



Coverage denied: A doctor's fight to save her own baby

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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!** Imagine finding out that your baby girl has a brain tumor that's causing seizures and disrupting her development, and your insurance company is denying treatment her doctor says she needs to survive and thrive? Where did one mother turn for help when repeated health insurance denials delayed time-sensitive treatment to shrink her baby's tumor? To find out, we spoke to **Dr. Eunice Stallman**, a psychiatrist in Idaho and mother of **Zoey**, who is two years old today and still undergoing medical treatment. This is the first episode in a two-part series.

Welcome to Code WACK! Dr. Stallman!

Stallman: Thank you for having me, Brenda. Looking forward to talking.

Q: *Thanks for being here and for sharing your story with us. First of all, tell us a little bit about your. Who are you and what do you do?*

Stallman: Yeah, so my name's Eunice. I'm a psychiatrist who works for the state of Idaho at one of our inpatient hospitals.

Q: *So you have a baby daughter named Zoey. Tell us a little bit about Zoey and when you first noticed signs in her of a possible health condition.*

Stallman: She's our fourth baby, our youngest one, and her pregnancy/delivery was great. Everything went smoothly. You know, her first couple months she was pretty fussy, but you know, we thought maybe all babies are fussy at some points, but it was maybe around six months or seven months that we noticed she wasn't quite meeting certain developmental milestones. She had a hard time rolling herself over. She had a hard time kind of sitting up unsupported. And then we started noticing that she was having these right arm twitches and they were happening more and more. So then we had her see our pediatrician who thought, 'well, I'm not sure, you know, some babies have certain twitches and some have certain muscle conditions that make them twitch and so let's just watch and wait.'

But after another month we were noticing again that they were getting more frequent. Her right hand seemed to be much weaker and it got to a point where she wasn't really opening her right hand at all. She wasn't grabbing things and it was just kind of, her arm was just kind of pinned to the side. And so that's when we really felt and knew, 'okay, something's not quite right.'

We went back to her pediatrician – she was around seven months at that point – and he agreed that it wasn't normal. And so we had an EEG done, which is where they place electrodes on her brain to make sure there's no seizures. And we got a call saying that it's abnormal and that from her left side of the brain there was seizure activity and then everything moved very fast from there. We had an urgent MRI scheduled for the next week. Then that was where her tumor was found.

Q: *Wow. I am so sorry. And so there was a brain tumor. Was it fast growing or what kind of tumor was it?*

Stallman: Yeah, it was very big by the time they found it and it took up a huge portion of her left brain. The doctors were pretty amazed that she looked as good as she did and all she was presenting with was the twitches really, and then the weakness. There were also some atypical signs because when there's a tumor that big, most often the brain starts shifting to make room for it. But she didn't have that. The rest of her brain looked good and her midline was still in the center and so that told them that it was probably fast growing at one point, but her brain had adapted and it had slowed down and by the time we found it, they felt that most likely it was a slower growing tumor at that time because the rest of her brain didn't look 'angry' was the word.

Q: *Wow. And so this was a cancerous tumor?*

Stallman: It was unclear until they biopsied it. So there's a few that are non-cancerous. We had urgent surgery to take a piece of it out to know exactly what it was. And her type is a glioma, which technically counts as a cancerous type of tumor, but in babies, gliomas don't really spread to other parts of the body. And then for her, her type was when they did all the molecular classification, all of that, it was low grade glioma, which means it grows slower, which is good.

Q: *Okay. Wow. So yeah, you guys do the surgery. Mm-Hmm, <affirmative> and then what happens in terms of getting her treatment?*

Stallman: Yeah, so the surgery was done, it took maybe a week or so for some of the pathology results to come back. They sent it to UCSF to have more experts take a look at it. And then they also sent a section over to Nationwide Children's in Columbus, Ohio where they're able to do a lot of the genetic testing, molecular testing and so from that point, it was a matter of kind of waiting until we knew what we were looking at. The changes that have happened in the pediatric brain tumor world is that they've found that a lot of babies have mutations in these tumors that are targeted now by specific inhibitor medications that are newer and so the hope was that she would have a mutation that we can target with an oral chemo medication rather than having her be admitted for the inpatient IV chemo. And so we were hoping and crossing our fingers that she would have a mutation and that would completely change the course of her treatment and she did, and that was great news, <laugh> the best possible news considering the situation.

Q: *Oh, wonderful. Okay. So now you're able to treat her with medicine essentially. And so what challenges did you come across with your insurer, health insurer, Blue Cross of Idaho to get that treatment covered?*

Stallman: Yes. So the mutation was targetable by a medication called Lorlatinib. And this was reviewed by a few different institutions. Everyone agreed that Lorlatinib is the best medication for her. So then our doctor put in the request, put in the prior authorization. We thought it would be a pretty clear cut case of here's a mutation, here's a medication that has been shown to work, and it minimizes the side effects of going in every inpatient once a month for a week at least to do IV chemo, which is much more devastating. So then we hear back from the insurance, they came back saying, 'it's not medically necessary and it doesn't meet our criteria, so therefore we're going to deny it.' That was really upsetting to hear. That probably took a week and a half. I was calling in the meantime to ask, 'when would you have the results?'

And it took, you know, you kind of get thrown around to different people saying, 'okay, tomorrow give us a call back tomorrow.' Tomorrow you give a call back, you're talking to someone new. They say 'Um, I don't know, <laugh>, give us a call back tomorrow.' And so that happened. Finally a week and a half of almost daily calls we had heard that we got the first denial. And so then our doctor put in an urgent appeal and sent in more papers supporting the use of this medication, sent in another long letter about why this is the right medication. And so then Blue Cross took another look at all of that and they again denied it saying that it was medically unnecessary. The other thing they said was that Zoe doesn't have metastases and so therefore it's not needed at this time.

And that was very frustrating. So I had a conversation with them about, 'okay, who is reviewing this?' Because if there was any neuro oncologist who is well versed in the pediatric brain tumor world, they would know that this is the right course of treatment. This is the first course of treatment.' And they kept saying, 'well, we can't give you that information. It was just our medical director or medical director.' Then, well, I asked, 'so is there someone who knows <laugh>, the research and the literature who can review her case?' And they said, 'well, we can send it to a third party.' And so that's where they sent everything over to MCMC, which is a third party reviewer and we heard back later that day that MCMC, the reviewer at MCMC also recommends denial. And we got his name and the reasons.

And so then we were looking at this denial and found out that his reasons were completely irrelevant. He had cited a completely different mutation that was not Zoey's mutation. He had one or two sentences that said, 'it's not urgent, it's not

necessary.' And so that was incredibly frustrating. Then our doctor, again reached out and said, 'I need to do a peer-to-peer review.'

She gets on the phone maybe one or two days later to do the peer-to-peer review, and she gets on the phone and it's with the pharmacist reviewer. And he's not someone who is in the oncology world. He's not someone who is a pediatric pharmacist either. He was just a regular pharmacist who left his clinical job and went to a reviewer position. So she did a peer to peer in quotation marks, 'cause he's not really a peer to a board certified neuro oncologist and basically she had called back afterwards just saying, you know, 'we had a long conversation. He said it wasn't needed. He gave us reasons that the medication is not FDA approved for her tumor,' which there's no way it could be because the tumor is so rare, you can't get the number of patients needed to run a clinical trial for it. And so he basically just gave reasons for why it's not needed. So that was the kind of the third denial that we dealt with.

Q: The pharmacist, was he from Blue Cross or was he from the third party?

Stallman: Yeah, he was from Blue Cross. He's a Blue Cross employee and they were calling him a medical director this whole time. In my mind, I had thought it was an MD or a DO who was reviewing it. But apparently, his role, it was called a medical director, but he's a pharmacist who was doing all of these reviews and denials and then got on the phone for the peer to peer.

Q: Wow. So you mentioned this was very frustrating for you. What else is going on in your mind as the treatment keeps getting denied?

Stallman: Yeah, I couldn't believe it. You know, I thought, it seems like there's just a disconnect. You know, we see that she has this big tumor, we know that there is a targeted treatment. We know that, you know, I'm reading through the literature, I can look up all of these papers and the ones that our doctor's sending and we're working in close contact with them and it's just so obvious <laugh> what the right thing to do is. And so for this to happen, for someone who is much less qualified to have the power to say 'she doesn't need it and it's not urgent or it's not medically necessary,' and you have this baby whose seizures [are] getting worse, it just was unfathomable. I've never been so angry in my life. I've never felt just this pure rage. And it just, I kept thinking about how the reviewers are not involved in her care at all. They're sitting in an office just looking at papers, looking at records.

They're not the ones who are taking care of Zoey, seeing the urgency of it. They're not the ones who experienced, you know, finding out about the tumor. They're

not the doctors who are sitting with us after surgery helping us through this or trying to get her seizures under control. They should not have this power. And so the fact that the care was delayed and delayed and delayed because of insurance was unbelievable to me.

Q: You mentioned that Zoey's seizures were getting worse. What are the potential ramifications of prolonging treatment for someone as young as Zoey and in her situation?

Stallman: Yep, so seizures are really damaging for brains, and they're especially damaging for baby and kid brains when there's so much development that goes on during that time and so basically she was not able to develop a lot of her milestones while the seizures are happening. She couldn't use her hand. Her arm was getting weaker and weaker. Cognitively she was very delayed too. That's a big point of urgency too, is we need to get those seizures under control for her to start developing. And two weeks is a long time in a baby's life, <laugh>. A lot happens in a day and a week and two weeks in a baby's life. And so for that delay to have happened, and it ended up taking, you know, six more months on treatment on the Lorlatinib to stop those seizures, to shrink the tumor enough. It all snowballed and added up. So it was so awful. The feeling of just, you know the right thing to do, you're helpless to stop it, and then you're watching your baby go through this is awful.

Q: So what did it take for Blue Cross of Idaho to finally cover the medicine that she needed to shrink her tumor?

Stallman: Yeah, so by the time we had the second or third denial, I was desperate because it seemed like it was atypical for there to be so many denials, even after a peer-to-peer review. I'm in this group of physician moms. It's called Physician Moms Group, and it's on Facebook and so I in a moment of desperation posted about what's going on, and I asked for help about 'how do we get through to insurance to get this approved.' And I got hundreds and hundreds of responses from people who kind of pointed me to what to do. And so what ended up happening was from that, there were a few physician moms who had connections to the press. They connected me to a few reporters from, you know, Medscape, from ProPublica and so we worked with them to update them on Zoey's information and they called on our behalf saying that they're looking into this, they're planning on writing an article.

So that was one part of it. ... We had a few physician moms who worked at St. Jude who said, 'we have this medication, St. Jude doesn't need to use insurance. Do you want to come over here for treatment?' And so that was another thing. And then the rest of it was, there was a lot of suggestions. There was someone who had a following on Twitter who said, 'I can post your story on Twitter. We can tag Blue Cross of Idaho, sadly, but usually that does something.'

So I said, 'okay.' So that was another part. And then the other things that were recommended and that we did was contacting our Office of Group Insurance, the people who help with Blue Cross for all the state employees and so there's a group there. They contacted Blue Cross. We contacted <laugh> the attorney general's office at the recommendation of the Physician Mom's Group. We contacted the governor's office, we contacted the Office of Insurance, the Department of Insurance for Idaho. There were so many things happening <laugh> urgently during that time and it was a combination, I think, of all of those things. And it took great effort but I think it was a combination of all of those. And ultimately what happened after the peer-to-peer denial was, I think a key part of it was one of the journalists that we were working with had called Blue Cross saying, you know, 'what is your justification? What is going on? I'm going to write an article on this.'

And after she had communicated with them, I hear back from the nurse manager at Blue Cross who said, 'okay, this never happens. But we called a big interdisciplinary meeting with our vice president of medical affairs and then our public affairs department, the pharmacist, and we got our MD involved in this. And so I'll give you a call afterwards.' So we were, you know, headed to our next MRI. We got a call afterwards saying, 'well, this never happens, but our chief medical director stepped in and overturned all the denials, and so it's going to be approved for I think it was 90 days. Then we want to see an MRI to make sure it works before we, and then we'll want to re-review it.'

So it was so many things going on, and I have a feeling ultimately press involvement was what pushed them into getting everyone together and overturning the denial. And apparently it's very rare. Whatever it was, it worked.

Q: So you got the call two weeks after you were first denied?

Stallman: Yeah, it was about two weeks after that.

Q: And how are you feeling when this happened, when you get that great news?

Stallman: I think we were, we were overjoyed and also just mad that it took all of this <laugh>. It shouldn't take all of this. And we're lucky to have the resources to be able to have all these connections and time off to be able to call and email and work with the press and all of this and so that was another part of just feeling disgust <laugh>. We're overjoyed, but also how do other people get the, you know, they're not used to having such a big backlash, such a big amount of fight, I think that goes on. And so that was a big part of just, I don't know, guilt, disgust that it took all of this for her to be approved.

Thank you, Dr. Eunice Stallman. Stay tuned for next time when we dive deeper into health insurance denials and how Zoey is doing today.

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