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Jack, 4, with his mother Tasha Nelson (Provided photo)



by Tasha Nelson

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Jack, 4, with his mother Tasha Nelson (Provided photo)

I've experienced life before and after the [Affordable Care Act](#). I have never been more terrified, now that there's a good risk of losing it.

Early in my second trimester of pregnancy with my first child, my husband and I learned that we both have a gene mutation, which meant there was a 25% chance our baby would be born with a disease called cystic fibrosis. The Affordable Care Act (ACA) had not passed yet, so having a baby with cystic fibrosis could be financially ruinous for our family.

Doctors warned us that our child could reach lifetime caps on his health insurance before his first birthday. But as a devout Catholic, I believe in the sanctity of life and knew that my husband and I could handle the challenge. Cystic fibrosis affects many major organs, can be fatal and has no cure.

Doctors urged me to get amniocentesis, a test of the amniotic fluid that would tell us if our baby had this disease. When I asked why the test was so important, they told me "so that you have an opportunity to terminate and save him from suffering if he has this disease." I declined. I already loved my baby. Guided by our faith, my husband and I knew we wanted him no matter what.

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In early 2011, the ACA — sometimes referred to as "Obamacare" — had just been signed, but it would not be fully implemented for several more years. My doctors began educating me on the realities of raising a child with cystic fibrosis. They

explained that cystic fibrosis is a pre-existing condition and that medications to slow the progression of the disease can cost thousands of dollars per month. They warned that if I were ever to lose my job, the baby could easily become uninsurable and could suffer or even die as a result of not having access to medications that allow him to eat and breathe.

And even if I were able to keep my health insurance, they explained that the baby could hit the lifetime maximum insurance coverage while still an infant, and then he could be uninsurable. I was terrified, but knew we still had a 75% chance that he would be born without the disease. I've often wondered how many mothers who had amniocentesis made the heart-wrenching choice of abortion not because they didn't want their baby, but because they could not afford the medicine and health care their baby would need.

Our son Jack was, in fact, born with cystic fibrosis. The love that washed over me the moment he arrived will never change. He received his first medication to treat the ailment, a drug called Creon, at 4 weeks old. The cost billed to insurance was \$1,200 per month. At three months, he started Pulmozyme, medication to help him breathe, which cost \$6,000 per month. As he has grown older, his medication regime — and the cost of the drugs — has grown with him. Today Jack is 9, a rambunctious lover of science, a video gamer and the funniest kid I know. His newest medication, Symdeko, bills to insurance at \$322,560 per year.

The Affordable Care Act does three things perfectly: It guarantees we can get insurance no matter what diagnosis comes our way. It removes lifetime caps, meaning no matter how expensive your care becomes, you or your baby can remain insured. And it expands Medicaid, which has allowed millions more people to access health care. I believe everyone should have a right to health care and that all our children should be cared for.

After Amy Coney Barrett was named a Supreme Court nominee, I learned that she was a devout Catholic like me. I thought that we would have the same stance on health care, but I was wrong. Barrett sided with two previous lawsuits argued before the Supreme Court to overturn the ACA. [Another case is scheduled to be heard](#) by the Supreme Court this month.

Without the ACA, Jack will hit his lifetime cap and become uninsurable before reaching his teen years. Without insurance, I will do everything I can to afford the

medicines he needs, but the stark reality is I do not have half a million dollars per year, and he will die. I want my son to keep living his amazing life, and that means protecting the Affordable Care Act.

[Tasha Nelson is a disability rights activist. She lives in Manassas, Virginia, with her family.]

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