

Testimony of Ms. Sonji Wilkes for the Committee on Energy and Commerce Subcommittee on
Health of the U.S. House of Representatives

“No More Surprises: Protecting Patients from Surprise Medical Bills.”

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My name is Sonji Wilkes and I am a mom and patient advocate from Englewood, Colorado. Thank you to Chairwoman Eshoo, Congressman Burgess, and Members of the subcommittee for the opportunity to discuss my family’s experience with surprise billing and to ask for your help in ending surprise billing for patients.

In 2001, my husband and I become first-time parents. As healthy twenty-somethings, neither of us had much experience with medical claims and insurance, but we knew that staying in-network per our insurance policy was important. We had our first daughter at an in-network hospital, delivered by an in-network doctor. We had expected to pay \$250 out-of-pocket. When the bill arrived a weeks after the delivery, it was \$500. Seems that the insurance company counted myself and our newborn daughter as two separate patients. We felt a bit duped but paid the claim and moved on.

Two years later, and still with a similar insurance plan, we decided to grow our family. A little older, and a little wiser, we made sure to ask specifically if we would incur two co-pays. We doubled checked that our OB/GYN and the facility we were to deliver at were still in-network. Per the documentation we had from our insurance provider, we were following the rules.

My son, Thomas, was born full-term and came into the world just under 10 pounds. By all appearances, he was a healthy boy. Within a few hours of birth, Thomas was circumcised. But several hours later, our pediatrician called to say he was concerned that the circumcision site was continuing to bleed and that he wanted to run a few tests. By the next day, our pediatrician called us back, in tears, to break the news that Thomas had severe hemophilia A, a genetic disorder that prevents his blood from clotting. The pediatrician told us that hemophilia was a rare, lifelong disorder and that he didn’t know much about it, but he had a hematologist waiting on the other line to talk to us. They decided to take Thomas to the Neonatal Intensive Care Unit so he could be closely observed. Within the hour, the hematologist for the local Hemophilia Treatment Center was standing in our hospital room, and after opening the conversation by asking if we had good health insurance, spent the next few hours explaining hemophilia to us. She had brought a dose of anti-hemophilic clotting factor to administer to Thomas to stop the bleeding, as the hospital facility we were at did not stock the medication in the pharmacy. In the NICU, the hematologist prepared the IV, and started an intravenous line in my newborn’s scalp while the NICU staff intently watched, as they were unfamiliar with hemophilia and did not know how to treat it. The hematologist was not part of the hospital or NICU staff; she was simply there as a caring, knowledgeable provider. We never saw a bill for the medication she administered or for the hematologist’s time and services.

Thomas remained in the NICU overnight for observation. As a nearly 10-pound baby in the NICU, he was a bit out of place. Neither my husband or I left Thomas's side and other than monitoring his vital signs, there was no other direct care given to Thomas. We were discharged within the normal post-partum period and went home to come to grips with the unexpected diagnosis of a chronic disorder for our baby boy.

A few weeks later, we received another shock. Opening the mail, we found a bill for \$50,000 for Thomas's stay in the NICU. My husband and I were dumbfounded. We had been in an in-network facility. How could we possibly be responsible for that amount?

The insurance company was adamant. According to them, we had a \$50,000 debt that needed to be paid. My husband and I were equally adamant – we should not be held responsible. We did some research and found out that the hospital had subcontracted the NICU out to a third-party provider. This third-party provider was not part of any insurance company's network.

We felt we had made a good faith effort to stay in-network based on the information that was provided to us. We refused to pay the bill and were subsequently sent to collections. Our credit was ruined, but our resolve was not. Several years later, the debt was dismissed as part of a class action lawsuit, but nevertheless, we struggled with the effects of a bad credit rating.

Before the bill was resolved, but after our credit was trashed, our mini-van lease was expiring. We had to either turn it in or buy it, and neither option was going to be easy. We knew we wouldn't qualify for a new lease and we had very real concern that the dealership wouldn't enter a contract with us to buy out the existing lease. We went into the dealership to talk with them and it was not looking good with the first guy we talked to. We asked to talk to the finance manager and I completely broke down in front of him when he said he didn't think he would be able to help us. I had to have a car: Thomas was being seen at the Hemophilia Treatment Center multiple times a week and getting there without a car was nearly impossible. My husband and I explained how the surprise health care bill had led to our credit rating as I emptied the Kleenex box sitting on the finance manager's desk. He started tapping on his computer keyboard, wiped a tear of his own, and said, "We'll make something happen for you. It might be at a crazy high interest rate and you'll have to keep that car until the day it dies, but I understand your situation. My family also got hit with an expensive medical bill we weren't expecting." Twelve years later, I'm still driving that mini-van.

When you are told that your baby is bleeding and his body lacks the ability to stop and that he needs immediate specialized treatment, your first reaction isn't, "Gee, I wonder if that's in-network;" your first reaction is, "By all means, do whatever it takes to help my baby." I would have never thought to check if the NICU, just 50 or so steps from the room I gave birth in, was in-network. I think any reasonable person would assume it to be because it seems reckless and cruel to me that it would not be. After all, when newborns end up in the NICU, it is an occasion of maximum family vulnerability, and it will inevitably entail high-cost care.

Consumers should be protected from expensive surprise medical bills in emergency situations or when they believe that they are appropriately seeking care from in-network providers. No family should face financial ruin because they are duped into thinking they are at an in-network facility or because their in-network provider contracts out services like radiology, lab services, imaging, or more without the patient's knowledge. While transparency and disclosure of any out-of-network sub-providers is critical, it's still not enough. My husband and I consider ourselves to be health literate, but navigating the nomenclature of health insurance policy is extremely difficult, and especially so for people who are dealing with the stress of a medical crisis, or for people who have not had many experiences in a health care setting. These families aren't often equipped to know how to appeal the bill, and even if they do begin that process, the collections agency can start calling.

According to a recent Kaiser Family Foundation poll, four out of 10 respondents said they had received an unexpected bill from a hospital, lab or doctor in the past year. But surprise billing is not a new issue: the personal story I just shared with you is from 2003. Patients need Congress to pass protections to stop these harmful practices.

While serious policy disagreements need to be worked out, you cannot let this effort grind to a halt. My family incurred a devastating surprise bill 15 years ago. Every year, millions of other families get similar bills. The time has come for this egregious practice to stop. Failing to pass meaningful legislation means you are letting millions more families experience the fear and pain my family faced. Please get this done.

Thank you for listening to my family's experience with surprise billing. Please protect patients from excessive bills and medical debt by ending surprise billing. My family and millions of others thank you in advance.