

Utah Down Syndrome Foundation and One Utah Family Speak Out



"I wish there was no need, but until we are willing to embrace Finn's difference, just as we accept and embrace so many other differences, we need this law to protect individuals with Down syndrome from discrimination - to ensure that they have the right to simply exist." Amber Merkley

"The second, and in my view, perhaps the most important part, of this bill hasn't been discussed enough. It's not quite as sensational so it's being overlooked. It addresses the need for accurate, fair and balanced information/support at the time a probable diagnosis is delivered. And that educational/support piece would be life-changing for expectant parents." Justin Merkley

As we've moved through our journey with Finneas, we have become softer, kinder, more compassionate and accepting of all sorts of differences. Finn has brought a "richness" to our lives that I doubt we would have found without him. We have our fair share of challenges, but we have extra love to meet them.



"Individuals with Down syndrome are sons and daughters, brothers and sisters, aunts and uncles, cousins and friends, neighbors and co-workers, and valued members of their communities. They deserve all of the protections afforded by this nation's founding principles. The unalienable rights of life, liberty, and the pursuit of happiness, without regard to abilities, are fundamental to our society's existence. All who believe these principles should support the proposed legislation regarding non-discrimination for individuals with Down syndrome. This bill simply prohibits the termination of life by abortion based on decisions made without a full understanding of and experience with individuals who have Down syndrome. We strongly support this proposed legislation and advocate the protections it offers."

The Utah Down Syndrome Foundation Board of Directors



HB-166

Downs Syndrome Nondiscrimination Abortion Act

I came to you during the most difficult time in my life. I was terrified, anxious and in complete despair... But instead of support and encouragement, you suggested we terminate our child. I told you her name, and you asked us again if we understood how low our quality of life would be with a child with Down syndrome. You suggested we reconsider our decision to continue the pregnancy. ... [But], you see, Emersyn has not only added to our quality of life, she's touched the hearts of thousands. She's given us a purpose and a joy that is impossible to express. She's given us bigger smiles, more laughter and sweeter kisses than we've ever known. She's opened our eyes to true beauty and pure love.

—Cortney Baker, letter to her OB-GYN as reported by ABC News.

A systematic review of U.S. abortion prevalence following a prenatal diagnosis of Down syndrome revealed alarmingly high rates of over 85 percent among nine hospital-based studies.

Many parents report difficulties in getting proper information about Down Syndrome from their physicians when receiving the diagnosis and discussing options; instead, the discussions often center only on the negative aspects.

Studies have shown that physicians are more directive in their counseling style than genetic counselors, particularly where reproductive choices are at issue.

In one anonymous survey of nearly 500 physicians who deliver a variety of prenatal diagnoses, 23 percent of them admitted that they urged termination of disabled unborn children.

The quality of counseling a mother receives after her baby is diagnosed with a genetic condition can greatly impact her decision to continue or end the pregnancy.