

## Commercial health insurance: Is denying care the business model?

"More painful than the chronic pain and the sadness of knowing how many people are denied care in this country is feeling like a burden to your family and I think that's one of the most punishing elements of bankruptcy of medical bills." - Kimberly Soenen

911. What's your emergency?

America's healthcare system is broken and people are dying.

Welcome to **Code WACK!**, where we shine a light on America's callous healthcare system, how it hurts us and what we can do about it. I'm your host, **Brenda Gazzar**.

(music)

This time on **Code WACK!** Are three-month long waiting periods for employment-sponsored health insurance just another denial-of-care tactic? What devastating consequences did one young woman face after she was seriously injured on her bicycle during such a waiting period? To find out, we spoke to **Kimberly Soenen**, the founder of Chicago-based "**SOME PEOPLE**," a not-for-profit organization and multiverse channel that examines the people, processes and systems that constitute the maintenance of and barriers to health.

Welcome to Code WACK! Kimberly.

**Soenen:** Thank you so much for having me.

### Q: Tell us a bit about yourself and your background. Who are you and how did you become interested in the issue of healthcare reform?

**Soenen:** Sure, well first off, I just wanted to mention that I am the Chief Operating Officer of <u>Ampers Radio Association</u> in Minnesota. And everything I share with you today is as a citizen and as the founder of "SOME PEOPLE," and not in my professional capacity with Ampers.

#### Q: Thank you. What else would you like us to know about you?

**Soenen:** I've been working in health journalism and journalism as a producer, editor, curator for about 25 years, and what catapulted me into that work was an injury. After that injury, I was working as a journalist and a producer and communication strategist. And also in my personal life, I started becoming extremely engaged in the single payer movement in the United States. And really, I've dedicated a large part of my personal work to advocating for single payer.

### Q: So sorry about your injury. Do you want to tell us a little bit more about what happened?

Soenen: It was 1996 in Chicago, and I was just back from working in Europe and I had gotten an internship with Harper's Magazine in New York City. And so I thought I'd wait tables at a restaurant for the time before I went out to New York City and I was working full time at a restaurant called the Big Bowl Cafe in Chicago, which was part of a restaurant chain that's pretty prominent. When I was hired, there was a 90-day waiting period for health insurance. So I was working full-time as a server at their State and Cedar location in downtown Chicago, which is kind of a big nightlife area in Chicago. It was a hotspot. And so we were on a two-hour wait every night. Celebrities were coming in. Locals were coming in. I mean, it was a really, really high volume, high octane restaurant when we opened our doors. I was commuting to that job on my bicycle. I was cycling down North Avenue in Chicago, and right at the intersection of Mohawk, a driver came over an intersection of construction and he hit me and I went over the top of his pickup

truck. Witnesses said that he appeared to be disoriented, and he was confused by the construction, and he hit me at a very high velocity. That incident changed my life.

Q: Wow. I'm so sorry. That sounds horrific. Once the collision happened and you were struck by the driver, did you have to spend time in the hospital? What were your injuries like?

**Soenen:** I went to the University of Chicago that day. A surgeon assessed me the next day. I was 26 years old, and he wanted to do surgery on my spine because of the pelvic injury. And I had been a Division 1 athlete. I played volleyball. I coached volleyball at a high level at the collegiate level and had water skied and downhill skied. And I've been a bicycle commuter. And so my body was really a vessel for expressing how I engaged with the world. I was a very physical person. I was a very athletic person. And when a surgeon says to you at the age of 26 that they want to cut into your spine, it's a difficult thing to get your mind around. And I thought to myself, a) I can't pay for that. And b), I think I'm gonna try and use other approaches to maintain my health and heal and recover.

You know, it's interesting when an accident happens, or at least for me, everything was in slow motion. I remember going over the hood, I saw him coming at me, everything goes into slow motion. It's almost like sports or what I've read about war. Things start moving in slow motion. And after an injury or illness or disability is diagnosed or a chronic illness, everything kind of for me started moving in slow motion. When the surgeon was talking to me. My mind wasn't working as quickly as it usually does. Everything became a little bit more of a slog.

And depression results from chronic pain, insomnia, results from chronic pain, mood swings because kind of biophysiological your body locks down. And it's not uncommon with injuries where the part of your body that wasn't injured goes into triage mode to support the side of the body that is injured. And so it's, it often works over time. So the pain kind of starts to bleed a little bit because your body is trying to keep everything aligned and stable. So, you know, it's not uncommon for people to have an injury, but then, you know, because our bodies are integrated, that other parts of it are affected. So my body started to kind of lock

down and my mobility was limited. My athleticism was my lung capacity around my ribs. My breathing capacity was limited. And so all of those things kind of meld to handicap you.

And also it's very draining. It's draining emotionally, it's draining financially, and it's draining bio physiologically. So you're losing your identity kind of in slow motion.

Q: Wow, that's a lot to deal with. So then your insurance hadn't kicked in yet. You, how many days did you have left before it kicked in? And then how did you navigate all the medical bills that ensued?

**Soenen:** Well, that was day 88 of a 90-day waiting period. So back then it was very, very common for [insurance] companies and employers to make employees wait 90 days for commercial health insurance. And the public reasoning behind that was in case the employee was fired, if it was a probation period, et cetera, et cetera. But really it's just another denial mechanism for commercial health insurance companies. So I was on day 88 of a 90-day waiting period. So what that meant for me and my pelvic injury was that anything related to my injury was not gonna be covered going forward. And before the ACA was implemented,

#### That's the Affordable Care Act.

**Soenen:** pre existing conditions, you know, that was another term and mechanism architected by the commercial health insurance industry to deny care. And so everything going forward related to that day, and that injury was not covered. And so I began paying out of pocket for physical therapy. I began paying out of pocket for anything medicine related to pain management. And so those out-of-pocket costs all add up. And it's very difficult to be paying premiums and deductibles and then in addition over the top paying out of pocket for care. So that's what really pushed me in the direction of bankruptcy, personal bankruptcy from medical bills and hyperinflated medical bills.

Q: Do you recall how much you had to pay out of pocket, how much you were charged for all the medical bills?

**Soenen:** It is impossible to calculate that. And here's the reason why. As it's happening and as you're just trying to keep your life going forward, you're just trying to maintain your household budget, you're just trying to keep your career on track, manage your pain, et cetera, and all the other residuals that come with injury, illness, and disability and chronic illness is the money's just going out in the moment, and you might be paying out of pocket for medicine, you might get a bill that says you have to pay out pocket for the lab fee or the blood draw. And all of that kind of mounts up and it wasn't actually until I had to make the case with lawyers and judges in the state of Illinois that I did have to itemize all that.

So to answer your question, do I remember now what the financial damage was or the out-of-pocket costs were for me? No. But I did have to itemize everything, and it took me about nine months to a year to do that on my own without a lawyer in Illinois at that time, at least, I don't know about now. But you did have to vet it through about three lawyers that worked for the state and two judges to prove that you were indeed being bankrupted specifically by medical bills.

### Q: When you realized that you weren't gonna be covered, that the medical expenses weren't gonna be covered, what was going through your mind?

**Soenen:** Well, then the game begins, and I started doing a deep, deep dive research wise, that's kind of in my DNA as a citizen or a person, but it's also as my career to do research and kind of muckrake and investigate how these systems work and why denial of care was allowed. And again, this is kind of right at the dawn of managed care. The late eighties, the early nineties, people started getting denied care and denials and they thought, 'oh, I'll appeal. This is either an administrative mistake or must be my mistake,' or 'this is strange.' Then they'd appeal and get denied again. And it was all done by snail mail back then. So it's very slow process. And I'd get denied for something and then I'd think, well, I'll appeal it. And then you appeal it by snail mail. And it just became very clear that denial of care was actually an apparatus.

It was a business model and a system designed to extract profits from consumers who were paying by the way. No other industry operates the way commercial health insurance does, which is consumers pay in, and then when they need the care, they are denied that product. So it's very uniquely American, even though

Americans are known for being savvy and very consumer forward, you know, just always looking for the best deal. They don't want to be hoodwinked, they don't wanna be hustled. And Americans are kind of known for consumer research, you know, and in this one area, commercial health insurance really hoodwinks the American consumer. We pay in, we pay our premiums, our deductibles, our out-of-pocket costs, and we don't get the product or service we're paying for when we need it. And so as I went along, I realized that this is not, this was not just me.

Yeah. And when I began to talk to more people, report on it, and start really digging into what these mechanisms were at the corporate level and how this was (being allowed) to happen, and I'd hear more and more stories. And so here we are 30, 35 years later, and we're seeing a sea change by the electorate. But it's glacial. It's really glacial that people are starting to understand that denial of care is the business model. It's not a one off. These stories are not unique. They're not personal. Patients have not made a mistake. It's not an administrative error. There's no reason for it. There's no rationalization for it. It's just the model that they use to extract profits.

### Q: So just to confirm then, the accident that happened, is that what led you to file for bankruptcy?

**Soenen:** Yes. Yes. And I remember, you know, I remember that day, it was an extremely hot day. I had all my files together, all my paperwork together, and I walked down to the federal building in Chicago, downtown. It was so hot and humid, like really Chicago hot and I thought I knew what to expect, that it would just be the final step in finalizing my bankruptcy. But I wasn't quite prepared. And I remember walking into this pretty ominous building downtown, and I walked in, you have to go through security. So that's kind of nerve wracking. And then I had gotten in the elevator, I went up to the bankruptcy floor, or I was directed to the area where I needed to check in to finalize everything and I walked in and I was expecting a quiet personal experience. I thought there would be a few people there.

And it would be kind of a closed door situation where I would meet with a judge and finalize everything with a witness and when the doors opened on the elevator, there were probably 70, 80 people there also waiting to file for

bankruptcy and I was really taken aback by that, as informed as I thought I was. I wasn't prepared to see so many people in that room. And I was ushered or directed to go sign in at the front of this room. And there was a clipboard, very analog, very antiquated, just a clipboard and a pen with a string on it. And it said first name and family name and I remember filling out my first name and when I saw that family name, all of a sudden it was like the children's toy. It's like a viewfinder with little slides and photos where you click it when you're a kid and you go through like a reel of slides.

And I kind of, in my mind, when I saw "family name," I saw images in my brain of my great grandma coming over to the United States at the age of 17 alone. I saw both of my grandparents, paternal and maternal working as janitors, munitions, factory workers, owning a grocery store at Jackson and Kilborn, my mom and dad working so hard for 30, 40 years to educate, give us an education as sewer water contractor and a teacher, my brother as an entrepreneur, my sister as an entrepreneur, and my cousins as well, who were business people, activists, advocates. And I just had all these flashes of my body, water skiing, rock climbing, slalom skiing, barefooting, downhill skiing and cycling. And it all went through my mind in a flash. And I actually vomited and I vomited in a room in front of all of these people and the security guards.

And it was almost like a primal release of everything I had been through up until that time. And it was just kind of a breaking point that I didn't want my family name, I didn't want my family name to be tarnished. I didn't want people to think I didn't have a good work ethic, that I was irresponsible, that I was, you know, incapable. And, and so I felt shame. I know that that shame was off point because it wasn't my fault, but I felt such shame and I just struggled to write S-O-E-N-E-N. And so that was how that day started. We wrapped up everything administratively about an hour and a half, two hours later, because it was very long, and I remember walking home that day kind of in a fog and something really broke in me. And all of this advocacy work and journalism work and investigative journalism work has filled that vacuum kind of, that just crack in my body has just been filled with kind of this fire to change the system.

Q: Wow. Such a powerful story. And it does sound like a very pivotal moment for you. Basically, you're forced to file for bankruptcy for medical bills, and you're doing it alone, from what I understand. You don't have an attorney representing you.

Soenen: Yeah, I can't afford one.

Wow. And then see the flashbacks of your ancestors who wanted a better life for their children and grandchildren and how difficult that must have been for you. But I love what you said about allowing those cracks to be filled with the advocacy and the passion and the fight to change the system to change this model that's not working.

**Soenen:** It's really denial of care debt. Or when people talk about medical care bankruptcy, it's really denial of care, harm for profit bankruptcy, and what happens when somebody files for bankruptcy that hairline fracture travels for years at that time in Illinois. It stays on your public record for seven years. I think state to state, it varies, but for me, that meant I couldn't get a business loan, couldn't get a mortgage. Everything I did was scrutinized for financial responsibility. It jams people up and it alters the trajectory of their life, sometimes irreversibly. So this notion that millions and millions and millions and millions of Americans are carrying medical debt on average \$3,000-\$4,000 per household is not only bad for the economy, but it's bad for competitiveness. It's bad for public health. It's bad for stability. But taking it back to the individual level, it's a very scary thing to be working full time and have a great work ethic and be on a slippery slope like that.

And it's also your future. And it's hard to bring somebody else into your life when you know you have that past or you've been through something like that because you don't want to bring them into instability. And so it really affects all your social, cultural, all of those foundational cornerstones of what it means to be human. So the system has very, very, very damaging effects on, you know, it kind of, it, it can beat people down. It can beat people down. And, and again, I'm speaking as somebody who's able-bodied, despite my injury and despite depression and all of the things I battled for persons who aren't able to be mobile or ambulatory or they have physical limitations or developmental disabilities or

disabilities. It's a whole nother conversation for them. You know, this notion of employer sponsored health insurance is antiquated. It was started during World War II.

And so you know, just tethering access to health care to employment is quite an absurd concept. So, but yes, it, it really, it really changed. And also, I, I got a little bit, I was young and I got angry at our government structures for not, you know, for feeling unprotected, for being, feeling out to sea. And we had, we're not a litigious family. We did everything right as Americans like to say. And I, it planted a seed of anger that is still very much alive in me, within me today.

# Q: What would it have meant for you if we had had single-payer health care, comprehensive health care that covers everybody, at the time that you were struck?

**Soenen:** Just asking so many great questions. That's why we love Code WACK! My earning power in my career would have increased. I would've been able to access the physical therapist or therapist of choice who had worked with athletes and specialized in working with athletes, so I would've been able to access care and not been cut off. So commercial health insurance companies will let people see a physical therapist maybe four or six times, and then they cut 'em off. Still to this day as we talk, I would've been in physical therapy at least once every two weeks, if not once a month for health maintenance. I would've been able to go to integrated care, meaning Rolfers, Thai massage, athletic training at the Ability Lab at Northwestern or downtown Chicago. It's a lot of work that you can't do alone. You need pressure, you need weight, you need manipulation. You need to be working with another person to do it.

And I would've just been significantly healthier. Not only financially, I would've been healthier, but physically, spiritually, emotionally, and I wouldn't have burdened my own family economically, which is also a weight that's too personal to go into publicly for me. But I have experienced many, many times in my life, suicidal ideation. And that comes from chronic pain because you just sometimes feel like you can't see past the pain. It's just so overwhelming, but more painful. And I know this is hard for some listeners to believe, but more painful than the chronic pain and the sadness of knowing how many people are denied care in this

country is feeling like a burden to your family. And I think that's one of the most punishing elements of bankruptcy from medical bills. That feeling of being a burden or not being independent is something that I'll kind of carry with me my entire life, and the weightedness of that never goes away.

Thank you Kimberly Soenen. Stay tuned for next time when we talk about Kimberly's organization SOME PEOPLE, and what it's doing to push back against the commercial health care industry.

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