

Hello, my name is Lisa Irvin-Chisnell, I am writing today to advocate for Emery and Elliot's bill S.B. number 151.

Like Amanda Finnefrock I also had been rushed to the hospital emergency room several weeks early in my pregnancy due to bleeding.

But the treatment my son received as a preemie was very different, and my son now 18 years old is one of the wisest, kindest, most gifted people I know. I could not imagine the world without him. He has a caring heart, a wisdom beyond his years, and has been a rock of support to many of his teenage friends online who have struggled in the last year because of lockdowns and the pandemic.

I know that nothing was done to try and save Emery and Elliot.

I know that passive euthanasia is the denial of life saving treatment, regardless of the intention.

I know that both Emery and Elliot were denied lifesaving treatment despite, mother, Amanda pleading with medical staff to save her sons.

I know what life saving treatment of a preemie looks like and wish to share my experience briefly.

I also think I may know the reason why Amanda's sons were denied lifesaving treatment, and at the end I have one question with regard to that likely reason.

When I realize the treatment that Emery and Elliot and their mom should have received, I cannot help but think of my son. Had my son been denied treatment, he too would not be here, and how many lives would have been severely impacted.

I, also, know that my son's condition at birth was worse than Emery's or Elliot's, but because my premature son, Luke received treatment immediately in the delivery room and then in the NICU, he is now living the life he was meant to live.

I can attest to what lifesaving measures in the NICU look like, and why it is crucial that these proven medical treatments for preemies continue.

I know that Emery was moving his arms and kicking his feet.

I know that Elliot came out crying and that both boys were breathing but struggling and suffering as they gasped for air.

I know that my son was neither crying nor breathing when he was born and was immediately resuscitated.

I know that preemies have lungs that lack enough surfactant, and this causes the lungs to begin to collapse.

I know that when preemies who receive help with oxygen, and continuous positive airway pressure (CPAP) this will prevent the lungs from collapsing and will save their lives.

When I arrived at the hospital in my sixth month due to bleeding, I had a consult with the perinatologist in the emergency room, who recommended no intervention for a few days, but to administer steroids to help strengthen my son's lungs before birth.

I continued to bleed as I was moved to another room where my son's heart rate was continuously monitored. The bleeding continued.

My OBGYN arrived and made his own assessments which differed from the perinatologist. Sometimes doctors disagree.

With conviction and strength in his tone, he turned to my husband and said, "If it were my wife, I would go in and get the baby."

I did not wait for anybody else to answer, "Go in and get my baby."

I was prepped for surgery and taken to a room where a curtain divided my top half from the surgical team performing my emergency c-section.

Another team was standing around a smaller table topped with fresh white bed linen waiting for my son Luke's arrival.

"You're going to feel some pressure," my OB told me from behind that curtain, "and it's normal."

He then announced it was a boy.

I then saw someone from my operating table carry my baby over to the team that was waiting for him as my team continued to operate on me.

The room was silent.

It seemed that it was quiet for far too long. Nobody said anything. Far too much time seemed to pass, when Luke's cry ripped through the silence, and I cried a grateful cry.

"Well, the plumbing works," someone said, and most everyone in the room laughed.

Luke had to be resuscitated. He was quickly diagnosed with respiratory distress syndrome (RSD) and immediately given oxygen, and was taken out of the room by his team. In the NICU, Luke began making grunting noises, indicating continuing distress even with the oxygen. He was then given the CPAP. This saved his life. He only required the CPAP for a few days but continued to need oxygen for a few more weeks. Medical staff in the beginning first told me that Luke would need to be in the NICU for two or more months. He did so well, he went home just under a month.

When Amanda had given birth to Emery, medical staff was not in the room with her, and Emery landed on the edge of the bed nearly falling off. He was moving his arms and legs and struggled to breath for 45 minutes before passing away. Elliott was stronger, came out crying and struggling with his breathing for two and a half hours before passing away.

No monitors

No assessments

No team

No doctor

No oxygen

No CPAP

No medical treatment

If the hospital had tried to save both Emery and Elliot and one or both of them would have died, the twins' parents Amanda and Sean Finnefrock would have grieved. This is certain.

The passage of time, along with the reassurance that everything medically was done to try to save the twins would have greatly contributed to the natural healing process which occurs in any grieving over the loss of a child.

But there was nothing natural about what occurred at the hospital that night in June of 2017, or humane. Amanda's sons were passively euthanized before her eyes, helplessly in pain and struggling to breathe with medical staff milling about, having the ability to save them but choosing not to do so. Because of this, Amanda will always bare the scaring memory of the pain both of her sons endured, their little faces in pain, and the sounds of them gasping for air, as she begged and pleaded with medical staff to help them.

I know that medical staff, including the neonatologist Amanda had a consult with when she first arrived at the hospital told Amanda that it would be inhumane if her children lived because they might end up with a disability. Amanda was told the twins might become a burden on her, her other children, and on her marriage.

I know that while there are still many wonderful doctors and nurses in the field of medicine, yet there is a growing embrace of a philosophy in alignment with eugenics. I know that the philosophy of eugenics advocates for the reduction of human suffering with the end goal of eventually eliminating disease, disabilities and what they define as undesirable characteristics from the human population. They use words and phrases such as good genes, quality of life, incompatibility with life. But disabilities cannot be eliminated without first eliminating the disabled person.

There is nothing more rewarding than helping another human being and helping to make a difference in someone's life for the better.

This is what Amanda Finnefrock is doing for others, and in honoring the lives of her son's Emery and Elliot. Her love for them grows, and now with this bill may grow to touch many other lives to save them from the tragedy which has befallen her family.

Isn't that why we are all here? To help one another? To use our gifts, talents and knowledge to contribute to the very society in which we participate, and the one we will leave to our children's children?

Each of us can think of at least one person – a teacher, a friend, an employer, even a stranger in the grocery line, who did something or said something which helped guide us on a good path in a pivotal moment in life. What if that person had not been here?

Most unfortunate for all of us is the truth that we never have to wonder about what that world would look like. For this *is* the world we are living in. There are many in the world, now missing. Like Emery and Elliot, there are countless other victims who have been denied living the lives they were meant to live, simply because a eugenic like philosophy which reasons that letting the disabled die is more humane than letting them experience some suffering.

Passive Euthanasia, regardless of the intention, is the withholding of life-saving treatment.

There is a growing consensus that letting the disabled die is more humane than letting them experience some suffering.

But suffering is simply a part of life. There isn't any one of us who escapes that experience.

Amanda Finniefrock said that if ,years afterward, we asked these preemies now grown, who were treated in the NICU whether they would have preferred to have been treated and suffered or if they would rather have died, they would not opt for the latter.

So, I asked my son that very question. Luke had been a preemie 18 years ago, treated in the NICU for less than a month despite original assessments estimating it would be two months or more. He did suffer in the NICU. But he did not suffer as much as Emery or Elliot. What was done to those little boys is the epitome of inhumanity.

My son answered, "Well, I don't remember any of the suffering from when I was a preemie. Things in the world aren't easy for me or anyone right now. There is a lot of suffering for everyone now, and everywhere, obviously with the pandemic. But I want to be alive! I'm glad I am alive!"

I then asked my son, Luke, what he thinks it actually means to be "alive".

Luke said, "Well, there's the technical side of being alive: breathing, growing, blood flow, heartbeat and all of that. But I mean I want to be ALIVE! Which to me, means caring and love, feeling passionate about things, sharing ideas with others, making things for others and helping people, trying to do what's right, seeking justice, being truthful and just trying to live my life as best I can."

He also added that he knows every life has some suffering in it and said that "None of us really likes to suffer, let's face it."

He then quoted from one of his favorite novels:

"I wish the ring had never come to me, that none of this had ever happened.

"So do all who live to see such times, but that is not for them to decide. All you have to do is decide what to do with the time that has been given to you."

That time was taken away from Emery and Elliott, and from many others.

While I cannot be certain, I cannot help but wonder if the reason behind the passive euthanasia (denial of life saving treatment) is because a philosophy of eugenics has become embraced by a growing number in the medical community.

The number of cases like Amanda's where children with a disability or the potential for a disability are being denied lifesaving treatment at an increasing rate, not only in this country, but throughout the world.

I support Emery and Elliot's Law which will undoubtedly save many lives. It will also help deter medicine from continuing this recent and dangerous trend of passive euthanasia.

If modern medicine's embrace of eugenics is the reason Emery and Elliot were denied medical treatment, I have but one important question:

*If as a global culture, we embrace a Darwinian 'survival of the fittest', ideology, and a supremacist agenda, what then will be our outcome?*

*If we accept – in the name of "quality" and "good genes" – the extermination or euthanasia of others because they are old, young, weak, disabled, or "feeble-minded", what then is our cost?*

*For, we will have become a super-powered population of physically strong, cognitively sound, competent, and enduring MASS MURDERERS.*