



Forsaken? The problem with for-profit health care

“I think if we had a single payer for all, we're actually able to then get on board with what much of the rest of the developed countries do right ... and actually provide healthcare that doesn't leave people stranded.” – Dr. Eunice Stallman

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!** What justification did a major insurance company give to repeatedly deny coverage to treat a baby's brain tumor? What can be done to prevent these denials of life saving treatment in the future? To find out, we spoke to **Dr. Eunice Stallman**, a psychiatrist in Idaho and mother of two-year-old Zoey, who has suffered seizures and developmental delays because of a brain tumor discovered when she was an infant. This is the second episode in a two-part series.

Welcome back to Code WACK! Dr. Stallman. In the last episode, you shared with us how Blue Cross of Idaho repeatedly denied coverage of a medicine that your daughter's doctor believed would shrink her brain tumor. You also mentioned that the medical reviewer for the insurance was using incorrect guidelines when they denied coverage of this medicine, Loralatinib. What can you tell us about that?

Stallman: Yes, so as we were going through the denials, they were citing what protocol they use for the denials and so they said they use a certain medical policy for prior authorization. I had pulled that up and took a look at it and they have a certain pathway for oncology medication approvals, and rare oncologic disorders and so in there it states that they use the NCCN guidelines to make determinations. And NCCN stands for National Comprehensive Cancer [Network] Guidelines. I was able to pull those up for pediatric brain tumors and follow through the protocol that clearly supports that we can use... The recommendation is to use inhibitor medications for a targetable mutation. In the meantime we had gotten letters coming back saying the reasons for denial are 'this and this and this.' And so we're looking through those.

They're citing a different NCCN guideline and they're citing things like 'she doesn't have metastases and she doesn't have lung cancer' and so we thought, 'well, what's going on? This is irrelevant.' So then we look up the specific NCCN guidelines that they've been citing, and it's the adult brain tumor guidelines. They weren't even looking at the right ones for how you treat brain tumors in kids. They were looking at how you treat brain tumors in adults, which is a completely different protocol.

And we're looking back, you know, along the way we were looking back at all of these. They keep citing the same things from the adult guidelines. So we had written several grievances and this went way into, even after her treatment was ultimately approved, we said, 'well, why was it denied all these times in the first place? And prove to us that you did take a look at the pediatric guidelines.'

Well, they weren't able to do that. They kept saying 'she doesn't have metastasis, she doesn't have lung cancer. And that's what Lorlatinib is used for.' And it is used for that in adults, but it is used differently for kids in the pediatric world with a primary brain tumor. And they never took responsibility or accountability for that. Ultimately [they] just said, 'well, we disagree.' And then finally after, you know, maybe five or six rounds of grievances, I had reached out to Dr. [Ammar] Gajjar, who's the panel chair for the children's NCCN guidelines, asking him, 'am I interpreting this right? Is it right that your guidelines state that Lorlatinib would be the appropriate treatment for her mutation?' And he said, 'yes, this is exactly what it is. It fits the recommendation. Her doctors did exactly what the first line thing would be to do for her mutation.' And so we brought that to the insurance company in one of our grievances, and they just responded saying, 'respectfully, we disagree.' And we did look at pediatric guidelines. It just wasn't documented. And so that was unbelievable. <Laugh>. We've just had to sit with that discomfort

and feelings and we haven't really had the bandwidth to pursue back and forth more grievances on that.

There's making a mistake as a human, right, but this goes beyond that. This seems like willful disregard.

Stallman: It sure felt like that <laugh>. And I think if someone had more experience, if someone were a treating physician or had experience in treating pediatric brain tumors and brain cancers, then it would've been clear that you're not looking at the right guidelines.

Q: I understand that you started a GoFundMe page or someone started a GoFundMe page. Why was that done and how did it help?

Stallman: Yes. So we started, I think it was by the end of the peer-to-peer denial, we said, 'well, this is enough.' You know, we're willing to pay out of pocket if we have to for this medication because we don't know how long it's going to take for the appeals to go through. The people that we talked to at Blue Cross said 'usually this can take a month or two to get another neuro oncologist, maybe to talk with your oncologist. And then there's a lot of things that happened after that, so maybe a month or two.' And so at that time, two weeks later, after the first request was put in for prior authorization, we said, 'well, we can't wait <laugh> anymore knowing that there is treatment.' And that's when we started the GoFundMe to raise money to be able to pay out of pocket for the first month or two of medications in case it did take that long.

Luckily with this crazy turn of events, it did get approved and so we've kept that pocket of money for her copays, which are still very high with her medication. We've also had to use it for different medical equipment and things. She's had some different side effects with low blood oxygen and respiratory distress and high blood pressure. So we've had to get equipment for monitoring her oxygen, monitoring her blood pressure, all of that.

And then the other thing that we found out is that it's really hard to get insurance coverage for PT [physical therapy] or OT [occupational therapy] equipment that a kid needs, that there's a long process with that. And so we've been lucky with the extra GoFundMe money to be able to get and pay out of pocket for whatever her medical equipment needs were for PT, for OT to help her develop.

Q: How expensive is the medication that she's on?

Stallman: Yeah, it started at \$15,000 per month ... and the dosage has to depend on a baby's weight for that medication. And so when she was eight months old, it

was \$15,000 a month if you were to pay out of pocket. The bigger she got, the more expensive it was because you needed to titrate or build up to the right dosage for her weight. Her current weight, I think if we were to pay out of pocket, it would be about \$20,000 a month for her medication.

Q: Wow. How expensive are her copays for the medicine?

Stallman: Yeah, they were about \$4,000 a month until we reached her out of pocket, which is about \$10,000 per year.

Q: Anything else you wanted to say about having to fight your insurance company to get coverage for Zoey when this was the recommended treatment for her? What bothers you the most about your experience?

Stallman: Yeah, I think what bothers me the most is that her doctors have experience and they've had years and years of training and decades of experience and they know how to treat patients. And so for her doctors and multiple doctors across multiple tumor boards to say, 'this is the right course of treatment for Zoey,' for that to happen and then simultaneously for someone or some groups of people who don't have nearly as much experience in treating patients and treating Zoey's tumor to have the power to say, 'oh, that's not needed, or that's not necessary, or it's not urgent enough,' I think that's just, that's unacceptable <laugh>. It should be that people who have experience can, you know, review that and say, okay, yes, or, you know, maybe try this. But there was no, there was no other knowledge. It was just, 'nope, she doesn't need it.'

And so then when we asked them to speak to, 'well, what is needed? What is your recommendation as an alternative?' What we got back was, 'well, go talk to your doctor about that.' You can't have it both ways. You can't have the power to deny your doctor's treatment recommendation and then also defer back to the doctor saying, 'well, they know best they know what the next treatment is.' So that was infuriating.

It's so scary to know that our health lies not in our doctor's hands, but oftentimes in our insurance company's hands.

Stallman: Yes, exactly and you hear so often of people having devastating side effects from those repercussions, where they deteriorate to a point where they can't get better or they pass away and that's the fault of the insurance company.

Q: So Dr. Stallman, what policy solutions do you support to prevent these kinds of potentially life-threatening denials in the future?

Stallman: Yeah. Well, I think that going through all of this and talking with our local medical society and what work has been done, I think one of the things is that Medicare and Medicaid have moved towards streamlining prior authorizations and who can do the approvals and who can do the denials. And so what they have now is that only MD's or DO's

A doctor of osteopathic medicine....

Stallman: ...are able to do denials, and they should be in the same specialty as the treating doctor. And I think that's a great thing that needs to be implemented across commercial insurance plans, too, is that you need to have someone who has the credentials to be able to review these cases and make approvals or denials. I think, you know, there needs to be more clear guidelines on how you deal with rare diseases because what these commercial insurance plans do is they just say, 'is there a randomized controlled trial for this? Is there a randomized controlled study?'

When you're looking at rare diseases, there's never going to be enough patients, never going to be enough money to fund a study to that extent. And so there needs to be more clear guidelines on what you do next or what you do in these rare cases. Zoey has her type of tumor. There's maybe 30 or something kids with this type documented and when you need to do one of those trials, you need thousands of patients. And so if you're concrete to a point where we need to have <laugh> this type of study only, then you're never going to get approval easily for people who have rare conditions or rare needs. And then I think also that the guidelines for how insurance companies look at prior authorization just need to be standardized.

It's so determinate on the insurance company, and they keep it all under wraps, how many denials there are, how many approvals there are, right? And then there's also, there's just no, when you're trying to point at, 'well, what are, what criteria are you looking at?' It's all, you know, hand waving. Like, 'well, we look at this, we look at, you know, whether or not there's been a peer review journal.' And then we're saying, okay, 'there is a peer review journal. There is these studies in a peer review journal.' And then they say, 'well, that's not strong enough,' and there's no standard for what is strong, what is okay. It's the policies that can be interpreted and bent in however way that they choose to do so to justify a denial. So I think all of those things need to happen.

Probably the easiest way is to just have certain criteria for whether or not prior authorizations are needed or not, and then if so, then who reviews them? And you need to have the right people to review them or deny.

Q: So what are your thoughts on single-payer Medicare for All?

Stallman: I think that when health care is for-profit, when insurance companies are for-profit, you're never going to get the best care <laugh> for patients when money is on the line for how you save money, how you don't save money. I think that right now, there's so many differences between the commercial plans and how they're approved and even how much a copay costs and all of that, that it just creates so much chaos in health insurance coverage, not to mention there's so many people who don't have health insurance because it's tied to their jobs or that their employers don't provide that.

And so, you're leaving a lot of people stranded without health care. And so I think if we had a single payer for all, we're actually able to then get on board with what much of the rest of the developed countries do, right, and actually provide health care that doesn't leave people stranded, and health care that is standardized, and health care that does save money in the long run. When you're thinking about all the costs that go into these approvals, denials, all the delays, people getting sicker, it's not the right way to go.

Yes, 100 percent. All the back and forth makes everything more expensive - and stressful. So tell us about Zoey's upcoming surgery.

Stallman: Yes. So we've been in treatment for about 16 months on the Lorlatinib. Her tumor has stabilized to a point where there really hasn't been much to shrink or much shrinking happening in the last six months. And so at that point, you know, we revisited the idea of 'do we need surgery?' That was always on the table. Once we shrink the tumor enough, then we can get the resection done. The studies also show that when kids get to two years old is where the tumor really stops growing and [for] the majority of those kids two years is the magical age. So she reached two, we reached out to a few different institutions and ultimately got accepted at St. Jude in Memphis and so we're going to go there this Sunday and she'll get her surgery to try to remove the rest of the tumor that exists. Try to, you know, get rid of probably the rest of the things that are dead tumor tissue that are in her brain to clean that up.

A quick update: Zoey had her surgery in November, it went well and most of the tumor was removed. However, a small portion near her motor strip and blood vessels had to be left behind, and a few live tumor cells were found. As a result,

Zoey has a longer road of treatment ahead than expected. She may soon need several months of traditional chemotherapy.

Thank you, Dr. Eunice Stallman. We wish you and sweet Zoey the very best.

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