

Alyce Ornella  
Harpwell, Maine

Two years ago, my husband and I were expecting our first child. At the time, we were self-employed as small-business owners and could not afford the high costs of health insurance. When the Affordable Care Act was passed, we found an affordable plan on the marketplace. Suddenly, all my prenatal care was covered. The pregnancy was completely normal and uneventful, just as every parent hopes. The plan we signed up for through the marketplace even fully covered advanced testing for the most prevalent genetic disorders, and my results came back clear. But then the unexpected happened.

No one wants to face the devastation of their baby being born with life-threatening medical problems, but that is exactly what happened to us. Our son, Sam, was born with multiple congenital birth defects, none of which could be detected before he was born. He was rushed by ambulance to Maine Medical Center in Portland when he was just two days old; the pediatric surgeons there saved his life. The medical bills in his first month of life alone topped \$100,000. Within his two years of life, Sam was seen by nearly a dozen specialists, and he's gone through 20 tests and procedures to ensure his health remains stable.

Later in infancy, Sam was approved for SSI benefits which meant he also became covered by Medicaid. The transition to that coverage was seamless - I only needed to make sure his pediatrician put in authorizations for his medications and specialists. He was able to continue seeing his same specialists since birth, and his Medicaid coverage has fully provided for every test and exam he's needed. Knowing that Sam can receive all the care his doctors want for him has greatly lessened anxiety we've felt regarding his multiple conditions. His access to testing and exams has also enabled us to confirm positive status changes in some of his conditions, which allowed him to go off certain medications sooner than expected.

Sam is now a thriving, happy 2-year-old who seems just like any other kid his age. I've been able to return to work part time since he is doing so well, which has had a positive impact on our family. Sam's health care needs, however, will require a team of pediatric specialists to care for him throughout his entire childhood. The protections the Affordable Care Act has provided our family ensure that we have been able to get him the tests, medicines, therapies and doctor visits he needs to stay healthy. The Affordable Care Act ensures he can never be denied coverage and that our family is not charged exorbitant premium fees and high deductibles because of his medical needs. It means he will never face lifetime limits in coverage for conditions he has had since birth. The Affordable Care Act has been critical to how well he is doing today.

Due in part to our fears regarding ACA repeal, my husband and I have both given up self-employment so that we can attain more security regarding health coverage in the future. My husband has recently accepted a job that will take him away from home more than we are used to, but it comes with solid employer-based health coverage for our family. This is our priority now that the new administration and Senate Republicans have made ACA repeal their first goal. However, I cannot rest assured that Sam's long term future will be as secure if we lose the provision for no denial of preexisting conditions. I fear the return of yearly or lifetime limits on coverage and high risk pools. What if my husband loses his job? What will health care access

look like for Sam five or ten years from now? What will be available to him when he's an adult looking for coverage, as a person born with multiple medical conditions and has a complex medical history?

No one should face financial ruin because they need medical care. And no one should be forced to go without the medical care they need. It would be irresponsible for our representatives in Washington to pull the rug out from under millions of people around the country, who have health care because of the Affordable Care Act. I know how it would affect my son's life if that were to happen, and it would be devastating for him and our family.