

Paul Gibbs Testimony

Since the inception of the major healthcare reform law of 2010, it has commonly be referred to as either the Affordable Care Act of "Obamacare", I prefer to use its full name, the Patient Protection and Affordable Care Act, because the patient protections included in this law have been a gift from God for people like me and families like mine.

My healthcare story begins in November of 1974, when my identical twin brother Patrick and I were born. We both came into this world with serious medical conditions. In Patrick's case, it was an intestinal problem called Hirschsprung's disease, which required him to undergo 17 surgeries before the age of five years old. In my case it was a kidney condition called bilateral ureteral reflux, which essentially means that urine was going back up into my kidneys instead of down where it belongs, and this caused hydronephrosis which damaged my kidneys and impaired their ability to function. I was relatively lucky in that getting this under control only required me to undergo 9 surgeries by the age of five. For my parents, even with my father's employer sponsored insurance, this incurred enormous financial costs, and they never fully got out of the hole this medical debt left them with. Within the past 10 years both passed away with very little material wealth to their names, but with a legacy of caring for their family as well as anyone ever could.

My damaged kidneys lasted until November of 2008, when I was informed in a doctor visit that they had declined to the point where I was in end stage kidney failure, and needed a transplant as soon as possible. I had no idea how I was going to pay for this roughly \$79,000 surgery. I was working, going to school, and generally doing my best to be a productive member of society. However, I was uninsured, and had no prospects of getting insurance because my bad kidneys were a very significant pre-existing condition. This meant that getting coverage was either prohibitively expensive, or I would be outright denied. I am a member of The Church of Jesus Christ of Latter-day Saints, well known as a generous church and one that takes care of members in need. But the Church can't pay for members to get a \$79,000 surgery. I also had an amazing support system as part of Utah's live theatre community, where numerous friends offered to be tested as potential donors. The most successful live theatre in the state even raised \$10,000 for my medical bills. But again, that doesn't pay for a \$79,000 surgery. And as it turned out, I needed two surgeries, as my own kidneys were in such bad shape that my doctors felt they posed a risk of infection for a new one and had to be removed six weeks before the transplant. I have heard opponents of the ACA state that Americans don't die due to lack of healthcare, because they can't be turned away from the Emergency Room. But you cannot get a kidney transplant at the ER. I was eventually able to get the surgeries due to qualifying for a combination of Medicare and Medicaid coverage. This took months and a lot of red tape, as Medicare has very narrow criteria to fit for a younger person with kidney failure, and Medicaid was much harder to get in the days before expansion through the ACA.).

The considerable costs associated with my transplant didn't end with my surgeries. A kidney transplant is a treatment, not a cure. Every day for the rest of my life I have to take immunosuppressant medications twice a day, and missing as many as two doses could cost my kidney. Along with these I have to take other medications which help with conditions like high blood pressure and chronic intestinal issues which are related to the transplant. And in 2013, my doctors discovered that my kidney problems were likely caused to begin with by a chronically distended bladder which never fully empties on its own, which means I now have to use a catheter up to five times a day to empty it. If you add all of these expenses together, it comes to a little less than the cost of my monthly mortgage payment. Without insurance this would be impossible for me and my family. And before the enactment of the Patient Protection and Affordable Care Act in 2010, I would not have been able to transition from Medicaid coverage to private insurance. But because of the protections in that law, I could do that. Instead of having to stay poor enough to qualify for Medicaid for the rest of my life, I was able to get insured, get married and start a family. My two sons, who are respectively three years and five months old, had a chance to be born.

My oldest son, Timothy, showed signs of kidney problems when he was born, but quickly improved. My second son, Peter, was not so fortunate. The function of his right kidney has considerably declined during his short life so far, and in June he had to undergo surgery for a condition called uteropelvic junction obstruction,. This condition was causing him to experience hydronephrosis much like I had. We still don't know for certain how successful this surgery has been, or whether his kidney function will continue to decline. But because of the ACA, we know that he cannot be denied insurance coverage for it. He won't face annual or lifetime limits. We'll be able to find plans that cover his needs, thanks to mandatory essential health benefits. But if the ACA is repealed and we lose those protections, Peter will be branded for life with a pre-existing condition that at best

would make insurance coverage prohibitively expensive, and at worst will lead to it being denied entirely. Peter didn't choose to have kidney problems, just as I didn't. These conditions were not caused by behavior or life choices. These were circumstances of birth. When I was born, laws regarding health insurance belied the bedrock American principle that all people were created equal, because I was created unequal as far as the insurance industry was concerned. I am eternally grateful for the fact that Peter was born in an era when law gave him the equal guaranteed right to the security of health insurance coverage.

If we lose the protections of this law, both Peter and I lose that guaranteed right to health insurance. Contrary to some rhetoric, none of the potential ACA replacement plans proposed in 2017 offered the same level of protection for pre-existing conditions. They allowed for people like me to be tossed into the dumping ground of prohibitively expensive high-risk pools, face devastating annual limits on coverage, or dangerous lockout periods for failing to maintain continuous coverage. All of these would have subjected someone like me to the potential for considerable risk to our health and potentially our lives. In his 2012 presidential campaign, my own Senator, Mitt Romney, who now says he has developed a potential ACA replacement, defended denying protections for pre-existing conditions to those without continuous coverage by saying "You don't play the game that way." But this is not a game. This is life and death for me, my son, and millions of others.

I've seen firsthand how important other parts of the ACA are. Because of my own experience with Medicaid, I've been heavily involved with the effort to bring ACA Medicaid expansion to Utah for the past six years, beginning with making a documentary film about people suffering in the coverage gap. These were people who do not or did not qualify for premium assistance on the ACA market but were ineligible for Medicaid because our state had not accepted the optional Medicaid expansion. Because of this film I was given a grant by MoveOn.org to document people in the coverage gap in Florida and North Carolina. I've seen firsthand how badly people are hurting because of resistance to the ACA. After we finally passed Medicaid expansion in Utah in November of 2018 through a ballot initiative, even though our state legislature went against the will of Utah voters by watering it down to a partial expansion, I've seen firsthand how much this is doing for people, as people who for years have been physically unable to work full-time but unable to fit the narrow qualifications for disability Medicaid finally have the access to coverage and healthcare they need to live productive lives. To take this away from them by repealing the ACA's expansion would be the height of cruelty.

Taking away the Patient Protection and Affordable Care Act would be devastating for millions of Americans who would lose their access to healthcare. For me personally it would be potentially catastrophic. Because of the Patient Protection and Affordable Care Act, I have my life. I have my family. There are millions for whom this is the case, and the continued attacks on this law put our health, our lives and our families in jeopardy. I find it ironic that our President is prone to accusing Congress of "harassment", as I and many others I know with chronic medical conditions feel relentlessly harassed.