Written Testimony of Chad Riedy

Adult with Cystic Fibrosis

"Examining Threats to Workers with Preexisting Conditions"

House Education and Labor Committee

February 6, 2019

Washington, DC

Statement to the House Education and Labor Committee
Chad Riedy
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Good morning. Thank you Chairman Scott, Ranking Member Foxx, and distinguished members of the House Education and Labor Committee for inviting me to testify before you today. My name is Chad Riedy and I have cystic fibrosis (cf). I am pleased to be part of this Committee's discussion about how to uphold the critical protections in the current law that workers with pre-existing conditions like myself rely on. Through this important hearing, you are contributing to a pathway of hope for myself, the CF community, and millions of other Americans living with chronic health care conditions.

I'd like to tell you more about my pre-existing condition. Cf is a rare genetic disease that affects roughly 30,000 people in the United States and about 70,000 worldwide. Cf is a degenerative disease that primarily affects the lungs by producing a thick sticky mucus that builds up in the airways, trapping bacteria and causing inflammation and infection. The damage this causes ultimately leads to either death or the need for a life-prolonging lung transplant. In addition to the lungs, cf also affects, the pancreas, liver, bones, and other organs. There is no cure for cf.

I was diagnosed with cystic fibrosis in 1984 at three years old. Upon my diagnosis, my parents were told that they should not expect me to live to see my twelfth birthday. Today, I sit here at the age of 37. I've been married to my wife, Julie, for over 11 years and am a father to our two boys, Liam, who is eight and a half, and Tate, who just turned five. Up through my early twenties I was relatively healthy, playing sports, working, and for the most part living a 'normal' life.

I'd like to share with you what a 'normal' life looks like for someone with cf. Staying healthy means undertaking a daily treatment regimen that includes taking roughly between twenty and thirty pills a day or between 7,300 pills and 10,950 pills a year, that help aid in digestion, fight off infection, reduce inflammation, open up airways and correct the underlying cause of cf. In addition to the pills there are three to four hours of treatments, one and half to two hours in the morning and then again in the evening. These twice-daily treatments start with an inhaled steroid to open up the airways in my lungs; next I have two nebulized treatments, the first is a highly concentrated saline solution to add moisture into the airways and loosen the mucus, the second help to thin the mucus so that it can be coughed up. After my nebulizers, I then hook up to my vest. The vest is worn so that it covers the lungs and is connected to a machine, roughly the size of a 'boom box,' by two tubes. When turned on, the vest inflates to a selected pressure and then starts to pulsate at a set frequency. This is done in five-minute intervals for thirty minutes with the frequency increasing at each interval. In between each interval, there are special breathing techniques used to move the mucus from the small airways to the larger ones and then out through coughing. Once time on the vest is complete, I follow this

up with an inhaled antibiotic through a nebulizer to fight any bacteria I have grown or may be growing in my lungs. This is the routine when healthy, if I have an exacerbation, treatments could increase to three or four a day and visits to my care team also increase.

Currently, I have four annual visits with my care team at Johns Hopkins University. At these visits, I see a pulmonologist, nurse, dietician, respiratory therapist, physician, and social worker that along with my family, and me work together to coordinate my care. At every visit, I take a breathing test called a pulmonary function test that measures my percentage of lungpower. Advanced disease is characterized by rapid decline in lung function and when you drop below 50 percent lung function, it's advised you start considering a lung transplant.

Up through my early twenties, my daily treatment regimen looked slightly different than it does today, primarily because we did not have the targeted treatments we have now. During this time my main course of treatment consisted of my parents preforming physical chest therapy where they would pound on my chest, back, shoulders and sides with their hands to help shake up and break loose the mucus in my lungs. It wasn't until high school that we started adding a nebulized treatment to the chest physical therapy. In addition to the daily treatment regimen I had occasional hospital stays to receive a "tune up," which usually meant intravenous antibiotics, a bronchoscopy and sinus surgery to remove polyps (another complication of cf). These "tune ups" only happened 3 or 4 times through college while I was on my father's employer-based coverage. Looking back, I'm grateful I was able to stay on my parents' health insurance as a young adult.

When I was 26 years old, I got really sick for the first time. My wife and I had just married and returned from our honeymoon when I started to notice that I was having a harder time breathing while performing routine tasks like walking upstairs or talking on the phone. After a visit to my care team and finding out that my lung function had fallen from around 45 percent to the low 30's, I was admitted immediately to the hospital where I stayed for seven days receiving intravenous antibiotics, chest physical therapy, and other procedures to get rid of an infection and stabilize my lungs. Because of the highly specialized care that my care team provides, thankfully, after seven days I was improving and was allowed to go home where I continued the IV antibiotics for an additional two weeks. While my lung function slowly recovered and crept back up to the low 40's, it required more antibiotics and therapies to stay healthy which came with greater cost.

My health care was covered under my employer-based insurance plan but it was the first time I realized the true impact that annual and lifetime caps could have on my life. I remember receiving constant reminders from the insurance company about how much they had covered and just how much I had left until they would no longer cover the medicine, procedures and doctors that I need to simply breathe and stay alive. I worried about what would happen if I got sick again and had to stay in the hospital for an extended period of time or if things got so bad that I needed a lung

transplant to stay alive. Would I exceed my limits or be denied coverage? Then what? How would I pay for these things? These were all questions that I used think about on a regular basis before the ban on annual and lifetime limits was passed into law as part of the ACA.

The next time I would get very sick would be in 2014, when the ACA was in place. Over the course of roughly eight months starting in August 2014, my lung function fell from the low 40's where it had been for about 7 years to the low 20's. During this time, I was seeing my care team almost weekly and on IV antibiotics for extended periods of time. I underwent numerous procedures to both track my lung function and determine what was causing the rapid and sustained decline in my lungs. Things progressed to the point where we started to have conversations about the possibility of needing a lung transplant for me to stay alive. I was so sick that not only was I occasionally missing work, I could not walk 10 feet across our living room floor without having to stop to catch my breath. I struggled carrying my kids, who at the time were ages four and one.

Thankfully, due to the protections afforded by the ACA and having coverage through my wife's employer, we did not have the additional worries of the cost of these procedures and medicines, being denied coverage for my cf, or being kicked off our plan. Instead we were able to focus on our family and my care and doing whatever we needed for me to stay alive so that I could be there for my wife and to see my children grow up. Because of these protections I was able to access the highly specialized care I needed to eventually stabilize my lung function and bring it up to the upper 20's and low 30's where it resides.

Today, I am more hopeful than ever because of the advancements that have been made to treat the underlying cause of cf and the significant progress towards a cure. In January of 2018, I started on a drug that has changed my life. The medicine, Symdeko, represents a major scientific advance and is a relatively new type of treatment that treats the underlying cause of my cf – not just the symptoms of the disease. It has brought more stability to my lung function over the past year, decreased the amount of respiratory symptoms that cause damage to my lungs, and most importantly allowed me to be a better husband, father and friend. My treatment regimen has allowed my lungs to open up and lessened the amount of panic and anxiety attacks that I used to have performing routine tasks. I no longer worry when carrying the laundry up a couple flights of stairs from the basement. When my boys are tired and want a piggy back ride upstairs to bed or are hurt and need some extra love, they know daddy is there for them.

My treatments and care help me breathe a little easier and stay healthy so that I can work to help provide for my family. At the same time, cf treatments and care are expensive. In 2018, the cost of my treatments was just under $450,000 and this does not include the cost for the visits with my care team and the associated procedures to monitor and maintain my health. While we still spend a lot on out-of-pocket costs, I am thankful that our insurance covers the majority of them for us.

This is my story. And there are so many more like it across the country. For people battling rare and chronic diseases, the policies we are here to discuss have a real impact on their ability to stay healthy and ultimately, stay alive.

I am deeply worried about the decision in the Texas v US court case. If the judge's ruling against the ACA is allowed to stand and insurance companies are allowed to implement annual and lifetime caps, I would reach them in a matter of years. In addition, the cap on out-of-pocket cost sharing is another vital protection for someone with high healthcare costs such as myself. If all of these and other 'pre ACA rules" came back, I would then be faced with serious financial tradeoffs in order to continue on the medicines that are extending my life or face the possibility of dying.

I also rely on the pre-existing conditions protections in the law. Knowing I can't be denied coverage, charged more for my coverage, or have services related to my cf excluded from coverage is a critical protection in the ACA. And finally, it is so important that young adults with cf are allowed to stay on their parents' health insurance plan until age 26. For someone with a lifelong chronic condition, this protection provides an enormous amount of security during the early adult years.

I am here today with hope for the future; a future where I grow old with my wife, see my kids grow up, graduate college, get married and start families of their own. This is all because of the access that I have had to adequate and affordable health care and the protections that the ACA has provided. I am not asking you to take care of me as I am already doing that every day, and I understand that the law is not perfect, but the protections it contains are critical to me and millions of other Americans with pre-existing conditions.

I thank the Committee for giving me the opportunity to share my story, and I ask that you will work to keep our hope alive as you consider legislation this Congress.