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Hearing before the

Senate Committee on the Judiciary

“The Continued Assault on Reproductive Freedoms in a Post-Dobbs America”

Wednesday, March 20, 2024

Dirksen Senate Office Building, Room G50

2:30 p.m.

Chair Durbin, Ranking Member Graham, and members of the Committee:

Thank you for the opportunity to testify at this hearing. It is an honor to be here. My name is Dr. Monique Wubbenhorst, and I am a practicing board-certified obstetrician-gynecologist with more than 30 years’ experience in patient care, teaching, research, health policy and global health. In my clinical career, I have focused on providing obstetric and gynecological care for underserved and disadvantaged populations in both domestic and international settings. For example, I have cared for women in such places as rural North Carolina, inner city Boston, Native American reservations, as well as women in India, Nepal, the Philippines, Kazakhstan, Ghana, Cameroon, South Sudan and most recently Kenya. I have chaired the Women and Special Populations Committee for the American Heart Association and worked as a senior consultant to the United States Veterans Administration, and was on the faculty of Duke University School of Medicine. Subsequently I was recruited by the United States Agency for International Development to a senior executive position focusing on global health programs and policy, prior to assuming my current role at the de Nicola Center for Ethics and Culture at the University of Notre Dame. I have authored over twenty peer-reviewed publications and been a member of review boards for several peer-reviewed journals, including *The British Journal of Obstetrics and Gynecology, Public Health, The Journal of Medical Ethics, PLOS 1, Journal of General Internal Medicine, Issues in Law and Medicine, Journal of Medical Ethics, and The North Carolina Medical Journal*. My research interests include the epidemiology and management of adverse pregnancy outcomes; adverse pregnancy outcomes and long-term cardiovascular health; the molecular biology of adverse pregnancy outcomes;

reproductive health; health services research; racial-ethnic disparities in women's health; women veteran's health; global health; and ethics in reproductive health. I currently practice OB/GYN in Indiana.

Following the Dobbs decision, which returned decision-making regarding abortion to the people of the United States and their elected representatives, there have been many changes and many opportunities to mitigate abortion's harms to women, their children and their communities. Abortion not only poses risks to the mother, it is always lethal to an unborn child. As the number of children who are aborted has decreased, the number of births in states such as Texas and Mississippi has increased, reversing a longstanding decline in fertility in the United States. Our current fertility rate is 1.7, well below replacement (which is 2.1). Future economic growth and national stability depend on healthy population growth by a country's citizenry.

The above-mentioned changes have also resulted in vigorous debate on various topics related to abortion and the humanity of the embryo, the unborn child. For example, there has been significant focus on abortion of disabled fetuses. In particular, there has been a great deal of discussion regarding such fetal anomalies as Trisomy 18 and anencephaly.

The unborn child is a human being. At the heart of this debate is whether the unborn child is a human being. Science clearly demonstrates that the unborn child is human. First, at conception, a human female gamete (the egg) and a human male gamete (the sperm), each with 23 chromosomes, combines to form a unique, new human being, a zygote with 46 chromosomes whose DNA is different from that of the parents. The zygote, and then the embryo and fetus, are human because they have unique human DNA and have been conceived by 2 human parents. The zygote is a separate, unique human being, not a part of the mother's body. All mothers are female with two XX sex chromosomes, but approximately half of their children are male, with an X and a Y chromosome. Mothers and babies often have different blood types. An unborn child's DNA is different, in every cell of their body, from that of the mother. The unborn child is therefore not a part of the mother's body, in the way that her heart or her pancreas are; he or she is a unique human being, in a unique relationship with his or her mother. There is scientific consensus that the zygote, embryo and fetus are human. For example:

1. Langman, Jan. *Medical Embryology*. 3rd edition. Baltimore: Williams and Wilkins, 1975, p. 3:

"The development of a human being begins with fertilization, a process by which two highly specialized cells, the spermatozoon from the male and the oocyte from the female, unite to give rise to a new organism, the zygote."

2. Thibodeau, G.A., and Anthony, C.P., *Structure and Function of the Body*, 8th edition, St. Louis: Times Mirror/Mosby College Publishers, St. Louis, 1988. pages 409-419:

"The science of the development of the individual before birth is called embryology. It is the story of miracles, describing the means by which a single microscopic cell is transformed into a complex human being. Genetically the zygote is complete. It represents a new single celled individual."

3. Ronan R. O'Rahilly, Fabiola Muller, *Human Embryology & Teratology*, , (New York: Wiley-Liss, 1996), 5-55:

"Fertilization is an important landmark because, under ordinary circumstances, a new, genetically distinct human organism is thereby formed… Fertilization is the procession of events that begins when a spermatozoon makes contact with a secondary oocyte or its investments… The zygote ... is a unicellular embryo…"

4. *The Developing Human: Clinically Oriented Embryology*, 6th ed. Keith L. Moore, Ph.D. & T.V.N. Persaud, Md., (Philadelphia: W.B. Saunders Company, 1998), 2-18:

"[The Zygote] results from the union of an oocyte and a sperm. A zygote is the beginning of a new human being. Human development begins at fertilization, the process during which a male gamete or sperm ... unites with a female gamete or oocyte ... to form a single cell called a zygote. This highly specialized, totipotent cell marks the beginning of each of us as a unique individual."

5. Keith L. Moore, *Before We Are Born: Essentials of Embryology*, 7th edition. Philadelphia, PA: Saunders, 2008, p. 2:

"[The zygote], formed by the union of an oocyte and a sperm, is the beginning of a new human being."

At the same Senate Judiciary Committee hearing mentioned above, scientific experts provided the following testimony regarding the humanity of the human zygote, embryo and fetus:

Dr. Alfred Bongiovanni, Professor of Pediatrics and Obstetrics, University of Pennsylvania School of Medicine, concluded:
"I am no more prepared to say that these early stages represent an incomplete human being than I would be to say that the child prior to the dramatic effects of puberty ... is not a human being....I have learned from my earliest medical education that human life begins at the time of conception."

Gordon, Hymie, M.D., F.R.C.P., Chairman of Medical Genetics, Mayo Clinic, Rochester: "By all criteria of modern molecular biology, life is present from the moment of conception...Science has a very simple conception of man; as soon as he has been conceived, a man is a man."

C. Christopher Hook, M.D. Oncologist, Mayo Clinic, Director of Ethics Education, Mayo Graduate School of Medicine:
"When fertilization is complete, a unique genetic human entity exists."

Dr. McCarthy de Mere, medical doctor and law professor, University of Tennessee, testified: "The exact moment of the beginning of personhood and of the human body is at the moment of conception."

The official Senate report from the 1981 Senate Judiciary Committee reached this conclusion: "Physicians, biologists, and other scientists agree that conception marks the beginning of the life of a human being - a being that is alive and is a member of the human species. There is overwhelming agreement on this point in countless medical, biological, and scientific writings."

It seems self-evident that an unborn child is human. As noted in the *Dobbs* decision, "When parents see the embryo on ultrasound, they recognize that this is their son or daughter"[1]. The unborn child is human, not a part of a woman's body; "...the zygote does not itself serve a functional role in the biological economy of either parent; it is a separate organism...its growth and development is...determined from within. It contains within itself the "genetic programming"...to direct its own biological progress. It possesses the active capacity for self-development toward maturity using the information it carries”[4].

The unborn child is also not any other type of life. Human embryos and fetuses are demonstrably members of the human family. “A human embryo is not something different from a human being, like a rock, or a potato, or a rhinoceros. A human embryo is a whole living member of the species *Homo sapiens* in the earliest stages of his or her natural development…He or she is not an individual of some other or intermediate kind of species. Rather, the human zygote, embryo, or fetus is a human being at a certain stage of development…”[5].

From the above evidence, “…there can be little question concerning exactly what the early embryo is. The early embryo is a human being at the earliest stage of his or her development. Not “potential” human being or a “pre” human being, or a mass of cells, or mere tissue, but an individual member of the species Homo sapiens”[6].

Human beings have rights at all stages of life. It is clear, then, that the human zygote, embryo and fetus are human from conception to birth. It is also clear that “when someone destroys a human embryo, it is a human being that is killed. This is true of any embryo, from the end of fertilization on: every embryo is a human being; therefore, ending an embryo’s life is ending a human being’s life”[7]. Not only this, but embryos and fetuses, unborn human beings, are the smallest, weakest, most defenseless and consequently most vulnerable members of the human family. Embryos and fetuses are human, “human beings as such as persons worthy of fundamental moral respect, and subjects of fundamental human rights”[8].

One of those rights is the right to life. No human being can exercise any of his or her other rights if they are never born. Neither can a human being exercise any right that disadvantages the inalienable rights of another human being. Yet disabled unborn children, as well as those who are “unwanted”, are subject to abortion, even though they are human and deserving of special protection.

The so-called right to abortion has been supported by the assertion that “abortion is safer than childbirth”. We can trace this to papers by Grimes (2006 and 2012) which were published in leading OB/GYN journals, and which reiterated earlier, similarly inaccurate claims. Studies making the claim that abortion is safer than childbirth contain statistical and methodological errors, they do not acknowledge that all pregnancy outcomes are not equivalent, do not address incorrect denominators, data limitations and faulty comparisons; and omit a breakdown of maternal mortality by gestational age at the time of the abortion. Further, they do not take into account the biology of fetal and uterine development and adaptation or the epidemiology of spontaneous abortion, induced abortion and term delivery.

When induced abortion mortality is compared to spontaneous abortion- and childbirth-related mortality in the proper context of gestational age and the biology of pregnancy, abortion does not appear to be safer than childbirth or spontaneous abortion. At higher gestational ages, comparatively, the risk for death from abortion appears to be greater than that from childbirth. Indeed, the risk for mortality – not morbidity, i.e. complications and injuries – from abortion increases exponentially by 38% for each week of increasing gestational age. Bartlett et al (Bartlett L, Berg C, Shulman M, Zane S, Green C, Whitehead S, Atrash H. Risk Factors for Legal Induced Abortion–Related Mortality in the United States. *Obstet Gynecol* 2004,103:729 –37) found that the risk for mortality from abortion increased exponentially by 38% with each week of gestation. This is not true for pregnancy.

The increased risk for mortality with increasing gestational age is worse for black women. These authors also found that “The second most significant risk factor for death [from abortion, after gestational age] overall was race. Women of black and other races were 2.4 times as likely as white women to die of complications of abortion . . . At all gestational ages, women of black and other races had higher case mortality rates than white women.”

Abortion is associated with harms to women. Abortion not only poses risks to the mother, it is always lethal to an unborn child, and approximately half of those unborn children are female. Most abortions are elective. Because elective abortions are not performed out of medical necessity, the bar for safety should be very high. There is evidence that the safety of both surgical and medical abortion is overstated.

First trimester medication abortion carries substantial risks to the mother. A study by Niimaki et al used data from Finland’s health service administrative database, which included all women in Finland undergoing abortion from 2000 to 2006 (42,619 women) and collected follow up data for 42 days post abortion (Niinimäki M, Pouta A, MD, Bloigu A, Gissler M, Hemminki E, Suhonen S, Heikinheimo O. Immediate Complications After Medical Compared With Surgical Termination of

Pregnancy. *Obstet Gynecol* 2009;114:795–804). This study design captured all outcomes for all women undergoing abortion in an entire country over a longer period of time than most studies of abortion complications. As a result, it is free of methodological problems and bias that plague other studies of abortion, including those conducted in the United States.

An example of the sort of methodological problems inherent in most studies of abortion can be seen in the study by Upadhyay et al. (Ushma D. Upadhyay, Sheila Desai, Vera Zlidar, Tracy A. Weitz, Daniel Grossman, Patricia Anderson, Diana Taylor. Incidence of emergency department visits and complications after abortion. Obstet Gynecol 2015;125:175–83). This study has many limitations, similar to other retrospective administrative database research studies. These include potential confounding associated with inaccurate coding; the absence of clinical data, especially on gestational age at the time of abortion and method of abortion; and the likelihood that women with complications did not engage with the medical system. As with many studies of this type, no charts were reviewed. There was very limited follow up. The authors acknowledge some of these issues and note as well that, for example, second trimester abortion complications in their study were lower than in other studies, suggesting that their population may not be representative, or that cases were incompletely ascertained.

In the study by Niimaki et al researchers found that 20% of women underwent medical abortion, and 5.6% underwent surgical abortion, stating that "The overall incidence of adverse events was fourfold higher in the medical compared with the surgical abortion cohort. The risk of hemorrhage with medical abortion was 15.6%, and 2.1% with surgical abortion. The risk of incomplete abortion with medical abortion was 6.7%, and 1.6% with surgical abortion. The risk of emergency surgery with medical abortion was 5.9% with medical abortion, and 1.8% with surgical abortion". In this study, women undergoing medical abortion had 8 times the risk for hemorrhage from medical abortions compared to those undergoing surgical abortion. They had 5 times the risk for a curettage to remove retained placenta or fetal parts and 4.2 times the risk for an adverse event compared to those undergoing surgical abortion. Other studies have confirmed the increased risk of hemorrhage with medical abortion.

First trimester surgical abortion carries immediate risks of hemorrhage, infection, continuing pregnancy, death, perforation of the uterus, damage to organs including hysterectomy. These complications are described in the National Abortion Federation 2020 Clinical Policy Guidelines for

Abortion Care. All of these findings have significant implications given the increased use of medical abortion.

Rates of complications associated with second trimester abortion are higher than for first trimester abortion. For example, Turok et al (Turok D, Gurtcheff SE, Esplina MS, Shahb M, Simonsena SE, Trausch-Van Horn J, Silvera RM. Second trimester termination of pregnancy: a review by site and procedure type. Contraception 77 (2008), pp. 155–161) studied differences in complications between second trimester abortions performed in 475 women, in hospitals vs. free-standing clinics. The authors found that major complications (defined as death, uterine perforation, hysterectomy, transfusion, clotting disorders, deep venous thrombosis, pulmonary embolus, stroke or heart attack, need for exploratory surgery, and prolonged hospitalization) occurred in 11% of women undergoing hospital D&E, 10% of women undergoing hospital induction of abortion, and 1% of women undergoing abortion in clinics (though there were no deaths in study participants).

Other complications included: need for readmission (24% in the hospital D&E group, 1% in the clinic D&E group, and 16% in the hospital induction group); need for curettage after abortion for retained placenta and/or fetal parts (0% in the hospital D&E group, 1% in the clinic D&E group, and 28% in the hospital induction group); infection of the fetal membranes after initiation of the procedure (1% in the hospital D&E group, 0% in the clinic D&E group, and 6% in the hospital induction group); and uterine infection (1% in the hospital D&E group, 4% in the clinic D&E group, and 5% in the hospital induction group). Of note, those women undergoing abortion or pregnancy termination in-hospital had more medical problems, were further along in pregnancy (higher gestational ages) and were more likely to be undergoing non-abortive pregnancy termination for fetal death in utero than those seen in the clinic. The authors also note that complications may have been underreported due to loss to follow-up.

Edlow et al. (Edlow AG, Hour MY, Maurer R, Benson C, Delli-Bovi L, Goldberg A. Uterine evacuation for second-trimester fetal death and maternal morbidity. *Obstet Gynecol* 2011;117:307–16) noted that “[higher] gestational age was significantly associated with maternal morbidity”, with women undergoing abortion at > 20 weeks’ being 2 ½ times more likely to suffer a complication than women undergoing abortion at < 20 weeks’ gestation.

Lederle et al. (Lederle L, Steinauer JE, Montgomery A, Aksel S, Drey E, Kerns JL. Obesity as a Risk Factor for Complication After Second-Trimester Abortion by Dilation and Evacuation. Obstetrics and Gynecology 2015 September; 126(3): 585–592) found a 30% increased risk for complications with each additional week of gestation.

There are many claims related to abortion that on closer scrutiny, are not supported by data. For example, it is stated that increasing contraception and sex education will decrease the abortion rate. Yet England, France and the United States have extremely high contraceptive prevalence, yet also have high rates of abortion. Induced abortion also does not decrease maternal mortality. Countries with highly restrictive laws at present or in the past (such as Chile, Malta and Ireland) have or have had extremely low rates of maternal mortality. In addition, African American women have the highest rates of abortion, and also the highest maternal mortality. Both cannot be true if abortion decreases maternal mortality.

“Reproductive rights” are not human rights, because they “disappear” the fetus, who is human. Human rights are not conferred by the state; if the state conferred them, then the state could take them away. Rather, such inalienable rights are inherent to being human. The so-called right to abortion does not exist because it requires the violent destruction of a human being, thereby violating their rights.

The unborn child is never the subject of such discussions of rights. So-called “reproductive justice” is in fact reproductive *injustice*, because it destroys black and brown babies, who are 100% of the future of their ethnic groups. The same eugenic mindset that led to the sterilization of African American, Native American and Hispanic women continues in the disproportionate rates of abortion in black women, and rising rate of abortion in Hispanic women. Racial-ethnic disparities in abortion receive enormous attention. But when it comes to racial-ethnic disparities in abortion, which are putting tremendous pressure on the African American population, and are the prevalent cause of the decline in African American births, there is silence from leaders, activists and the scientific community.

The issue of the humanity of the unborn child is also a topic of debate related to *in vitro* fertilization (IVF). In 2022, three infertile couples filed a wrongful death suit in Alabama because their frozen embryos were destroyed by a patient at the adjoining hospital who gained unauthorized access to the embryos. The families could have filed a property suit, but specifically chose to file for the wrongful death of their unborn children. On February 16th, 2024, the Alabama Supreme Court issued an opinion allowing the couples to seek compensation for the wrongful death of their embryos under Alabama's Wrongful Death of a Minor Act. This ruling set up a national discussion about in vitro fertilization (IVF). Unfortunately, much of the reporting on the subject incorrectly equates embryo protection with prohibitions on IVF.

The ruling correctly assigns value to the embryo. The ruling does not prohibit IVF. It speaks only to whether embryos should be destroyed. Louisiana, for example, has both allowed IVF and provided protection for embryos as people, not property, since 1986. Embryos are unique human beings who deserve to be respected and treated ethically. This court ruling allows for embryos to be treated with the highest level of respect and care. The plaintiffs in this case were couples who used IVF for their families. These families chose to seek justice for their destroyed embryos by suing for wrongful death of their unborn children. They knew there was something special about their embryos. This has been understood and recognized, for example in the heroic efforts by first responders to save embryos on the upper floors of a hospital flooded by Hurricane Katrina. These men and women would not have risked their lives if they were not trying to save lives.

Recognizing the biological fact that embryos are distinct human organisms with their own DNA creates an incentive to avoid the creation of excess embryos. This is an important point. As noted by Harvard Health Plan (Embryo donation: One possible path after IVF - Harvard Health):

> "If you became a parent through IVF and have remaining embryos, you are not alone. Estimates vary on the number of cryopreserved embryos in the United States, but it's likely to be in the hundreds of thousands. You may be among the many people or couples who plan to use their embryos, or among those whose family feels complete. And you may be starting to figure out what to do with your embryos, or you may be putting the decision on hold, paying for annual embryo storage and feeling no urgency to make a decision, since embryos can remain safely frozen for many years. **Having "extras" in deep freeze may offer comfort, kind of a psychological insurance policy after years of disappointment and loss.** Sooner or later, though, most people find themselves at a decision point, considering these options:
> **You can discard your remaining embryos**. This may feel harder than you anticipated but absolutely doable. You see these embryos as part of the IVF process that enabled you to have your cherished child or children. The word "discard" sounds harsh, but you are not prepared to parent another child and do not see donating them to others as an option.
> You can decide to have an additional child. A larger family wasn't what you'd planned on or hoped for, but you see extra embryos as part of IVF, and a new child as meant to be. You look at the family you have and decide it is worth undergoing at least one more embryo transfer before making a final decision to discard. You can decide to donate your embryos to science. Unfortunately, if you begin to explore this, you'll discover there is no easy route for it. Perhaps you will choose to explore other possible pathways, or decide to focus on one of the other options.

> **You can decide to donate your embryos to science.** Unfortunately, if you begin to explore this, you'll discover there is no easy route for it. Perhaps you will choose to explore other possible pathways, or decide to focus on one of the other options.
> **You can donate your embryos to another person or couple**. For some, this feels natural: you have been given the gift of children and you want to pay it forward to others longing for pregnancy and parenthood. However, for many the decision to donate does not feel easy or natural. Rather, it poses a huge dilemma: you want to honor the embryos and offer them a chance at life, but you have unsettled feelings when you think of your genetic offspring being raised by another family.
> **Not to decide is to decide**. In listing options, it is important to acknowledge that some of your fellow IVF parents are deciding not to decide. They are among the many who have "abandoned" their embryos (the term clinics use for families that avoid contact). **They stop paying their storage fees; they fail to respond to outreach calls and letters** [emphasis added]".

What happens to embryos whose parents abandon them? Is it not true that "donating embryos to science" constitutes human experimentation? Is preimplantation genetic testing, in fact, eugenics in its purest form? All of these questions show the moral and ethical dilemmas associated with IVF.

Some of these questions are summed up in the consent form for IVF. One such form states the following:

> "The option of preimplantation genetic testing…was discussed…We did discuss that sperm injection may be associated with an increased risk of sex chromosome abnormalities with most recent studies relating risk to intrinsic sperm issues. Risk of mosaic embryo was also discussed with special consideration of these embryos and genetic consult before possible transfer. Recommend transfer of all euploid embryos [those with normal chromosomes] before possible transfer of mosaic embryo due to increased risk of miscarriage or failed cycle with mosaic embryo transfer.
>
> We reviewed our desire to limit the number of embryos transferred to minimize the risk of multiple gestation. The potential complications arising from multiple gestation were reviewed including: low birth weight, prematurity, pulmonary, gastrointestinal and visual complications. The greatly increased risk of cerebral palsy was reviewed. Reviewed the possible risk of an IVF cycle including: ovarian hyperstimulation syndrome (OHSS), multiple gestation and complications from oocyte retrieval. However, we also discussed the overall strategy of IVF is to obtain many eggs for insemination…a percentage of the eggs will not be mature…approximately twenty percent of eggs will not fertilize, and approximately half of the fertilized eggs will stop developing prior to transfer or freeze….only a portion of the developing embryos are likely to be graded of high quality and have a reasonable likelihood of implantation…".

This consent form documents some of the risks associated with IVF, and also how the "highest quality embryos" are selected.

Louisiana and Germany have established ethics and safety standards for IVF that prevent embryo destruction. In Louisiana, per the most recently available CDC data (2021), there were approximately 1500 embryo transfers and over 700 live births in Louisiana. And, according to one fertility doctor, there are around 1,000 babies born through IVF in Louisiana each year. For comparison, the same CDC data reported only 966 embryo transfers and 437 live births in the state of Alabama. It is not IVF that is at issue, but rather whether embryos should be destroyed. People can be in favor of IVF without agreeing with the destruction of embryos.

Embryo destruction can be addressed by reducing the creation of excess embryos. For example, since 1990, Germany has had in law "The Embryo Protection Act." The Act regulates for what purpose and in what way embryos may be handled:

- In procedures, the number of fertilized ovum cells that mature into embryos in the laboratories may not exceed that of those that are transferred to the woman during a treatment attempt.
- No more than three embryos may be stored per treatment attempt.
- Sex selection is prohibited.
- Embryonic research is prohibited.

The IVF industry is highly profitable. Costs for an individual cycle range from $15,000 to more than $30,000, and the industry has been described as "the Wild West" (UVA Law Professor Examines the 'Wild West' of the Fertility Industry | UVA Today (virginia.edu); Fertility Industry Is a Wild West - NYTimes.com). IVF is associated with risks, including low birthweight, preterm birth, hypertension in pregnancy, placental complications, postpartum hemorrhage, increased rates of cesarean delivery, and ovarian hyperstimulation syndrome, as well as autism spectrum disorders (https://www.news-medical.net/news/20231121/Association-between-infertility-and-autism-spectrum-disorder-risk-among-children.aspx).

Anyone who knows, or has a family member, or who has cared for parents undergoing IVF can testify to the enormous mental, emotional and financial costs and burdens of this intervention. Prospective parents are willing to undergo these costs and associated risks because they want to build their families. But are all aspects of the IVF process compassionate and just, especially to the children who are created, and to the women who undergo the risks? These are the questions that we must grapple with.

Another issue related to the dignity of the unborn is how we view, and treat, the fetus with anomalies. For example, Trisomy 18 is a chromosomal abnormality associated with fetal and newborn birth defects. However, in Japan, where intensive intervention is often provided for infants with Trisomy 13 and Trisomy 18, one-year survival rates approach 56% in some centers. In the United States, Nelson et al. noted that although one-year survival for infants with Trisomy 13 or 18 has been stated to be less than 10%, forty-one percent of hospital records for children with Trisomy 13 and 32% of records for children with Trisomy 18 were for children older than one year. In more than 10% of discharges, children were older than eight years. This suggests that the prognosis for this anomaly is not as grim as has been stated, and that life-affirming physicians will continue to push the boundaries for conditions that have formerly been described as lethal, to the benefit of these children and their parents who are often pushed to undergo abortion.

Another fetal anomaly, anencephaly, is a congenital neural tube defect that is estimated to occur in approximately 2/10,000 pregnancies, with very wide variation across countries. Spina bifida and anencephaly are the most common neural tube defects. Per CDC, anencephaly "is characterized by a total (holo) or partial (mero) absence of the brain with absence of the cranial vault (calvarium) and covering skin"[62]. Anencephaly is a NTD that results from a failure of the anterior (rostral) portion of the embryonic neural tube (anterior neuropore) to close properly" at around 25-27 days post-conception. While the brain begins to develop normally, because it is not covered by meninges and bone, exposure to amniotic fluid causes it to disintegrate. As a result, the skull, cerebellar and cerebral structures do not develop. Children with anencephaly lack portions of the skull (acrania), scalp and brain. Specifically, the cerebral cortex and cerebellum are almost absent. Anencephaly is part of a spectrum of brain and neural tube fetal anomalies that includes spina bifida.

Diagnosis. Anencephaly is diagnosed either using maternal serum alpha-fetoprotein (a prenatal blood test), or by ultrasound. The diagnosis is established using ultrasound in more than 95% of cases. However, some infants diagnosed with anencephaly are found after birth to have other, less lethal diagnoses. Per CDC as referenced above, anencephaly can be "confused with craniorachischisis, acrania or amniotic band syndrome. For this reason, a prenatal diagnosis of anencephaly should always be confirmed postnatally. When this is not possible (e.g. termination of pregnancy or unexamined fetal death), the program should have criteria in place to determine whether to accept or not accept a case based solely on prenatal data"[63].

But prenatal diagnosis is by definition presumptive. That is, until postmortem examination of the aborted fetus has been carried out, the prenatal diagnosis cannot be confirmed. Confirmation of a diagnosis of fetal abnormality is mandatory to identify false-positive cases and to attempt to reduce or eliminate their occurrence. Situations where an erroneous prenatal diagnosis results in abortion of a normal child are devastating to parents[64].As a quality measure, pathologists have studied whether the fragmentation of the fetal body caused by D&E hinders confirmatory postmortem examination. Struksnaes et al (2016) carried out a study correlating fetal ultrasound and autopsy findings in 1029 aborted fetuses. They noted a 1.3% false-positive rate and emphasized that "fetal autopsy remains a quality control of ultrasound findings resulting in TOP [termination of pregnancy]". What this study seemed to show, however, was that 1 out of 100 diagnoses of fetal abnormalities in aborted fetuses was incorrect, and that a normal fetus had been aborted[65]. This has been noted in the media as well (These Prenatal Tests Are Usually Wrong When Warning of Rare Disorders - The New York Times (nytimes.com)).

Boecking et al (2017) studied 448 fetuses aborted by D&E. They found that for 89 pregnancies, a decision was made to abort the unborn child due to ultrasound diagnosis of central nervous system (CNS) abnormalities. In 86% of these, postmortem correlation was prevented by fragmentation of brain tissue and spinal cord structures, including "all 110 intracerebral abnormalities", which would include anencephaly[66].

Several risk factors are known to be associated with anencephaly. These include obesity in the mother and elevated blood sugar (for example in diabetes), which increase the risk threefold. Exposure to antiseizure medications, high temperatures (for example saunas, or fever) and opioids increases the risk of neural tube defects. Per CDC, "The birth prevalence of NTDs (proportion of babies in the population born with an NTD) has decreased by 35% in the United States, since folic acid fortification was required in 1998...Mandatory folic acid fortification of cereal grain products has helped about 1,300 U.S. babies to be born without an NTD each year"[67]. Folic acid supplementation in prenatal vitamins as a public health measure, especially around the time of conception, could likely reduce rates of neural tube defects even further.

Several studies have reported on maternal risks and outcomes for women with an unborn child affected by anencephaly. Stumpf et al (The Medical Task Force on Anencephaly) state, with no citations or data presented, that "Labor and delivery are commonly associated with an unstable fetal lie, dysfunctional labor (poor dilatation or dystocia [labor abnormalities], and postpartum hemorrhage”[68].

Ekmekci and Gencdal (2019) reported on 87 women who had children with anencephaly. They noted that the average age at which anencephaly was diagnosed was 18 weeks. 28 out of 87 patients chose to not abort their fetuses. 32% of births were stillbirths and 68% were live births. All died within the first week of life. 68% of patients gave birth vaginally. Of those who underwent cesarean delivery, 7 of 9 did so because of previous uterine surgery. Notably, 64% of patients underwent induction of labor, the reason for this was not given. 6 patients developed polyhydramnios. 2 patients had shoulder dystocia and one had postpartum hemorrhage. The authors also state that “shoulder dystocia is an expected complication” but the reference they provide does not support this statement[69].

However, because this was a descriptive study with no comparison group, other risk factors for shoulder dystocia and hemorrhage were not identified (including parity, maternal body mass index, maternal diabetes, fetal weight, gestational age, etc.). For these reasons, these results may not be generalizable to the population of pregnant women with an unborn child with anencephaly and do not appear to inform the literature on maternal complications with anencephaly.

Another study by Obeidi et al (2010) stated that “Common maternal complications reported include polyhydramnios, dysfunctional labor and postpartum hemorrhage”[70]. However, the citation given for this statement is listed as “Anonymous, 1990” “, and no reference with this title is provided in the literature cited.

The American College of Obstetrician-Gynecologists (ACOG) Practice Bulletin #187 on neural tube defects states that “Polyhydramnios can occur as a result of impaired fetal swallowing especially with anencephaly and higher-level spinal lesions and those lesions associated with aneuploidy, leading to uterine overdistention and increased risk of preterm contractions, umbilical cord prolapse, and placental abruption. Breech presentation is common at term with anencephaly and spina bifida”[71]. However, no studies are cited to support this statement. Polyhydramnios is a known and manageable complication of pregnancy, occurring with gestational diabetes and other clinical entities.

Jaquier *et al* performed a web-based survey of parents who had had children with anencephaly. She found that polyhydramnios (an excess accumulation of amniotic fluid) occurred in 27% of 211 pregnancies. Premature delivery was more common in the group with polyhydramnios. One mother had hypertension and one had hemorrhage. Cesarean delivery occurred in 26% of pregnancies. The authors note that "Many mothers asked for cesarean section with the aim of avoiding stillbirth"…Spontaneous vaginal delivery did not feel different to mothers who had previously delivered a healthy baby, contrary to the belief that delivery may be prolonged due to the small head". They concluded that "Contrary to common belief, only a small number of anencephalic fetuses died *in utero*. More than half of the babies were born at term, 10% even after term". This was a survey study and therefore also descriptive. The authors concluded that "Continuation of pregnancy after a diagnosis of anencephaly is medically safe and should be considered as an option"[72].

There appears to be a paucity of data, within the limits of this literature review, to indicate that complications such as hemorrhage, shoulder dystocia and dysfunctional labor are greatly increased in pregnancies where the unborn child has anencephaly. Polyhydramnios appears to be a common and treatable complication in pregnancies with an unborn child who has anencephaly, as it is in other clinical situations.

Information on the natural history of infants with anencephaly is important to accurately inform parents of their child's diagnosis. Most children with anencephaly die within the first month of life or less, but many survive longer especially when given medical care. Studies have documented prolonged survival for children with anencephaly.

In 1983 Baird et al published survival data from British Columbia for children born with anencephaly. They found that in contrast to the standard assumption that most of these newborns die within 24 hours, 42.5% "can be expected to survive longer than 24 hours…and of these, 35 percent will still be alive on the third day and 5 percent…on the seventh day…". In their series, one newborn lived for 2 weeks. They emphasized that "it is important to verify the diagnosis of anencephaly" since some survivors had been misdiagnosed, having instead less severe syndromes. These survival rates are of interest because the field of neonatology was in an early stage in 1983[73].

A 1993 study case report by McAbee et al noted two infants who survived for 7 and 10 months, respectively, without intensive medical support[74]. Dickman et al in 2016 presented a case report of prolonged unassisted survival in an infant with anencephaly who lived for 28 months[75].

In a review by Machado *et al* (2006) of 130 anencephalic children, 90% delivered vaginally and 10% delivered by cesarean delivery. 83% were born preterm. 38% of births were stillbirths. For the live births, postnatal length of survival was 1 minute to 48 hours. 67% of infants died within the first hour of life and 94% of infants died within 24 hours[76].

Jaquier et al (2006) found that of the 153 liveborn infants in their survey, 28% within 1 hour, 67% died within 24 hours, 25% within 2-5 days, 3% within 6-9 days, and 4% within 10-28 days. “The longest survivals were 10 days (four), 18 days (one) and 28 days (one)”[77].

Tolczyk and DeWitt (2022) cited studies reporting 100% mortality within the first weeks of life, with others reporting 100% mortality within the first year of life. The latter group often needed assistance to breathe with a ventilator. Their case report focused on an infant with anencephaly who survived at least 9 months with intensive medical intervention[78].

Additional media reports indicate survival for children with anencephaly of 3 years[79]; 3 years and 8 months[80] and one year and 8 months[81].

One of the most intriguing studies of a child with anencephaly, a boy, was entitled “Instincts and emotions in an anencephalic monster” and was carried out in 1949 and cited by Sekulic et al. This infant lived for 85 days. The diagnosis of anencephaly was confirmed by autopsy. This child’s survival was remarkable in an era when neonatal care was rudimentary, antibiotics were not widely available, and understanding of newborn and infant physiology was limited[82]. We should not dismiss all of these cases as exceptional. They point to the possibility that with improved care, many more infants with anencephaly could survive.

But any such advances at current are impeded by perceptions about these children. They are described as grotesque, misshapen. In a culture that prizes beauty and “the perfect child”, these children do not fit. Described as “monsters” as noted above, and uniformly assigned a bleak prognosis, they have not benefited from the same intensive research efforts and clinical care that are associated with improved outcomes in other children with severe and life-limiting disabilities.

The perception of children with anencephaly as subhuman or not-human likely hinders any efforts in this direction and results in parents being pushed to abort them. In fact, at present there is little information on survival of anencephalic infants, because so many are aborted.

Is the unborn child with anencephaly human? This critical question has been debated due to attempts to utilize newborns with anencephaly as a source of organs for transplant (see below). Like other unborn children and neonates, the child with anencephaly has human parents and human DNA. He or she came into existence after the fusion of two human gametes, the sperm and the egg. He or she is fully human, developing toward the adult form. The developmental accident that caused him or her to not develop a normal cerebellum and cerebrum does not make him or her a monster or subhuman, since we are human based on our being part of the human family, not because we lack certain characteristics. The only difference between children with anencephaly and those without is their disability. Berger notes in this regard that newborns with anencephaly are "living human beings"[83]. It has been pejoratively stated that children with anencephaly are "born dying". In fact, we are all born dying; from the time of our birth, we are on a journey that inexorably, and for everyone, moves toward and ends in death. Of course, the speed with which this process occurs varies, but again, the humanity of an individual or group of individuals does not depend on whether death is imminent. This argument, that the rights and dignity of human beings does not matter because they were going to die anyway, was used by the Nazis, and others as they attempted to justify horrific experiments on and abuse of their victims.

The dehumanization of children with anencephaly is widespread in the medical literature. But the child with anencephaly is clearly human and worthy of protection.

A 1990 article by Stumpf et al in the *New England Journal of Medicine* acknowledged that for the unborn child with anencephaly, some neurologic function is preserved. The authors go on to say that

"Many neurologic functions are retained in live-born infants with anencephaly, even though extensive areas of the brain stem may be malformed. Some brain stem functions may appear to be absent when they are not. Special sense organs and facial muscles are frequently malformed, impeding input and output from the central nervous system; this may compromise the ability to measure intact reflexes of the central nervous system that depend on this input and output. Many behaviors of newborns have been ascribed to cerebral hemispheric activity; however, the presence of these behaviors in infants with anencephaly indicates their brain-stem origins. These behaviors include responses to noxious stimuli, (avoidance, withdrawal, or crying), feeding reflexes (rooting, sucking, or swallowing), respiratory reflexes (breathing, coughing or hiccups), and many interactions involving eye movements and facial expressions that are seen in newborns with intact cerebral hemispheres”[84].

These authors go on to infer that infants with anencephaly cannot suffer, but as we have seen, more recent evidence does not support this conclusion.

Mothers also describe feeling their children with anencephaly move and kick while in the womb. This is borne out by research, suggesting that the central nervous system is functioning to some extent. A case report in 2005 by Andonotopo *et al*. compared *in utero* behavior for a normal fetus with that of a fetus with anencephaly using 4D ultrasound. The authors found that while the movement patterns for the child with anencephaly were different from those of the normal fetus, and appeared more limited, “a functional movement of [the] CNS was observed”. They concluded that “movements patterns are abnormal and can exist in spite of a serious reduction in the quantity and change in in the fetal CNS”[85].

Further evidence that the newborn with anencephaly has neurologic function is provided by other studies. Berger cites a study by D.A. Shewman which indicated that newborns with anencephaly “are functionally closer to normal newborns than they are to adults in chronic vegetative states”[86].

The newborn with anencephaly can perceive and respond to the environment and to his or her mother. Sekulic *et al* cite studies of infants with anencephaly whose behavior was studied postnatally. In one case, an infant lived for 85 days after birth. Postmortem examination (the child died from a brain abscess) proved that he did not have anatomical brain structures above the level of the thalamus. It was noted that if the child was

“…handled roughly, he cried weakly, and when the investigator coddled him, he showed contentment and settled down in the arms of the investigator. He would sleep after feeding and awaken when hungry. He expressed his hunger by crying. In response to painful stimuli, he withdrew his limbs…Sweet tastes of sugar elicit positive facial expressions of liking, whereas bitter or salty tastes elicit negative facial expressions of disgust in anencephalic newborns. If the skin of the anencephalic newborn is exposed to stinging, pressure or punching, they cry painfully. Based on neurological examination of anencephalic newborns it is concluded that responses to noxious stimuli such as avoidance, withdrawal, or painful crying are of a brain stem origin in the human species. They also express sleep/wake cycles. When novel acoustic stimuli were presented, the anencephalic infant showed an orienting response, and cardiac slowing...

What implications do the abovementioned behavior of newborns with anencephaly have on the process of the fetus starting to have pain? Pain contains sensory and affective components. The sensory component is clearly visible in avoidance reactions and withdrawal to noxious stimuli. Crying in response to rough handling shows affective components in interactions with the mother or with medical staff. Showing contentment and settling down as a response to treatment with care or kindness also shows affective components in interaction with other people. Such interaction is necessary for bonding between the mother and the newborn, and the further emotional relationship between mother and infant, and represents one step in the emotional development of the infant. If the general definition of perception is taken into account, stating that it includes the organization, identification, and interpretation of sensory information...anencephaly demonstrates that the basic, most general, appropriate interaction with the environment can be achieved with a functional brain stem"[87].

It is clear from this very precise scientific and clinical perspective that despite his or her handicaps, the child with anencephaly is not only human, but demonstrates behaviors similar to unaffected infants, including interacting with his or her mother.

What are the outcomes of pregnancies after diagnosis of anencephaly? Most pregnancies where the unborn child has been diagnosed with anencephaly are aborted.

A systematic review by Mansfield et al of termination rates following diagnosis of fetal anomalies showed that the vast majority of unborn children with anencephaly are aborted[88].

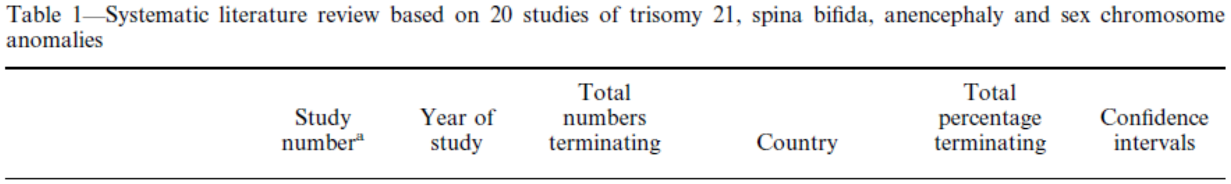
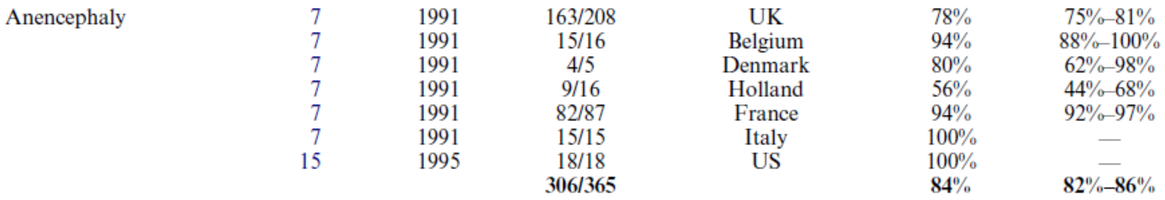


Table 1—Systematic literature review based on 20 studies of trisomy 21, spina bifida, anencephaly and sex chromosome anomalies

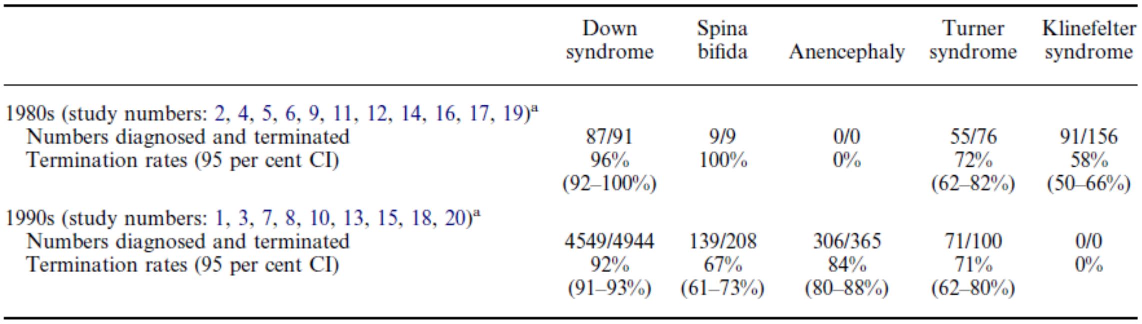
	Study number[a]	Year of study	Total numbers terminating	Country	Total percentage terminating	Confidence intervals



Anencephaly	7	1991	163/208	UK	78%	75%–81%
	7	1991	15/16	Belgium	94%	88%–100%
	7	1991	4/5	Denmark	80%	62%–98%
	7	1991	9/16	Holland	56%	44%–68%
	7	1991	82/87	France	94%	92%–97%
	7	1991	15/15	Italy	100%	—
	15	1995	18/18	US	100%	—
			306/365		**84%**	**82%–86%**

This study also found that abortion rates increased from 0% in the 1980s to 88 % in the 1990s.

Table 2—Termination rates (95 per cent CI) following prenatal diagnosis by year of publication



	Down syndrome	Spina bifida	Anencephaly	Turner syndrome	Klinefelter syndrome
1980s (study numbers: 2, 4, 5, 6, 9, 11, 12, 14, 16, 17, 19)[a]					
Numbers diagnosed and terminated	87/91	9/9	0/0	55/76	91/156
Termination rates (95 per cent CI)	96% (92–100%)	100%	0%	72% (62–82%)	58% (50–66%)
1990s (study numbers: 1, 3, 7, 8, 10, 13, 15, 18, 20)[a]					
Numbers diagnosed and terminated	4549/4944	139/208	306/365	71/100	0/0
Termination rates (95 per cent CI)	92% (91–93%)	67% (61–73%)	84% (80–88%)	71% (62–80%)	0%

Limb and Holmes (1993) studies outcomes for pregnancies where the child was affected by anencephaly before and after the widespread use of abortion after diagnosis. These investigators were careful to document the race of patients in their study by tracking as far back as the four grandparents of each infant. 74 infants with anencephaly were diagnosed from 1972-1990, with 47% being diagnosed prenatally in 1972-1974 and 90% being diagnosed in 1979-1981. From 1972-1974, "before the advent of routine prenatal diagnosis in the second trimester, 47% of the affected infants were liveborn and 53% were stillborn. By the early 1980s more than half of the pregnancies with affected infants were terminated electively. By 1990 all of the affected infants were detected prenatally, and 100% of the pregnancies were terminated". The authors also note that "The fact that there have been no live born infants with anencephaly in recent years is relevant to the **proposed use of affected infants as organ donors**"[89]. This is an entirely eugenic sentiment. It is also noteworthy that the 100% of abortions performed in this study (and comparable rates of abortion contemporaneously) typically occur in the late second trimester, with accompanying painful death of the fetus and elevated risk to the mother of not only complications and injury, but death.

How have attitudes toward fetal and newborn children with anencephaly affected their care? Because these children are not seen as human, there has been a push to use them as sources of organs for transplantation, apparently starting in the late 1980s. An article in the *New England Journal of Medicine* in 1989 “speculated that, with increased awareness across the country of the feasibility of transplantation surgery in newborns, the list of waiting recipients will grow…However, this increased awareness will also intensify the already critical shortage of small organs. Therefore, some other mechanism for increasing the donor pool of solid organs for infants must be sought. Possible options include…**a change in the current law to allow the procurement of organs from anencephalic infants as a separate category of donors to whom the current standards for total brain death would not apply**”[90]. In other words, these authors were proposing the removal of organs from living children with anencephaly.

This was apparently already being done. In another article in the *New England Journal of Medicine* (The Medical Task Force on Anencephaly, 1990), the authors reiterated that “Infants with anencephaly are potential sources of organs for transplantation”. They state, without providing any scientific data whatsoever, that “infants with anencephaly presumably cannot suffer. Anesthetic agents…are not necessary to minimize or prevent suffering”. They proposed four general approaches to obtaining these children’s organs. In one approach, “The infant is immediately placed on maximal life-support systems at birth. The organs are removed as soon as technically possible, without regard to the presence or absence of various brain-stem functions (whether or not brain death has occurred)”, that is, while they are still alive. They cite a 1987 study by Holzgreve *et al* in which kidneys were removed from 3 infants while they were still living, perhaps (as the authors suggest), without anesthesia[91].

Evidence has been presented above to show that these children can feel pain. One must therefore wonder what it was like for them to be cut open and to have their organs removed, possibly without anesthesia, while their hearts were still beating and they were still alive. Did they cry? After their kidneys were removed, were they left to die from shock and exsanguination? What were the final moments of their lives like?

Contemporaneous with the above report, this question was addressed by the American Medical Association’s Council on Ethical and Judicial Affairs. The AMA’s website describes the debate on this subject under the title “ Anencephalic Newborns as Organ Donors”:

In June 1988, 2 resolutions concerning organ donation were brought before the AMA House of Delegates and referred to the Council on Ethical and Judicial Affairs (CEJA) for investigation. One requested the AMA to reexamine the criteria used to select organ donors. The other sought ethical guidelines to address the use of prenatal diagnoses and organ "harvesting"; both concerned the transplantation of organs from anencephalic infants, some of whom were now able to survive for up to several days. The implicit question in the resolutions was this: Is it ethical to declare organ donor status for anencephalic newborns on the basis of prenatal diagnosis and, with parental consent, to procure the organs before the infant died of its neurologic devastation? In December 1988, CEJA reported its recommendation to the House of Delegates. The answer was, "No."

Here are CEJA's words: “[CEJA] supports the voluntary donation of organs in appropriate circumstances. However, the Council does not view the use of organs of anencephalic newborns prior to a determination of death, i.e., the complete and irreversible cessation of all brain function, as appropriate for transplantation purposes." The 1989 edition of the Code contained no separate entry on anencephalic neonates as organ donors. The first separate opinion on anencephalic neonates as donors appeared in the 1992 edition, giving public voice to the view expressed in the 1988 report. The new opinion stated that the newborns could be kept on ventilators and provided other treatment to sustain ‘organ perfusion and viability until such time as a determination of death can be made in accordance with accepted medical standards and relevant law.’ The opinion went on to emphasize that retrieval of organs was "ethically permissible only after such a determination of death is made."

Articles similar to the one above by Peabody appeared in journals, pushing for the use of children with anencephaly as organ donors, and for modification of the laws regarding transplantation. Then,

“By 1994, things had changed. In June 1994, "after more than a year of deliberation," the Council issued a lengthy report, a version of which was subsequently published in JAMA [the Journal of the American Medical Association]. The extensively researched and documented report grounded its conclusions on 3 facts or assumptions: anencephalic newborns faced certain death, usually within 3 days; they lacked any degree of consciousness; and parents of such newborns often requested that their children's organs be donated. The Council reached the conclusion that, with prior consent of the newborn's parents, it was ethically acceptable to transplant the organs of anencephalic neonates without waiting for them to die naturally.

In each case, justification for permitting retrieval of organs from anencephalic newborns before they had been declared dead seemed to outweigh the arguments against doing so. The Council's recommendation was accepted by the House of Delegates and replaced the former opinion on organ donation by anencephalic neonates in the 1994 edition of the Code. After defining anencephaly, the new opinion stated: It is ethically permissible to consider the anencephalic as a potential organ donor, although still alive under the current definition of death only if: (1) the diagnosis...is certain and confirmed by two physicians who are not part of the organ transplant team; (2) the parents of the infant desire to have the infant serve as an organ donor and indicate such in writing; and (3) there is compliance with the Council's Guidelines for the Transplantation of Organs...the opinion drew special attention to the fact that its new opinion marked a noteworthy exception to its guidelines on donation of organs necessary for life because these infants have "never experienced and will never experience consciousness."

Reaction to the report and opinion was immediate, widespread, and highly critical. During the year following the opinion's release, the AMA and CEJA received protests from individual parents and physicians, advocacy groups...and medical specialty societies. And the Council became aware that its new opinion on anencephalic newborns as organ donors was incompatible with the policy of the United Network for Organ Sharing (UNOS), the organization established by the US Congress in 1984 to administer the nation's Organ Procurement and Transplantation Network. UNOS policy stipulates that organ procurement must occur after declaration of death by medical and legal standards.

The Council on Ethical and Judicial Affairs considered the clear message it had received from members of the profession and the public. Society was not about to tolerate alteration of principles derived from the closely held value it placed on the sanctity of life, no matter how damaged that life might be. If the owner of that life, himself or herself, vehemently refused treatment to sustain it, that was one thing, but others who had never known the will of the person in question should not end its life. In its December 1995 report entitled, "The Use of Anencephalic Neonates as Organ Donors—Reconsidered," the Council rescinded its 1994 opinion, pointing to concerns about accurate diagnosis of anencephaly and incomplete understanding of the possible level of consciousness in these newborns. The report urged the scientific community to continue to investigate the consciousness of neonates and provide knowledge to guide future policy making on this topic. Promising to continue assessing relevant information, the Council recommended—and the House of Delegates approved—reinstating the 1992 opinion. Nearly a decade later, the 1992 opinion remains in the Code[92].

The 1994 conclusion reached by the CEJA was horrifying, and properly condemned as inhumane. But the committee opinion makes a key point. Once vulnerable members of society, such as children with anencephaly, indeed any anomaly, are dehumanized and their rights abridged – including through license given to abort them – it is only a matter of time before further erosion of their dignity and worth occurs. These articles demonstrate the grave danger of a eugenic approach to these children, which categorizes them as less than human. Those who deem them less than human can justify aborting them using the brutal second-trimester D&E procedure. For those who are not aborted, the same reasoning can be used to justify any use that can be made of them, including cutting their organs out while they are still living. In most countries, this would be impermissible even for animals being slaughtered for food.

What are the mental health outcomes in women whose fetus has been diagnosed with an anomaly, including anencephaly, following abortion or carrying to term? Multiple studies indicate that women who undergo abortion for fetal anomalies experience significant negative mental health outcomes. Calhoun et al (1997) noted that a disproportionate number of adverse mental health outcomes occurred following abortion for fetal abnormalities, citing a study by Zolese et al (1992). The authors of that study stated that “Those requiring therapeutic abortion on medical grounds because of foetal abnormalities or serious medical complications are consistently found to be associated with poorer psychological outcome…”[93].

In a review of published research, Sullivan and Faoite (2017) noted that “Data from the studies examined indicate that many women, having aborted due to serious anomaly, suffer from PTSD [post-traumatic stress disorder], a mental health problem”[94]. According to the American Psychiatric Association “PTSD is a psychiatric disorder that may occur in people who have experienced or witnessed a traumatic event, series of events or set of circumstances. An individual may experience this as emotionally or physically harmful or life-threatening and may affect mental, physical, social, and/or spiritual well-being… People with PTSD have intense, disturbing thoughts and feelings related to their experience that last long after the traumatic event has ended. They may relive the event through flashbacks or nightmares; they may feel sadness, fear or anger; and they may feel detached or estranged from other people. People with PTSD may avoid situations or people that remind them of the traumatic event, and they may have strong negative reactions to something as ordinary as a loud noise or an accidental touch"[95].

Sullivan and Faoite continue by saying that "The disorder is shown in multiple studies to continue for months and even years in some women". While the percentage of women with PTSD appears to diminish over time, "…the number of women still dealing with PTSD a year or more after termination of pregnancy remained surprisingly high". The authors reported that "Kersting et al (2009) found that 45% of subjects were demonstrating signs of PTSD 14 days after the abortion. Korenromp et al (2009 and 2007) found that 44% and 46% of women, respectively, were suffering form PTSD four months after pregnancy termination. Davies et al (2005) found that 67% of participants screened positive for PTSD at six weeks, which fell to 50% at six months".

The mental health effects of pregnancy termination often lasted more than a year. For example, these authors state that "Kersting et al (2009) found that 30.9% of women were still experiencing post-traumatic stress 14 months after pregnancy termination. Korenromp et al (2009) reported that at 16 months after termination 20.5% of patients still showed pathological levels of PTSD". Davies et al (2005) reported that 41% screened positive for PTSD at 12 months post abortion". Similar findings were noted in these studies for depression. "Davies et al (2005) documented a slow increase in depression following pregnancy termination", with 30% of subjects screening positive for depression at 6 weeks, 39% at six months, and 32% at 12 months. Sullivan and Faoite concluded that "These articles repeatedly conclude that abortion for reason of potentially fatal anomalies can have a lasting and negative psychological impact".

Interestingly, they note that "experiences highlighted in the research suggest that induced termination did play a role in the psychological issues these mothers faced. Gammeltoft et al (2008) found: 'Even though their obstetrician had advised abortion, most felt that the ultimate decision to terminate the pregnancy had been their own, made in consultation with their relatives. The harshness of their loss seemed to be magnified by the fact it was 'chosen' by themselves'".

Hunsfeld *et al* (1993) of women who were carrying babies that had been diagnosed with severe or lethal anomalies who were surveyed shortly after their diagnosis and again after giving birth. While a high percentage of these mothers (45%) were diagnosed with “severe mental imbalance” shortly after their ultrasound diagnosis, by 3 months this number had declined to 22%. The percent of women with sleeping disorders (69%) declined dramatically at the 3 month mark to 5%. The percentage of women with eating disorders declined from 56% to 14%[96].

Research has specifically examined the question of whether outcomes are better for women who undergo termination of pregnancy for an unborn child with anomalies vs. carrying to term. Rates of mental health problems for women who underwent induced abortion for a fetus with anomalies are higher than those for women carrying an affected child to term. Cope et al (2015) studied the impact of abortion vs carrying a pregnancy to term when the unborn child was affected by anencephaly[97]. The authors also explored the fact that the psychological impact of pregnancy loss on men is understudied, noting that “Descriptive studies of men have reported that men struggle with grief, anger and helplessness following the loss and often feel forgotten by health care providers and society…the few published studies indicate that men also experience grief, depression and post-traumatic stress…”. In this study, women who underwent abortion had much higher scores on a standard measure of perinatal grief than women who continued with their pregnancies (52% vs. 33%, respectively). Women who underwent abortion also had higher rates of depression than those who continued their pregnancies (48% vs. 27%). The authors note that “A significant number of women and men reported symptoms of grief, post-traumatic stress and depression within the pathogenic range…psychiatric distress tended to decrease over time. However, it is important to note that there was tremendous individual variability…there were participants whose pregnancies ended over 10 years ago still scoring within the pathogenic range”.

Of note, “Pregnancy continuation was also associated with less psychiatric distress in women. As a group, women who continued reported significantly less despair, avoidance and depression than women who terminated. And “items related to guilt were significantly associated with termination in women. The active choice involved in termination does appear to increase the likelihood that guilt will be experienced, even in the case of lethal fetal anomalies…Termination at a later gestational age was associated with greater psychiatric distress in both men and women, although this was only statistically significant in men. Cope *et al* concluded that “There appears to be a psychological benefit to continue the pregnancy following prenatal diagnosis of a lethal fetal defect”[98].

Can compassionate palliative care for newborns with anencephaly improve outcomes for parents? Malloy et al stated “As Hoeldtke and Calhoun note, while the explosive growth of prenatal diagnostic technologies in particular has resulted in earlier diagnoses of life-limiting and life-threatening diagnoses, ‘the ability to accurately diagnose a fetal condition often outstrips the ability to prevent or treat that condition. This is especially true for some specific fetal congenital defects’ and would include anencephaly. “Infants carrying these diagnoses who are born alive may die in the neonatal period or experience long stays in intensive care units. Parents of these fetuses face significant emotional, logistical, and social challenges related to the outcome of their pregnancy. Recently, options for perinatal hospice have become more prevalent and established for those whose pregnancies are complicated by such diagnoses. A subset of perinatal or prenatal palliative care, perinatal hospice care, is an extension of established adult and oncologic palliative care models, which originated in the 1960s. Perinatal hospice care provides comprehensive prenatal, perinatal, and postnatal medical care and support to infants with life-threatening and life-limiting diagnoses, and their families, in order to improve their quality of life. Perinatal hospice is family centered and addresses the emotional, social, spiritual, and other needs of families within their cultural contexts. This nascent field is rapidly developing, with more than 200 perinatal hospice programs in the United States”[99].

Between 40-85% of women will typically choose perinatal hospice or palliative care for a fatal fetal anomaly, if given the option[100-104].

Malloy et al further noted that “Perinatal palliative care services can also help care for those parents who choose to terminate their pregnancy. Such families often experience significant loss and grief, without adequate support, which could be provided by a palliative care team…In a five-year study of families choosing perinatal hospice for their newborns, 49% of cases were infants affected by Trisomy 18 or 21, or by anencephaly. Families in this study expressed a wide variety of needs and preferences related to their fetus' diagnosis, which were or could be addressed by perinatal palliative services. These included participating in a perinatal hospice program which could help them develop a birth plan, provide counseling, address concerns regarding resuscitation, and bring support in navigating social issues such as how to tell friends and family about their diagnosis. The authors also noted that ‘many families experience spiritual distress, highlighting the need for a spiritual counselor’ as part of the team”[105].

Similar to the goals of adult and oncologic hospice, the goals of perinatal hospice can be simply stated - to provide healing without cure for the patient. Palliative perinatal care, however, does not consist of comfort measures only, and may include cesarean delivery and newborn intensive care. For example, in Japan, where intensive intervention is often provided for infants with Trisomy 13 and Trisomy 18, one-year survival rates approach 56% in some centers[106,107]. In the United States, Nelson et al. noted that although one-year survival for infants with Trisomy 13 or 18 has been stated to be less than 10%, forty-one percent of hospital records for children with Trisomy 13 and 32% of records for children with Trisomy 18 were for children older than one year[108].

A common theme in research on perinatal hospice is parents' positive experience of the process, even when their child's life was brief[109,110]. For example, "Guon et al. reported that many parents noted that their family was 'strengthened and enriched since the birth - and often the death - of a child with a chromosomal abnormality". They also found that while "many parents experience intense grief reactions regardless of the choice they make," in multiple studies, those who received support through perinatal palliative care described positive experiences[111]. Another common theme was parents' "unanimous and strong need to acknowledge the personhood of their baby, and his/her role in the family," and their desire for "people to legitimize the baby's life and not to pretend the infant does not exist[112,113]. Perinatal palliative care has helped parents with this process in the prenatal period by using the baby's name to reinforce the child's identity[114-116].

Increasingly efforts are being made to facilitate parents' desires to give birth to their child affected by anencephaly as a viable alternative to abortion. A case report by B. Chapman (2013) described parents giving birth in a perinatal palliative care pathway. The parents were aware of the diagnosis prenatally. According to the author, "Hope's journey illustrates how integration of the multidisciplinary hospital team and community care can assist and support the family when planning a way forward, tailored to the family's personal, physical, emotional and spiritual needs. After her mother's full term pregnancy and vaginal birth after caesarean section (VBAC), Hope was discharged home seven hours after her birth as her parents wished for palliative care. She lived 14 hours, a life filled with love, dying in her family home as her parents wished. This case illustrates how perinatal palliative care pathways can support and assist professionals working in maternity units when parents decide to continue a pregnancy with a baby with a terminal condition. It also provides a framework to facilitate the parents to have the option of taking their baby home to die with appropriate support in place...This case study illustrates how the parents can be kept at the centre of care providing space for them to make informed choices with the support of integrated care from both the hospital and community”[117].

Jaquier et al (2006) surveyed parents whose unborn children were diagnosed prenatally with anencephaly. The survey collected information on 211 pregnancies and noted that “Contrary to common belief, only a small number of anencephalic fetuses died *in utero*. More than half of the babies were born at term, 10% even after term…Judging from these data, and collected via this homepage [Anencephaly info] and compared with the notion of Limb and Holmes, it seems that a larger proportion of mothers carrying an anencephalic fetus are opting to continue the pregnancy rather than elective termination. From the perspective of these mothers/parents, it is important to experience as normal a bonding as possible between mother/parent and baby and to see and touch the baby, stillborn or liveborn. It is impressive to hear from these parents who contacted homepage that none have regretted their earlier decision to continue the pregnancy…On the other hand, a considerable number of mothers who contacted the homepage following an elective pregnancy termination, mentioned their regret at not having seen their baby”[118].

My clinical experience is in agreement with this. In caring for a newborn with anencephaly, a cap is usually placed on the baby’s head and he or she is swaddled. The parents’ first impression is often that the baby “didn’t look as abnormal as they thought it would”. They may receive their child cautiously, then happily, even though they know that he or she might not live for very long. In my experience, holding their baby was an important part of parents’ honoring his or her life.

Thill notes that “A dichotomy exists in the practice of medicine” due to differential treatment of two equally human fetuses:

> “…one fetus is accorded patient status and humanity, to whom beneficence and nonmaleficence are owed, while for the other fetus, this status is withheld. This cognitive dissonance disturbs and causes significant tension within the practice of medicine in view of objective medical evidence as well as in light of the fundamental mission of medical professionals as healers. There is an ethical obligation to prevent unnecessary pain and suffering, as well as an obligation for beneficence and nonmaleficence, which must be judiciously applied to both the pregnant woman and the fetus, while safety and health concerns are carefully balanced”[119].

An article by R. Wayne Willis published in 1990 summarizes many key points regarding the humanity and human dignity of the child with anencephaly. In an article published in 1990, he provides a hypothetical debate on this topic, responding to critiques that the child with anencephaly is not human, again in the context of organ donation. But the arguments apply to abortion of the child with anencephaly as well.

"You employ the word "use" when you speak of the anencephalic newborn. I'm sorry, but I don't believe human beings are meant to be used [or aborted]. Things are to be used. Objects are to be used. People are to be loved. One of the fundamental principles of civilized societies is that people are not to be used solely as means to an end. You are proposing that this anencephalic newborn be *used*. You see this baby as having no rights...I think most moral people believe that is wrong. You showed your true colors, revealing your utter disregard for the rights or the inherent worth of this handicapped baby, by referring to the baby as "an anencephalic". You make the baby an "it", a thing. She is not an anencephalic *newborn* or an anencephalic *baby* or an anencephalic *infant*. We depersonalize patients when we refer to them as a diagnosis, as a "heart" or a "head" or a "Down's," or "an anencephalic". Sir, are anencephalic babies persons or things? They can suck. They can cry. They can swallow. They can withdraw from painful stimuli. They can distinguish their own mother from other persons. Are they persons or things?...there are several documented cases of newborns who were originally diagnosed with anencephaly, a flawed diagnosis that later proved out to the microcephaly or hydranencephaly. Making the diagnosis of anencephaly cannot be done without an occasional error...One famous physician put it this way: "The level of civilization attained by any society will be determined by the attention it has paid to the welfare of its infants and children"[120].

In 2019 a physician wrote an article for the series "On being a doctor" in the 4 June 2019 issue of *Annals of Internal Medicine* called "The Myth of Choice". In it, he or she decries the withholding of abortion from a mother whose unborn child had anencephaly:

"A woman meets a man, starts a relationship, wants a family. She comes to your hospital so pregnant that her belly is huge. She hasn't come before because she has no car. Her man works long days, paid cash for his labor. Turns out the baby has no brain, no skull. Only a stem. This condition has no survivors. None.

You are in OB triage, crammed on a stool between the woman's stretcher and the wall. When you move, the stool squeals. Her hand rubs her belly. You find an interpreter, you sit beside her, you tell her congratulations and you are so sorry all in the same breath. The interpreter is a stranger on a screen, mounted to a pole on wheels. You try to angle the screen so the interpreter sees your face. He is aghast at what you ask him to repeat. The cadence of your words is carefully measured, but your beautiful cadence is mangled by his hesitation.

You wait for the patient to break the silence. The baby's heartbeat trots through the monitors while you softly hold her gaze. Her eyes plead with you. End it. You talk to the obstetricians, because eventually it will end. But nobody will do it. Not in this state. Not in this hospital. And so, the mother goes home, pregnant and grieving.

She returns a few days later. She's having a miscarriage. Her labor is managed just like that, like labor. The baby is born with no skull, eyes like gumballs too big for their sockets. Alive, briefly. It hurts to look. Grotesque is all you can think, but you cannot say it. Thinking it calms you inside so you can calm everyone else. That is your job. To lead, to calm. Because everyone is upset. Some of the nurses need you to fix it, to save this baby with the magic of medicine. You remind them that he is very premature, that he has no brain, that he cannot survive. This is not an ambiguous diagnosis. You encourage the mother to hold her child, but she does not want this bond. She cannot see the deformed creature she birthed, because once seen it cannot be unseen.

It doesn't last long, these precious but vulnerable moments. Gently, the baby dies. He is warm, whole, and not alone. There are no doughnuts at the nurses' station that night as this young mother is wheeled to a room in the back corner of labor and delivery, away from the other mothers and their pink, crying babies. She will walk out of the hospital with breasts swollen and weeping for her dead child. Her hips loose and large will force her pants to tug. She will struggle with her gait for weeks, punctuating loss in the waddle of each step, until, gradually, she retires her maternity pants and her steps become firm, upright, and forward.

You've done this before, cared for women whose wishes were warped by politics. You've commanded millions of health care dollars on behalf of infants born with fatal diagnoses. You've seen these infants cut, lanced, and battered in the name of intensive care. Do everything. Because who does not want to save her child? Sometimes all we can control is our grief. The middle-of-the-night pangs for a world where motherhood means potty training and muddy cleats. Sometimes the idea of choice is just a lie. And sometimes all you can provide is compassion. Dignity in grief is the gift. You've enabled false hopes, not for cures but for time to bond, hope, and heal. It is the parents you are healing. The hopes false. All these children died in the end[121].

While the author does convey that “It doesn't last long, these precious but vulnerable moments. Gently, the baby dies. He is warm, whole, and not alone” – and the baby would be none of these if he had been aborted – the physician paradoxically also expresses disgust at the appearance of the newborn, seeing him as “grotesque”, a “deformed creature” who like other newborns with “fatal diagnoses” seems to not be really human, who needs to be aborted rather than having healthcare dollars wasted on them, since “All these children died in the end”. This leads the physician to the conclusion that “hope’s false”.

Responses to this article were quite informative. One physician stated eloquently that

“The anonymous author laments that at his/her institution pregnancy termination and withholding of care for babies with very serious defects is not often possible. The author then concludes with statements concerning providing compassion and dignity in grief. What are compassion and dignity? Who defines these terms and determines how they are applied? The Oxford English Dictionary defines compassion as: “sympathetic pity and concern for the sufferings or misfortunes of others.” The same dictionary defines dignity as: “the state or quality of being worthy of honour or respect.” The author is concerned about the parents, the health care team and society (costs). The position taken clearly places the interests of the unborn and newborn child subservient to others. Traditionally, the patient’s interests are paramount. Disturbing changes in medical ethics have devalued the humanity of patients when they are seriously disabled and ill. There is a growing trend towards paternalism and unilaterally applying the concepts of societal over individual interests.

The author uses language that is contradictory such as “baby” and “infant” followed by objectifying, grotesque, and dehumanizing descriptions followed by the paternalistic cry of “end it.” Is the unborn or severely disabled child human or not? Is such a child worthy of dignity and care? The author’s revulsion betrays the true subject of “compassion” and “dignity.” It is not the child but the suffering author who represents each of us in this story.

Does this approach capture the fullness and true meaning of dignity and compassion? In the Judeo-Christian tradition, compassion can be described as: “Quality of showing kindness or favor, of being gracious, or of having pity or mercy” and human dignity is grounded in the imago Dei. Therefore, human dignity is: “The unalterable, inherent value due every person by virtue of being a human being.” Utilitarian ethics are foreign to these concepts and ministries that flow from them.

The author fails to identify the cultural and religious beliefs and values of the parents and in turn the child. Actions desired by the author as compassionate may be abhorrent to others. The family’s view of human dignity may extend fully to their anencephalic child. They may view abortion as murder. External pressure by providers, hospitals and insurers adds to their agony…Tragedy and suffering do not demand a utilitarian response but one of grace, mercy, kindness, and love towards all those affected”.

At the heart of the debate are two opposing worldviews: utilitarian and Judeo-Christian. History attests that the utilitarian worldview takes us down the same dark road as the Baby Bollinger Case and the Aktion T4 program. We must teach current and future generations of physicians to critically think these issues through and understand the true meaning of compassion and dignity lest we repeat the same horrors”[122].

In another response to this nihilistic depiction, Dr. Elvira Parravicini, a neonatologist, and Frances McCarthy, a clinical coordinator, from Columbia University Medical Center, wrote a beautiful paraphrase, filled with hope. They note that “This is the real story of a real family who delivered in 2015 at Morgan Stanley Children’s Hospital / Columbia University Medical Center in New York, NY under the care of the Neonatal Comfort Care Program”, commenting that “In the US there are more than 200 services of Perinatal Palliative Care”.

A woman, pregnant with a baby with anencephaly comes to your hospital. Long-term survival is not an option. Her eyes plead with you. Help me. You take her hand, look her in the eye and offer to walk with her through this journey that she does not wish to be on. You explain to her that while her child’s life may be brief, it is precious and that she is not alone. The mother’s love for her baby does not die with the diagnosis or with the death of her child. Choice is the not the issue. Grief is. The truth of medicine is this: patients die. The issue here is about valuing the relationships that we, as providers, have with our patients. It requires us to be with them in the discomfort of delivering a terminal diagnosis.

Can we then, walk with them during such sad and difficult times in their lives?

When born, the baby is gently placed on her mother skin to skin. She dies quietly, peacefully in the arms of her mother, never knowing hunger, pain, or sadness. Her mother will grieve her in some way for the rest of her life. She has loved and lost, but she has also gained. She was able to bond, to love and to hope and she will heal. She is changed but not defeated.

She is not the first and she will not be the last to face the death of a child. Hope for a cure eludes us daily but hope for healing is different. Healing is not just about disease; it is about the spirit, the resilience that rests in all of us. This baby's life, while brief, was filled with love and dignity and without pain. This baby made her a mother. This baby changed her. All of us die in the end. It is the nature of everything that lives. Death is the final act but it does not tell the whole story. In medicine, we cannot be there only for the living; we must be there for the dying as well[l123].

The rights of a mother with an anencephalic fetus, or one with Down syndrome, or even an unexpected or "unwanted" pregnancy are not in opposition and should not be seen as competing, nor should we pit them against one another. Rather, their rights are intertwined. Both the mother and her child have inherent human dignity. Both deserve not only compassion and justice, but love, because love seeks the best and highest for another. They also deserve the best of care, which does not include abortion because abortion is not health care. Abortion violates the bodily integrity and the rights of the mother, exposes her to injury and death, and kills the unborn child, with no evidence of benefit. The value of a child's life has nothing to do with how long it is, or how he or she was conceived.

To conclude, the Dobbs decision, as noted, returned legislative decisions about abortion to the people of the United States and their elected representatives and also resulted in vigorous, even fractious, debate. Debate is positive. A similar debate should ensue on IVF, if only to address pressing questions, such as the commodification of reproduction, and the fate of the estimated one million frozen embryos in the United States. Values, especially as they relate to human dignity, as well as compassion, justice, and scientific and clinical data, should inform this process.

Thank you.

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