

**Written Testimony of Bobby Schindler, M.S.**

**In Support of S.B. No. 151**

**Submitted to Health Committee**

**September 15, 2021**

Dear Chairman Huffman and Committee Members:

Thank you for allowing me the opportunity to submit testimony in support of S.B. No. 151 to provide medical care and treatment to preterm infants and infants born with a disability.

My work as a disability rights advocate began with fighting for the life of my sister, Terri Schindler Schiavo who was starved and dehydrated to death by court order at the demand of her estranged husband in 2005.

Terri was a disabled American; she had been neither actively dying nor near death, but death was intentionally caused by the denial of her basic care, food, and water.

In response to Terri's death, my family established the Terri Schiavo Life & Hope Network to help protect those who face the real threat of their medical liberties being ignored, which in many cases can lead to a premature and preventable death.

For 16 years, the Life & Hope Network has responded to requests from close to 4,000 families and has been directly involved in hundreds of cases, offering support, advocacy, guidance, and a network of professional resources, at no cost to families, to help their brain injured and medically vulnerable loved ones.

Since my work began as a patient and disability advocate, it has become alarmingly evident that our health care system is incentivized to impose death upon vulnerable patients, and the powers of law and medicine have become weapons rather than shields.

Indeed, the medical protections for the elderly, disabled, chronically ill and other treatable health issues, have been eroded, thereby increasing the risk that these patients will face an encouraged or imposed death by a healthcare system that has been given sole authority to make medical determinations based on value judgments, and a patient's "quality of life", which is why Emery and Elliot's Law is here before the committee today.

The state must step in and act as an advocate when the medically defenseless need protections from unilateral decisions to withdraw or withhold treatment against the expressed wishes of the patient, their family member, or a surrogate. Such action is especially necessary when the patient is a vulnerable infant and unable to speak for himself.

Effectively, without laws that can act as shields for these individuals, a patient's life can be terminated without proper consent or any type of due process of law, as happened with Emery and Elliot. In fact, if something is not done, it will grow worse.

Families are the defenders of life, and healthcare is about what is best for the patients. It is not in the best interests of patients to put an arbitrary limit of time on a patient to heal or the intolerant laws and policies so that a hospital can undermine the dignity and the rights of vulnerable patients.

The subjective quality of one's life does not determine the objective and fundamental value of one's life. The state has a duty, a solemn responsibility to keep all medically vulnerable individuals safe, and out of harm's way.

Indeed, as Martin Luther King Jr. once said, "While it may be true that the law cannot change the heart, it can restrain the heartless."

I respectfully urge a vote in favor of S.B. No. 151.

Sincerely,  
Bobby Schindler, President  
Terri Schiavo Life & Hope Network  
bschindler@lifeandhope.com  
855-300-HOPE (4673)