5% expressed a desire to trade their sibling in for another brother or sister without DS. Among older siblings, 88% felt that they were better people because of their siblings with DS, and more than 90% plan to remain involved in their sibling's lives as they become adults. The vast majority of brothers and sisters describe their relationship with their sibling with DS as positive and enhancing."[3] With more than 2000 parents surveyed, 99% reported that they love their son or daughter; 97% were proud of them; 79% felt their outlook on life was more positive because of them; only 4% regretted having

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[3] Skotko BG, Levine SP, Goldstein R. Having a brother or sister with Down syndrome: perspectives from siblings. Am J Med Genet A. 2011 Oct;155A(10):2348-59.

[4] Skotko BG1, Levine SP, Goldstein R. Having a brother or sister with Down syndrome: perspectives from siblings. Am J Med Genet A. 2011 Oct;155A(10):2348-59.

them. The vast majority “indicated that their sons and daughters are great sources of love and pride.”[4]

Most opponents of this bill mean well, and ask us to recognize the fear and trepidation that some women will understandably face with such a mysterious and stigmatized diagnosis. But understanding is not a substitute for moral judgment. Nor does understanding require us to ignore the empirical evidence in the medical literature which suggests that Down Syndrome children and their families can have a good life, and that what we need is a not a validation and promotion of fear which diminishes mother and child. Rather, our response must be solidarity, a “mantel of love” from beginning to end, and a communication of the reality that there is help.

In my practice as a pediatrician in serving these patients, I have been witness to the struggle which some mothers and fathers go through in trying to navigate the challenging medical and behavioral aspects of this human condition, while also managing the aspirational, economic, and emotional costs of having someone with special needs in the family. I hope no one, on either side of this issue, underestimates the struggle. It is not something that we as citizens of this great state can or should ignore. It is my duty, and that of any pediatrician, to create a climate of love and support for these families and their children. To show solidarity with them, to be, for what its worth in our brief visits with them, a face of love and hope. You as legislators, whom we have entrusted to codify the shared moral values of our society and state, also have that obligation.

Down syndrome children are persons worthy of dignity and worthy to be cherished. If you meet them face-to-face in the clinic or the hospital, you would understand what I mean. But my limited experience pales in comparison to that of the families who care for them. Of course, these mothers would not trade their decision to keep their child and love her for any amount of economic relief or emotional amelioration. On the contrary, my clinical experience and interaction has been that those who care for children with Down Syndrome experience “another” in a way that we can only theorize about. For them, “the other” truly becomes “the I.” We must affirm their often heroic, but unsung efforts to love and value life when everything else in society screams no. We must see them and their special children, as we see ourselves.

I end my comment on the medical aspects pertaining to quality of life with a paraphrase from Irish Bishops many years ago, a quote which still rings true today: “Life has the right to quality and dignity because it exists. Life does not somehow derive the right to exist from the quality which circumstances seem likely to give it.”

IV. Ethical Aspects: The Nature of the Person and the Nature of Choice

I would now like to briefly address certain ethical aspects of the case for HB 135. I will not rehash the arguments regarding the morality of abortion itself, which from my view clearly support the pro-life side, both from the point of view of medicine, science, and ethics.

For the sake of brevity I wish to focus only on one aspect of the ethics of abortion in cases of Down Syndrome, and that is the nature of the human person. In philosophy, we call the study of the underlying view of the person "philosophical anthropology"—what are the *essential* characteristics of a person. What makes us (if anything) the same, and if so, why should we value those characteristics?

In bioethics, issues are often debated while philosophical anthropology is ignored. For example, take the issue of suffering—whether the statement "a person should not be allowed to suffer" is true or not is entirely dependent on how you view the person herself—is suffering foreign to the nature of the person, or something embedded in her reality?

Today in this debate, there are two clearly competing philosophical views of the person. This is not just the obvious one—i.e., when does unique human life *become* a person. Rather, there are also two opposing views of what our nature is as persons when we elect to choose life or death.

One view is called the empiricist view. On this view, a person is simply a random collection of atoms, created by chance, with no other purpose except happiness in this life. Only what we can see, feel, or touch constitutes reality. On this view, suffering is to be avoided. The greatest asset we have is "choice," because our life boils down to absolute autonomy. Freedom becomes freedom to choose, because that is all there is. When a prenatal diagnosis of Down Syndrome is given, the unborn child is merely matter; feelings attached to her are epiphenomenon of matter. The primary purpose of life is to feel validated in one's choices, and to avoid suffering or perceived suffering for oneself. The heart of the person is merely conscious choice, individuality—the non-interference with the desires of another.

If this were the only view, the pro-choice opponents of this bill would be right. However, there is a view that offers a deeper, richer notion of person. On this view, promulgated by a philosophy known as *personalism,*[5] a person is one who has the capacity to reason, to love, to act in freedom, and to live in communion or solidarity with others. All four aspects are critical. We were not placed here by chance, but by purpose. Love is our greatest, distinguishing characteristic. But not love of self alone. A human person is, by nature, relational. She must look to the other, even the smallest, most defenseless, most vulnerable other. She must see that other in herself. On this view, freedom is not merely the poor, selfish notion of a "freedom to choose." Rather, freedom becomes choosing the *good*. A person fulfills his or her nature when they make a choice for an objective, true reality outside oneself. A person fulfills her nature not through a dogma of non-interference with the preferences of another—through apathy—but rather, when they choose love. Society, on a personalist model, sees the individual person herself as the central unit of value, on which the entire structure of society must revolve around, never to

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[5] Championed by philosophers Jacques Maritain and Karol Wojtyla, as well as Martin Luther King, Jr.

sacrifice her inherent worth. We must create a world in which we believe that society is created for the person, not the other way around.

Our goal ought to be to start with valuing the gift we have been given with these vulnerable children. We have a real chance to do this with HB 135. This is not just an issue for pregnant woman facing this diagnosis and their doctors. It is an issue that affects all of us, if we are to love those women and their unborn children, as we ought. As Martin Luther King once said in summing up the personalist philosophy: "In a real sense all life is inter-related. All men are caught in an inescapable network of mutuality, tied in a single garment of destiny. Whatever affects one directly, affects all indirectly. I can never be what I ought to be until you are what you ought to be, and you can never be what you ought to be until I am what I ought to be...This is the inter-related structure of reality."

V. Legal Aspects

Bioethics arises out of the intersection of law, medicine, history, and ethics. My remarks here will be short and to the point. It has been argued by some that this law is "unenforceable" since it requires the attending physician to indicate they have no knowledge that the abortion sought was procured solely for the purpose of aborting a possible or definite baby with Down Syndrome (Sec 2919.201). I would suggest two counterarguments.

First, the purpose of law, which I needn't explain to this body, is manifold, but includes punishment, but also fairness, the maintenance of order, and the codification of the moral attitudes of society's members. In short, laws can and do have a significant effect on attitudes, whether or not they can be enforced completely or not. There is evidence from the social sciences that supports this claim.[6,7] Take for example, contemporary examples of marijuana or gay marriage legalization and societal attitudes, or, alternatively, the prohibition on prostitution. HB 135 will send a message to the citizens of Ohio that Down Syndrome children, whether born or unborn, are equal in dignity and value to the rest of us. Such a law will have a protective effect on already-born children and adults with Down Syndrome that transcends "symbolism." No one can look at them and their parents and question their choice—*why* they are among the 7% of Down Syndrome babies who lived. We will be able to say that these children deserve our protection.

Second, the language of the law requires the honesty of the abortionist to make the report. If the law is truly unenforceable then opponents should be pleased, for women will still be able to make this terrible choice. If the law is truly unenforceable, however, then opponents are also further impugning the integrity of

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[6] Jakobsson, N, Kotsadam, A. Do laws affect attitudes? An assessment of the Norwegian prostitution law using longitudinal data. 2010. Accessed online 6.12.15 at: https://andreaskotsadam.files.wordpress.com/2010/06/law.pdf
[7] Vertova, P, Galbiati, P. How Laws Affect Behavior: Obligations, Incentives and Cooperative Behavior. 2010. Accessed online 6.12.15 at: http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1615349

the physicians who choose to destroy innocent human life simply because of a potential disability.

VI. Lessons from History

I conclude these remarks with a warning. I have taught and researched, both at Wright State University School of Medicine and at The Ohio State University, a course on "Medicine and the Holocaust." In that course, which I taught for more than four years, I have helped medical students understand the origins of the Holocaust through the pseudoscience of human eugenics and the active role that physicians played in bringing about such wanton destruction of human life. We also apply the "lessons learned" from that terrible period in history to contemporary issues in bioethics.

The analogy here is in the impact which laws and societal attitudes toward the disabled can have on culture. The Nazi physicians (and many American physicians at the time) believed that having a disability polluted the gene pool—and made a person "useless" to the overarching goals of the race or the state. Human lives were seen, to quote Karl Binding's 1920 book, "lives unworthy of life." The Nazi euthanasia program, called T4, began in 1939 with the killing of disabled children. Four justifications were used for this killing: a) it was good science; b) it was good for the race and state; c) it was rational (that is, if anyone disabled could choose to live or die, they would of course, choose death); and finally d) it was the most humane, for the parents and family. That program led directly to the deaths of 5,000 disabled children by 1941; more than seventy thousand perished by the end of the program. But most importantly, it set precedence within the culture that life, if it was not perfect in the eyes of some, was disposable.

A diagnosis of Down Syndrome does not mean we have a life that is unworthy of life, a life so doomed that the most humane thing we can do for the mother and child is to snuff out that life. On the contrary, to repeat the lessons of history is to affirm a life—for the mother, for the child herself, for the physician, for all of society—which to our imperfect eyes is called “imperfect,” but who, through these so-called imperfections perfect us and our world with unconditional love.

I end with this quote from Dr. Jerome Lejeune, the French physician and geneticist who discovered the cause of Trisomy 21: “People say, ‘The price of genetic diseases is high. If these individuals could be eliminated early on, the savings would be enormous!’ It cannot be denied that the price of these diseases is high—in suffering for the individual and in burdens for society. Not to mention what parents suffer! But we can assign a value to that price: It is precisely what a society must pay to remain fully human.”

I thank you for the opportunity to testify before this distinguished committee and urge all of you—prochoice and prolife—to come together to pass HB 135.