

Opposition to Ohio H.B. No. 256 Amendment

Chair, Members of the Committee:

I come to you as a mother who has become the voice for my son Damon, as he no longer has one. While believing deeply in the altruistic value of organ donation, we personally have experienced the severe shortcomings and exploitation permitted under our current laws. My son, who was not an organ donor, had his body harvested without his consent due to the legal loopholes in Ohio's current legislation. This experience has left our family in anguish and continues to raise critical concerns that this bill fails to address the transparency in anatomical gifts and organ donation.

Personal Testimony and the Need for Reform

In Ohio, it only takes the consent of **one** parent to authorize organ or tissue donation. My son Damon was **not** a donor and it was not marked on his identification. However, his biological father, with whom he had a strained relationship, was able to authorize over the phone, permission to harvest his "gifts". As a result, my son's death remains shrouded in unanswered questions surrounding his passing. The necessary autopsy was conducted only **after** multiple tissues had been removed, including his heart tissue, skin, eyes, and even his brain, making it impossible for the autopsy to be conclusive. My son's eyes were sent to Argentina from the Central Ohio Lions Eye Bank, despite being unblemished. His skin was rendered "damaged" due to **unspecified** lab errors that went unanswered from a company called **MTF Biologics**. This should not happen in Ohio. Families deserve the right to honor their loved one's wishes with dignity and informed consent, and they deserve answers and closure without interference.

Anatomical Gifts Act of 2006 and Unregulated Profit

The Federal Anatomical Gifts Act of 2006 introduced the term "anatomical gifts," creating a nonmedical definition of body parts that, unlike 'organs', could be sold by non-profit organizations to for-profit entities. Today, non-profit organizations involved in organ procurement—such as Lifeline of Ohio—generate millions in revenue, some of which comes from anatomical gifts that can be sold to plastic surgeons for non-life saving procedures, pharmaceutical research institutions, and international hospitals. In case you're wondering, a set of eyes goes for roughly \$120,000. This bill does nothing to address this modification, effectively allowing these organizations to profit off the altruism of donors and families without their full understanding.

As someone who believes in organ donation, I want to emphasize that families **deserve** to know the exact use and destination of their loved one's body while maintaining the anonymity of the recipients. People should be able to make informed choices without feeling misled. When families agree to donate, they believe they are making a purely altruistic decision. They do not anticipate that their loved one's tissues will be sold to plastic surgery companies or shipped internationally. We need to ask ourselves: who benefits from this lack of regulation?

Organ Procurement Transparency and Legal Actions

Lifeline of Ohio has faced previous legal challenges and controversies, including a 2011 case in which it was alleged that they failed to protect donor information adequately, allowing third-party access to private donor records. Furthermore, in 2015, Lifeline of Ohio was criticized when a donor's family reported they had not been fully informed about the scope of tissue recovery, including skin and bone, which they learned could be used for purposes such as research or cosmetic procedures. These incidents underscore the need for better transparency and stricter protections for donor families.

In Ohio, the state's organ procurement organizations have faced multiple issues. A whistleblower in 2018 reported that an Ohio-based OPO pressured medical staff to prematurely declare patients brain-dead to increase organ donation rates, raising severe ethical concerns. Additionally, a 2020 federal audit reported that some OPOs in Ohio were failing to meet performance standards, citing low recovery rates and questions about **accurate** death determinations. These controversies highlight the importance of regulating and monitoring organ procurement organizations for ethical and transparent practices. I personally have filed grievances with Lifeline of Ohio and there is no external system of checks and balances.....they govern themselves.

Additional legal cases concerning organ procurement and anatomical gifts act include:

- *Burke v. Lifeline of Ohio Organ Procurement, Inc.*: In this case, the plaintiffs alleged misconduct by Lifeline of Ohio in the procurement process. The specifics of the allegations are detailed in court documents.
- *Siegel v. Lifecenter Organ Donor Network*: This lawsuit involved claims against an organ procurement organization regarding the handling of donor organs. The court's decision provides insight into the legal challenges faced by such organizations.
- *Pennsylvania Hospital, Ohio Parents Settle Organ Donor Suit*: An Ohio couple settled their lawsuit against a Pennsylvania hospital, accusing it of prematurely declaring their son dead to harvest his organs. This case underscores the potential conflicts of interest in organ procurement.
- *The Case of Thomas "TJ" Hoover II*: In October 2021, Thomas "TJ" Hoover II was declared brain-dead following a drug overdose and was prepared for organ donation. However, during the organ retrieval process, he showed signs of life, leading to the procedure being halted. This incident raised significant concerns about the accuracy of death determinations and the potential for premature organ harvesting.
- A report in 2019 by PBS NewsHour highlighted instances where families and doctors disagreed on the implementation of DNR orders, for the purpose of organ harvest, complicating decisions about end-of-life care and organ donation.

The Financial Loopholes in Organ Procurement

Consider this: the hospital, Medicaid, and organ procurement organizations (OPOs) involved in the organ donation process are labeled as non-profit entities, yet they benefit from a robust financial system surrounding organ and tissue donation. Medicaid sets prices for the recovery of organs and anatomical gifts, essentially funding these non-profit organizations. These anatomical gifts, once harvested, are sometimes sold at a profit—an act facilitated by the loose classification under the Anatomical Gifts Act. Even in death, individuals and their families are not immune from becoming part of a commercial transaction. Lifeline of Ohio, for instance, reported over \$14 million in revenue, with a substantial portion going to executive salaries, including \$353,705 for its CEO Andrew Mullins and \$241,369 for their chief financial officer Lindsey Durham, making them in the top 5% of income earners in Ohio. This creates an entire infrastructure profiting from people's deaths, cloaked under the guise of public service and altruism. Ohioans have a right to transparency.

Lack of Public Education and BMV Training on Organ Donation

Donate Life Ohio, the state's primary organ and tissue donation awareness program, spends millions on marketing annually, including over \$2.5 million on campaigns and community education in 2022. Despite this significant investment, the Bureau of Motor Vehicles (BMV) training on organ donor registration is often minimal and focuses on procedural knowledge rather than fully educating Ohioans on the true implications of registering as a donor. When individuals agree to become organ donors at the BMV, they often do not receive a comprehensive explanation of how their donation may be used—including that some anatomical gifts may be sold or shipped internationally. This gap in education leaves many people shocked when they later learn about the full scope of what organ and tissue donation can entail, as outlined in consent forms. Clear and consistent education about organ donation is essential to preserving public trust.

A System that Denies Autopsy Integrity and Truth for Families

My family's experience reveals another tragic flaw in the system: autopsies are often conducted after the harvesting process, which can prevent accurate cause-of-death determinations. Vital organs and tissues that provide essential insights for a medical examiner are removed prior to an autopsy, forever altering the results and leaving families without answers. My son's autopsy was inconclusive due to this process. This is not just a question of medical accuracy; it's about families' rights to grieve with understanding and closure.

Similar concerns have been voiced by the medical community, many reporting they feel they are not able to respect the rights of their patients due to laws with OPO companies being contracted with hospitals. DNR orders are directives that instruct healthcare providers not to perform cardiopulmonary resuscitation (CPR) if a patient's breathing or heart stops. These orders are typically established to honor a patient's wishes to avoid aggressive life-saving measures in terminal or irreversible conditions. However, the presence of a DNR order can complicate the organ donation process. For organs to remain viable for transplantation, certain medical interventions

may be necessary after death, which can conflict with the stipulations of a DNR order. This creates ethical dilemmas for healthcare providers who must decide between adhering to the DNR and preserving organs for donation, in many cases life sustaining efforts are demanded due to the anatomical gifts act of 2006.

The Call for Accountability, Transparency, and True Choice

Ohio's citizens deserve to make choices about their bodies and the bodies of their loved ones based on complete information, transparency, and trust. If organ donation is to remain an altruistic act, we must close the loopholes that allow non-profit organizations and corporate interests to exploit this system for financial gain. By failing to regulate the Anatomical Gifts Act, H.B. No. 256 does nothing to protect families or honor the dignity of those who give the ultimate gift of life.

I empathize deeply with families who have chosen to donate their loved one's organs and those who have received life-saving transplants. However, I also stand with the families who have experienced the unintended consequences of this system. Let us preserve the integrity of organ donation by ensuring that Ohioans understand fully how their choice will impact others—and that it will never lead to unintended exploitation. Last year I spoke with senator Mark Romanchuk and representative Marilyn John to discuss my concerns regarding anatomical gifts, I'm happy to see that she's on the committee for this amendment.

In closing, I ask you to reconsider the implications of H.B. No. 256. to amend this bill to prioritize transparency, informed consent, and respect for donors and families. Without these protections, the noble act of donation risks being overshadowed by profit motives and commercial interests.

Forever Damon's mother and advocate,

Andrea Mauk