

Testimony in Support of Simon’s Law

Laurie Nelson

Mother of a child with Trisomy 18

When my husband Andrew and I were at our final prenatal appointment at Children’s Minnesota, we were told our daughter would not survive. We were told Trisomy 18 was “not compatible with life,” and that there was nothing that could be done.

We were encouraged to prepare for her death—not her life.

But our daughter, Abigail, is alive today. She is nine and a half years old. She is joyful, deeply loved, and has changed our family for the better in ways we never could have imagined. Her brothers adore her, and she brings joy into our home every single day.

At that appointment, we advocated for full care for our daughter. Each time we asked for something, we were given a reason why it would not be done.

At one point, I paused and prayed silently. Then I asked,
“If she didn’t have Trisomy 18, is there anything that could be done to help her live?”

They paused and said yes.

They told us they could give her a medication called prostaglandin. It’s a medication that can help keep blood flowing properly in babies with serious heart defects.

I began asking questions.

Would it help her live long enough for her brothers to see her? Yes.

For her grandparents to meet her? Yes.

How long?

Eventually, they said that if she survived birth and responded to the medication, it could work as long as she continued receiving it.

I sat in silence. In that moment, I realized that options existed—but they were not being offered because of her diagnosis.

When we left, we made it very clear that we wanted full intervention. We requested ongoing monitoring and asked that it be documented that our daughter was full code.

Shortly after leaving, I received a phone call from a nurse. She confirmed that we had clearly requested full code.

Then she told me something I will never forget.

A Do Not Resuscitate (DNR) order had been placed in our daughter’s chart.

Despite our clear wishes, a life-ending order had been entered for our child.

From that moment forward, we felt we could not assume anything. We checked records, confirmed her status repeatedly, and advocated daily to ensure that no decisions were made without our knowledge or consent.

No family should have to live in that kind of fear.

We were no longer just fighting for our daughter to live—we were fighting for her right to live.

Simon’s Law protects families. It ensures that parents are informed and involved in decisions about their child’s care. It prevents life-ending orders from being placed without parental knowledge or consent.

This law is not about forcing treatment. It is about transparency, informed consent, and respect.

Children like Abigail—and like Simon—deserve a chance.

Please support Simon’s Law so that no family is left out of decisions about their child’s life.

Thank you.

Testimony for Simon's Law-Mary Kellett

When I was 19 weeks pregnant, a routine ultrasound revealed markers for what the doctor's believed was trisomy 18. They wanted me to have an amnio, which I declined because I knew there were risks. It didn't matter to us what our baby had, he was our son and we loved him and I didn't want to risk hurting him. The doctor told us no one carried these babies to term and offered abortion. He said if our baby made it to birth, which was unlikely, that babies that had this didn't live beyond two weeks of life.

At every appointment abortion was offered and there was pressure to have an amnio. Nothing positive was ever said and no hope was ever given. We named our little boy Peter. At 33 weeks Peter had slowed down moving in the womb and was delivered by a c-section. He was given great care up until day two of his life when results came back showing he did have trisomy 18. At that time, it was recommended that we stop all treatment, wrap him in a blanket and let him die. They assured me they would make Peter comfortable, and I could hold him as he passed away. It is important to know that the treatment Peter was receiving would not be considered futile. It was ordinary care any preemie born at 33 weeks would receive.

We fought to help Peter get the same care any other child would get and not be discriminated against. When we found out through our daughter that there were many children and even adults living with trisomy 18, we asked the doctor why he had lied to us telling us these kids didn't live beyond two weeks. He said, well we have to think about resources and Peter will never contribute to society and he will be a horrible burden on your family. We recommend that you let him go.

The reality was Peter was a great joy to have in our family. He was the youngest of 11 children and everyone's favorite. He thrived at home with so much love and attention and did many things they said he would never do, like eat by mouth, communicate, know us and love us. He was the happiest sweetest little boy, and we miss him terribly. He died at age 6 ½ after having his appendix out.

We started a ministry shortly after his birth called Prenatal Partners for Life to help other families with support, information and encouragement. There is discrimination, a lack of transparency, inaccurate, incomplete information and negativity that are common and that so many families experience. Please pass Simon's Law. Thank you!



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March 24, 2026

Dear Chair and Members of the Committee,

On behalf of Gender Justice, I write in strong opposition to HF4568.

While framed as a parental rights bill, this legislation would layer a bureaucratic maze of distrust onto urgent medical emergencies, with harmful consequences for Minnesota families, patients, and health care providers. It goes far beyond existing law by inserting the government into deeply personal medical decisions and restricting the ability of providers and families to make compassionate, medically appropriate end-of-life decisions for children, including newborns.

In the most heartbreaking circumstances, when a fetus or infant has conditions incompatible with life, or when a child is suffering and will not recover, families and providers work together to determine the most humane course of care. Often, that means focusing on comfort: holding the child, alleviating pain, and allowing families to spend meaningful time together.

This bill would interfere directly in those moments. It would delay or prevent the provision of comfort care, force unnecessary and invasive interventions, and risk separating families from their children in their final moments. It replaces compassion with mandates.

Importantly, this portion of the legislation is rooted in misinformation. Health care providers do not refuse care to viable infants. Existing laws, medical standards, and professional oversight already ensure that patients receive appropriate, ethical care. What this bill does is undermine those standards by substituting political mandates for clinical judgment.

We are also concerned about the impact of the bill on minor children and their families. The bill notification requirements, mandatory waiting periods and transfer timelines seem complex and difficult to implement in urgent and medically complex situations, replacing medical judgement with mandates. It creates new causes of action, mandatory reporting to law enforcement, and potential professional discipline for failing to comply with complex and rigid requirements. This will have a chilling effect on providers, making it harder for them to offer honest medical guidance and appropriate care. The bill also further undermines the role of courts and child welfare systems by limiting their ability to act in the best interests of a child.

Minnesotans deserve dignity, compassion, and medically sound care. We urge you to vote no.

Sincerely,

A handwritten signature in black ink that reads "Megan Peterson". The signature is fluid and cursive.

Megan Peterson
Executive Director, Gender Justice