New York Health Act Public Hearing Testimony

Jeff Collins, Candidate for State Senate, District 46

I am Jeff Collins, I live in Woodstock. I am a small business owner and I am running for State Senate in District 46. But I am not here today as a candidate for public office--I'm here as a person whose family has been personally impacted by our system of health insurance and by our healthcare system in general.

I would like to thank the Health Committees of the Assembly and State Senate for holding this and other public hearings and for their openness and willingness to listen to testimony from their constituents. My testimony concerns the complexity of navigating our current disjointed system of health insurance, the impact that it has had on my family, and ultimately the economically discriminatory nature of our health insurance and our health care system in general.

In late 2009, my wife Lisa developed Trigeminal Neuralgia. Trigeminal Neuralgia is a chronic pain condition that affects the trigeminal nerve, which carries sensation from your face to your brain. For those people who have trigeminal neuralgia, actions such as brushing your teeth, eating, and talking can trigger a jolt of excruciating pain. This pain can last for seconds or minutes at a time. Trigeminal Neuralgia pain is one of the few types of pain considered more painful than childbirth.

Over the next 4 years, Lisa's symptoms would come and go. In the spring of 2014, her symptoms returned and grew steadily worse. This is where our experience dealing with our disjointed, profit-based model of health insurance started. Our General Practitioner attempted to treat Lisa's symptoms through medication. After some trial and error, our doctor found and prescribed a medication that worked. However, it was not on the FDA approved list for Trigeminal Neuralgia and our insurance company denied coverage. We believe that the denial of coverage was largely based on the $800/month cost.

Our doctor appealed the denial of coverage, but ultimately lost the appeals. We were left with the choice of paying for the medication out of pocket or having Lisa suffer pain equal to or greater than childbirth every time she ate, talked, brushed her teeth, or simply touched her cheek. We were fortunate enough to be able to pay for the mediation out of pocket - so that is what we did.

In 2014, we were informed that the health insurance that we had through our small business was no longer going to be available and that the only option that we had for insurance was to purchase it through an ACA plan. This corresponded in time with Lisa finding that one of the top Neurosurgeons specializing in Trigeminal Neuralgia has his practice on Long Island. After visiting him, it was clear that Lisa needed a surgical procedure to address her condition.

So, as I researched which insurance plans on the ACA to purchase, I did so with the understanding that Lisa would need brain surgery to address her Trigeminal Neuralgia. The first thing that I learned is that none of the plans available on the ACA cover out-of-network doctors, and that Lisa's surgeon was out of network to all of the plans. This meant that we would have to cover his entire cost for the surgery. Fortunately, I also discovered that there was a small loophole that forced insurance companies to cover out-of-network doctors for a period of time after switching to an ACA insurance policy. We were within the timeframe for this loophole. In order to cover the operation, we purchased a Gold Plan from the ACA for $1,066/month.

Lisa had her first surgery in October, 2014. Unfortunately, the surgery failed. Shortly after the anesthesia from the surgery wore off, the pain returned. The pain became so bad that Lisa went into the emergency room in November 2014. A second surgery was performed by the same doctor as the first surgery and this time the surgery was a success. Fortunately for us, because the surgery was performed on an emergency room basis, the insurance company covered our out-of-network doctor even though the loophole that previously applied no longer applied. Without insurance, each of these operations would have cost approximately a quarter of a million dollars.

For the next 3 years, Lisa had no symptoms. Then, in the late summer of 2017, the symptoms returned and Lisa needed another surgery. At this time we were on a Bronze level plan with the ACA that cost us $959/month and had a large deductible and large co-pays.. We considered switching to a Gold level plan in order to more fully cover the operation, but we would have to wait until January as that is the only time you can switch plans on the ACA. Lisa could not wait the 3 or 4 months it would take to switch policies. We had to find another solution.

I discovered the availability of Professional Overhead Expense Insurance policies and fortunately, we could get this type of insurance through our small business. So, Lisa changed her insurance to get it through the POE company, while I stayed on ACA. Her new insurance policy cost $1,800/month. Lisa's third surgery was in October 2017.

This surgery resolved the condition for about 9 months. In June of 2018, Lisa had her fourth surgery. This was a different type of surgery and would have cost us approximately one hundred thousand dollars if it had not been covered by the insurance that she still had through the POE company.

In order to save money, we switched back to a Bronze level ACA policy at the beginning of 2019. Lisa's symptoms have once again returned. We are not sure exactly how we are going to manage the insurance for the new procedure that she requires.

One of the most common words that I have used in the description of our navigation of the disjointed insurance market is "fortunate", and I will repeat it again. We are fortunate to have been able to manage what we needed to in this process, but many - if not most - people are not so fortunate. Our current health insurance system is economically discriminatory. It kind of works for those who are fortunate, but it clearly does not work for those who are not so fortunate.

My description of the process that we had to go through is convoluted and complex and I am sure that many of the listeners are a bit confused by all of this. That is the point of what I am testifying about. Getting healthcare should not be convoluted, complex, or confusing. The fact that it is shows that something is seriously broken.

When someone does have a condition such as Lisa's, or any other medical condition, they should be able to work with their doctor and get the treatment that they need to correct the condition. When a doctor prescribes a medication for a condition and that medication works, the insurance company should not be able to deny coverage because it is too expensive. Being sick or in need of medical attention is stressful enough. Adding the necessity of dealing with complex insurance rules on top of that only adds to the stress.

In closing, I would like to point out that every elected official in New York State has high quality, government-funded insurance that is paid for by our tax dollars. That means that every elected official sitting in front of me right now has their insurance paid for by the tax-payers sitting behind me. All the people sitting behind me are asking for is the exact same thing that those people sitting in front of me already have.