



The Shaw Family

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A Parent's Perspective: No medical professional should pressure any patient to abort any child with Down syndrome

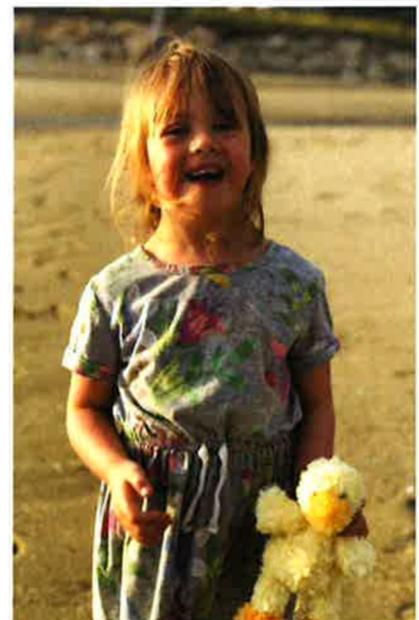
Dear PA House Health Committee,

I am a medical doctor and the father of 4, one of which is a wonderful six-year-old girl named Eva who is blessed with Down syndrome. She is such a joy to me and our family that we (including her siblings) cannot imagine our family without her.

I, like so many, have lived with inaccurate stereotypes of what Down syndrome is. I, like everyone else in America, live in an intensely achievement-based, success-oriented society that values what we can produce above almost all else. In such an environment it is easy to view those with disabilities of any type as lesser, undesirable burdens to be dealt with, though perhaps most would not be honest enough to say it bluntly.

I was stunned by the news of Eva's trisomy 21, grieved, overwhelmed, and frankly afraid. My mind was flooded with the disappointment of expectations I did not even realize I had. Would she attend college? Would she marry? Would she ever leave home? I even had the dark thought cross my mind that life would be easier if she did not survive to be born. But I knew she was ours, and I would not willingly take her life.

The sentiment that has ravaged Iceland in their quest to eliminate Down syndrome people from their country is alive and active in American medicine. Even as a medical provider I felt an overwhelming bias by those treating my wife to abort Eva when we were given the news that she had Down syndrome. For my



wife and I, the only answer to the repeated question "what are you going to do?" (a politically correct way to ask us if we were going to abort her) was "love her."

The first and most jarring time I answered this question was in the dark confusion just after learning of her diagnosis. We sat down in the office of our genetic counselor, and the first interaction was me telling her, directly and clearly, that there was no decision to be made, we were going to have her and were not considering abortion. We could continue straight to a discussion of facts and preparing for her arrival. **The counsellor's reply; "They really don't feel anything [when they are aborted]."**

I looked at my wife with blank astonishment, trying to make sure we were hearing what I thought we were. I reiterated to the counsellor with a little fire in my reply that for us, there is no decision to be made, we are having her. We were then asked to not make a hasty decision and keep our options open.

I was speechless. Many babies are diagnosed with Down syndrome when the baby can feel pain. But even if a baby were put under anesthesia and felt nothing when they are killed by abortion, the unethical coercion by medical professionals was based on the mere fact that my daughter had Down syndrome. I knew, medically and experientially (having treated many wonderful Down syndrome patients), that even in tough life circumstances these wonderful people live full, productive and meaningful lives, and that they are arguably the happiest people on earth. I had a personal moral conviction that I would not abort our child.

I am one of very few who have access to and understanding of advanced medical knowledge. Without this knowledge, conviction, and experience, based on the counseling I received and my immediate feelings after her diagnosis, in all likelihood we would have ended Eva's life. And this decision would have been based on our own inaccurate stereotypes and an intense and inherent bias in the medical system. We weep to think of what we might have missed out on -- and others do -- a source of incredible love and joy to us and those blessed enough to know Eva. **This should not be. No one should be pressured into ending the blessing of a child with Down syndrome.**

I know the weight and influence that my words carry with my patients. I know that *how* a decision is presented to a patient is usually more important than what is even said. The Down Syndrome Protection Act is vitally important to ensure a parent of a Down syndrome child does not have their autonomy trampled by their medical providers at a time when they are extremely scared and emotionally vulnerable.

The topic of abortion is a minefield fraught with much political tension, but I do not think there should be controversy in the condemnation of eugenics. If a child can be targeted for termination based on the diagnosis of Down syndrome, where will it stop? In the near future, when there are genetic markers for a propensity toward obesity, a propensity toward alcoholism, low IQ -- what will stop these children from being similarly targeted for termination based on genetics alone? The condemnation for this type of eugenics embodied in the Down Syndrome Protection Act is important and timely.

I ask this committee to help those with disabilities thrive – beginning in the womb – and especially for promoting a right view of their contributions to society. I believe supporting the Down Syndrome Protection Act is vital to accomplishing this, and hope you will support it.

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