Invisible Agony: Navigating Complex Regional Pain Syndrome

Guest: Candace Pierce DNP, MSN, RN, CNE

Dr. Pierce is a nurse leader committed to ensuring nurses are well prepared and offered abundant opportunities and resources to enhance their skills acquisition and confidence at the bedside. With 15 years in nursing, she has worked at the bedside, in management, and in nursing education. She has demonstrated expertise and scholarship in innovation and design thinking in healthcare and education, and collaborative efforts within and outside of healthcare. Scholarship endeavors include funded grants, publications, and presentations. As a leader, Dr. Pierce strives to empower others to create and deploy ideas and embrace their professional roles as leaders, change agents, and problem solvers. In her position as the Sr. Course Development Manager for Elite, she works as a project engineer with subject matter experts to develop evidence-based best practices in continuing education for nurses and other healthcare professionals.

Host: Jennifer MacLean

Jennifer MacLean serves as the Senior Product Manager for Nursing at Colibri Healthcare. With a profound dedication to supporting the ongoing educational requirements of nurses and healthcare professionals, Jennifer boasts an extensive career history, ranging from retail sales and customer service management to digital marketing. Throughout her nearly decade-long commitment to this field, she has found unparalleled satisfaction in contributing to initiatives that prioritize the welfare of nurses. Jennifer, originally hailing from North Dakota and raised in Montana, currently resides in Massachusetts with her husband and two daughters.

Transcript

Episode 1: CRPS: Navigating the Diagnosis

CANDACE PIERCE: Hi. This is Dr. Candace Pierce. With Elite learning by Colibri Healthcare, and you are listening to our Elite Learning podcast, where we share the most up to date education for healthcare professionals. Thank you for joining us for this podcast series topic Invisible Agony Navigating CRPS and the Health Care Journey. For this series, I'm going to be handing off the hosting reins to Jennifer MacLean, our Senior Product Manager for Nursing. Jennifer, I am passing the mic to you.

JENNIFER MACLEAN: Awesome. Thank you, Candace. I'm really, really happy and excited to be here with you today. You and I have worked together for a while now, so I'm familiar with your personal life and some of the challenges that you and your family face. So, we're going to be talking about a fairly personal subject today and am really looking forward to delving in and learning more about CRPS. So, this is probably going to be a little emotional.

PIERCE: Yes.

MACLEAN: Just given how close you are related to this particular condition. So, I want to warn our listeners that there might be some difficult conversations, and we'll get into them, but Candace, do you want to add anything to that?

PIERCE: Yes, I just want to add that one of the most difficult topics that we'll be talking about at some point in the series is suicide and suicidal ideation. So, do be careful if you have little ears around.

MACLEAN: Great. Thank you. So, start me off by helping me understand a little bit more about complex regional pain syndrome. Why should we be discussing this? What don't we know? And I'm guessing that's kind of a lot, everything, because I'd never heard of it before I met you.

PIERCE: Yes, it's very rare. It's a very rare diagnosis. And a lot of the information about CRPS isn't known. But really what complex regional pain syndrome is, is prolonged pain. It's an excessive pain of what you would think would be about, of what an injury would cause. And it is ongoing. And a lot of times it's really hard and takes a long time to get a diagnosis for CRPS. But it's a neurological disorder where our brain rewires itself to say that there's a traumatic injury. Typically, CRPS is going to be linked to a cause. The most common cause is a fracture, but it could be a sprain, it could be a strain, it could be surgery. Even just a minor traumatic injury that is going to set off this cascade of events in your nervous system.

There are two different types of CRPS. There's a type one, which is about 90% of your cases. And with type one, no matter the tests that you do, there is no obvious or seen neurological or like a nerve lesion or injury. And it was also called, let me get it right. I always get the acronym wrong RSD; Reflex Sympathetic Dystrophy is what it used to be called. So, a lot of your older physicians and older healthcare providers are going to know it more as RSD. Type two is that there is an obvious lesion. There is an obvious injury to the nerves. So, you do have two different types. You might also hear it under AMPS, amplified musculoskeletal pain syndrome, which is kind of this umbrella term that you will also hear juvenile fibromyalgia come underneath that. But the difference between your AMPS and your CRPS is that CRPS is almost always linked to something, some type of injury.

MACLEAN: Interesting.

PIERCE: Yes.

MACLEAN: So how much? And you might not know the answer to this, but how much more common is something like fibromyalgia compared to CRPS?

PIERCE: Overall, really, I can only speak to pediatrics, but AMPS in general is very rare in pediatrics. I see it more now, because now we live in this population. Now I'm a part of it, and you're in these support groups. And so, it seems to me like, how is this rare? There's so many people that have it. But there's not. It's just that's now our circle. That's now our life.

MACLEAN: So, you said that it used to be known as RSD. Is it becoming more of a known condition now or is it still really stuck in that RSD phase where it's not really up to date in terms of provider's minds?

PIERCE: It doesn't matter if you call it CRPS or RSD, it's still, providers can go their entire career and never see CRPS or AMPS.

MACLEAN: Do you know how much of the population has CRPS?

PIERCE: So, there are two studies that I was looking at when we first started down this journey, and one of the studies said it's like five point. Hold on. I have the exact numbers, 5.46 persons out of every 100,000 per year. And then there was a study that was specific to the United States, and they said that annually in the United States, about 200,000 people are diagnosed with CRPS.

MACLEAN: Interesting.

PIERCE: Yes. I was going to say some of the other interesting statistics about CRPS is that it typically occurs in women or girls. So, 3 to 4 times more likely for females to have it or to develop this than males. There's also psychological factors that are being looked at as well. A recent study found that if you have an anxious personality, you are more likely to develop CRPS. And if you are going through a time of high emotional stress, it also plays a factor into whether or not you develop CRPS.

And when my daughter developed CRPS was about three years ago. We're in our third year of this journey. It was a time, we are a military family, so we were given really unexpected orders to move, and we had like a month to, you know, to find a place to live and to figure out where we were going. She was starting middle school, which is also a really hard time.

And we were at camp, the same camp we go to every summer, and I donate time to the camp as the camp nurse for a week, once a year. And she was running down a hill in northern Georgia. And, they have these big trees and there's big tree roots coming out in the mountains. And she got her foot caught in one of the tree roots. And when her foot went underneath the tree root, the rest of her foot went over. And she got up and she went to go play. And she played for a while, and she was running up and down the water slide. And there was this moment where, and we'll come back to this to kind of talk about this moment. But there was this moment where she was running up the stairs again to go down the water slide with her friends, and something in her brain clicked and she couldn't, the pain was so intense she couldn't walk anymore. And so, they had to carry her to the infirmary. And I'd been, of course, the nurse for the whole time. And I walked into the infirmary. It's a Thursday. I've had no injuries, and there's my daughter sitting on this bench. So, we took her to the E.R., and they diagnosed her with a sprain. But we can definitely kind of come back to that, because that's just kind of part of our journey and our story, because CRPS is so rare that they say that the earlier the diagnosis, the earlier you start treatment, the better the outcome. But for most people, it takes years to actually get a diagnosis.

MACLEAN: And why is that?

PIERCE: Because there's no test to say that you have CRPS. It is a rule-out diagnosis. So, you're going to rule-out everything that you can rule-out before they're going to say, hey, you have CPRS. So, you're going to have all of your radiographic scans, you're going to have that physical assessment, you're going to have all of those diagnoses that they're looking for, that they're watching for before they finally come out and say there's nothing else. All that's left is CRPS, and you have CRPS.

MACLEAN: I'm curious, given how rare this is, which also seems like there might be a self-fulfilling prophecy. It's rare, so it's not well known how many people are actually living with CRPS that haven't been diagnosed, because either they don't have access to the right care, or their doctor simply is just saying it's all in your head. You're making this up.

PIERCE: Yes. You will find a lot of people who have been diagnosed as CRPS, they have had multiple physicians, they have had multiple diagnoses, and they have just been searching for help. Please help me. Please help me. The thing about CRPS is that it is really important to know is that this is nerve pain. So, the best way that I can describe it is your brain is working through your nervous system and it sends down a stimuli. It's just to say something that your body needs to do. And so normally when that signal goes to wherever it needs to go, CRPS is normally found in an extremity, so hands, full arms, foot and leg is typically where you're going to see CRPS. So, when your brain sends down that signal, normally it's going to dissipate when your body is done with that signal. So, it's like a dragstrip. So, it shoots down the dragstrip and then it dissipates, and it goes away. Well in CRPS the brain does this weird rewiring thing, and that dragstrip becomes like a NASCAR racetrack. And so that signal is constantly circling. It doesn't dissipate. And so, the pain from CRPS is typically described as bone crushing, burning. It's deep, constant tingling sensations.

My daughter describes hers as lava flowing through her veins. You might hear it described as tearing. It feels like something is tearing. Other people describe it as fire. I feel like I'm on fire, because it's nerve pain. Acetaminophen doesn't help. Ibuprofen doesn't help. Opioids don't help. So, you live with this intense pain that doesn't stop.

There is no known cure. There is limited evidence of any type of treatment that actually helps. And that's why CRPS is nicknamed the suicide disease. Because for many patients, that is the only way out that they can find. And part of that also goes with navigating the healthcare system. You don't have the knowledge and that inside knowledge to know how to navigate or find what's available. And then you have all these physicians who have never heard of it, who think it's in your head. And that is where a lot of your patients will, the path they will go down. But there are some criteria. It's called the Budapest Criteria, and it's signs and symptoms of CRPS. It is an international checklist basically developed by an international consensus panel. So CRPS is known around the world.

MACLEAN: It is. Ok. So, we already talked a little bit about that some doctors don't understand it or don't know it. This results in a long diagnosis process, sometimes never being diagnosed. What are some other misconceptions about CRPS?

PIERCE: Well, I think you're going to get to hear from my daughter in episode two, and she's going to talk a lot about this. But one of the misconceptions is that you're a drug seeker. You're making it up. But even if we talk about treatment, we can talk about treatment here in a minute. I want to talk a little bit in that area of even providers and how they treat the patients and how they think that CRPS patients should live, because yes, can we say that this pain is in your head? Well, it’s your nervous system? You're constantly in fight or flight. Your body doesn't come out of that. If we go back to the signs and symptoms of CRPS you're going to see the biggest hallmark is pain that doesn't match the injury. So, Judah was diagnosed with a sprain. During our journey, we have had 11 X-rays, two MRIs, and a CT scan. We have had three to four E.D. visits. We have gone through three to four providers because of referrals and things, and we spent six months, not six months. We spent six weeks with immobilization. And then we spent three weeks at a children's hospital for treatment. So, we have had this really long journey, and she's still not in remission with her pain. So, we're actually pursuing another avenue of treatment where we're going to have to go away for three to four months for a neurological rehabilitation program. But I remember the orthopedics. So, we started out with, going to E.D.'s and they're like, it's a sprain. It's a sprain. We ended up with our primary care provider, who sent us to an orthopedic, who sent us to a pediatric orthopedic surgeon, who then sent us to a rheumatologist, who was backed up for six months. And so, this orthopedic surgeon was amazing, a champion to get my daughter to Philadelphia for treatment.

But I remember, it was the last time we saw him. We had an x-ray, and he was getting ready to discharge us. And he said he said something to Judah, and she realized that she wasn't going to see him anymore. So, she asked the nurse, can I see Dr. Wilson again? And he came back and sat on the bed. She said, thank you so much for trying to help me. And I could see his entire face just drop. And he looked down at his hands and then he looked back up at us and he said, we're going to do another MRI, because he wanted to fix something. He wanted to find something to fix her.

But we didn't know that she had a break until we had the very first MRI. Her fracture was so minute that it showed up on no X-rays. It only showed up on an MRI. Her pain never matched her injury. And when I say her pain didn't match her injury, I cut off two splints because she was screaming.

MACLEAN: Oh my gosh.

PIERCE: Yes. And that's why we had three or four ED visits is because her pain was so intense that me as a health care provider myself, I was like, this is not a sprain. We're weeks out of this. We're months out of this. Why are we still in this? Something is not adding up.

MACLEAN: Even a break. It's painful. I know I have one right now, but I mean, it's painful, but it doesn't last for weeks and months.

PIERCE: It doesn't. You are right.

MACLEAN: It is not scream worthy.

PIERCE: Yes

MACLEAN: I mean, it blows my mind to think that there are providers who think you're just you're looking for drugs. This happened when she was ten?

PIERCE: Yes, somewhere. Somewhere between nine and ten. I think it was the year she turned ten, so she was still young when it happened.

MACLEAN: So how do some of these providers interact with you? Because she's nine, she's ten. She's not looking for drugs. I mean, we can talk to Judah about this, too. I'd love to hear her perspective, but like, did they just treat her like she was an attention-seeking child?

PIERCE: No, we didn't have that. Thankfully, it was more geared towards me. I took her to one of the EDs and it was the ED where our original primary care provider was. And he accused me of taking her splint off, which I had taken splints off, but this particular moment, we didn't even have a splint yet. His office didn't give us a splint. We had just seen them earlier in that week, and her pain was so intense that all I knew to do was to take her to the ED.

So, when he comes walking in, he's like, well, where's her split? I was like, you didn't give us one. You didn't give us anything. And so, it was more kind of geared towards me as a parent and not towards my daughter in those moments, which also makes you feel intimidated. I didn't feel intimidated because I had the knowledge and the background. So, I don't want to say fight back, but to just say I'm not stupid. I know what's happening. I know what's going on.

MACLEAN: But that is the advantage of you and your professional background that a lot of people wouldn't have. So, I can't even imagine being just a typical parent who doesn't have that healthcare background, like that must be really difficult.

PIERCE: Well, CRPS has symptoms, so we talked a little bit about how the number one, the hallmark is how pain is so bad. It doesn't match the injury, but you also have sensory changes. Specifically, allodynia is what we call it, but it is where stimuli that normally doesn't hurt, hurts. So, like, for example, taking a feather and just slowly, just very lightly rubbing your arm would not hurt you. It doesn't hurt. For someone with CRPS, you would think you had needles, and you were like jabbing it into them. So sensory changes is another, but you also have skin and temperature changes of the skin, as well as color changes.

So, it started off for us, and it can go any way. But ours started off as warm and red and swollen and then eventually went to cool, cold, pale, and bluish. So really, this is where that traumatic like where your brain has made that flip to be traumatic. And so, it was like, oh wow, okay, we've had a traumatic injury. We need to work on healing it. So, you know, you're going to send more blood to that area. And so that's that warm red and the swelling that you see. Well, then over time it's like, wow, hold on. We still have a traumatic injury here. We need to slow that blood flow down. So that's why you get the cool and the pale and the blue. It is literally slowing down the blood flow to that area because your brain thinks there's a traumatic injury here and that hurts. Even that alone is painful. It's like, you know, you take it, and you squeeze right here and eventually, it's like you get that tingling, it starts changing colors. You don't have to do that. Your brain does it all by itself, and you have no control over when it does it.

MACLEAN: So, there's just the pain of the syndrome itself, and then there's the pain of healing when your body's like, I'm going to heal this because healing hurts. Again, I have firsthand knowledge that healing hurts sometimes.

PIERCE: So, then you take in to we have like some motor issues. One of the hallmarks for my daughter right now that she still deals with is her ankle locks up. It'll just lock up and she'll have to sit there with her ankle in her hands and twist it and move it around to try to make it so that she can walk better. A lot of people with CRPS will stop using that extremity, so they will end up with muscle atrophy, which she has. They will lose function. The ability to use that extremity in the way that it's supposed to be, and the pain will spread.

So, hers started in her foot, and now we're in our third year has moved up to her leg all the way up to her thigh. We also currently have identified that she has some on the top of her scalp now. So, me trying to brush her hair is painful, because it's your nervous system, we have an issue with our nervous system.

MACLEAN: So is her pain constant and her pain or anyone with CRPS, is it a constant pain or is it are there ever moments of relief

PIERCE: She has moments where the pain is down, but she doesn't have moments where the pain is gone.

MACLEAN: Yes, that's a tough life for a kid. I mean, anybody. But my gosh!

PIERCE: Yes, we were talking to a physician to get accepted into their program that we're going to be going to soon. And one of the questions they asked her is if you could rate your quality of life on a scale from 0 to 10 with zero being death and ten being amazing, where would you rate it? And she rated hers at a five. And she just I mean, she just turned 13.

MACLEAN: Yes, I mean, I can't imagine as a mother how that that must hurt to hear.

PIERCE: Yes.

MACLEAN: And approaching this as both a healthcare professional and as a mom, like take the mom side out for a second. And as a healthcare professional, like how would you approach this kind of patient? And how have you been approached in your treatment and your interaction with providers that way? Like what would you do? And have you seen that?

PIERCE: So, my background is adult critical care. And so, I've seen a lot of fibromyalgia. I haven't seen anybody with a diagnosis of CRPS. But I think that fibromyalgia for adults, some of them could probably have been diagnosed with CRPS. And really it is that neurological breakdown. Basically, you're always in fight or flight. Your body to not get out of fight or flight.

But what I have found with my daughter is when I go to our primary care provider, he doesn't know what to do, and he will give me whatever I want, but I have to go and find it and research it. You know, and I'm grateful that he will help me, and he will get the referrals that I need. But it's hard because he told me at our last appointment, he said, I know she needs a specialist, but I don't know who it needs to be.

And so that's when I said a rheumatologist is typically who follows this, which is also very strange. Why rheumatology is usually who you find that's going to follow this. So, he's tried to put out referrals for neurologists, which is great, and rheumatology. But one of the biggest things that we started early on was physical therapy before we even started at the hospital that we went to. So, we've kept her in physical therapy because she did start to lose function. Her muscles did start to atrophy.

But so many kids with CRPS will move through crutches, wheelchair and eventually become bedridden because the pain is so bad. And I don't know if I said this, but for the pain. Did I say how bad the pain was on the pain scale? I can't remember if I said that.

MACLEAN: You didn't you didn't mention the pain scale. I think that would be a good point, actually.

PIERCE: So, on the pain scale, the pain from CPRS is rated to be higher than amputation without anesthesia and childbirth, which is again, it really kind of goes to plan to why this is considered the suicide disease. And it makes me really teary to think about that. Because one of the things that I hear a lot of is, mom, it hurts, and I can't fix it for her. And being, you know, a healthcare provider myself, you know, I have gone to school a lot and looking at all of those, I can't fix my daughter.

MACLEAN: And as a mom.

PIERCE: Yes.

MACLEAN: And a healthcare provider because helping others, they do want to fix they do want to help. That's why you're in it. But my gosh, your own kid, too. Like you're playing double duty on this one. And I would imagine that the emotional toll must be even more so as a result.

And we've actually come to the end of episode one already. I hope everyone will join us for episode two. We're going to talk a little bit more about navigating the healthcare system and some resources and support. And most interestingly, we're going to talk with Judah, your daughter, and hear her firsthand perspective on living with CPRS. So, thank you, everyone, for being here for episode one. And Candace, this has been incredibly informative, and I really appreciate you sharing your story.

PIERCE: Thanks for being an amazing host and being willing to do this with me.

MACLEAN: It was my honor and pleasure.

Episode 2: A Pediatric Patient's View

MACLEAN: Well, welcome back to our series on complex regional pain syndrome. Joining me to continue our discussion is Dr. Candace Pierce. In episode one, Candace, we talked a lot about the condition itself and its symptoms, some statistics I'd like to delve into, some talk about treatment and also really get into the more personal aspects that are so familiar with you and talk with your daughter, Judah, about her experiences with it. But I'd also like to get to talking about navigating the medical system when you have a rare condition like this, because I'm sure that there are quite a few people with, not just CPRS but navigating any rare condition that is not well known. So why don't we talk a little bit about treatment and what's available and how that goes.

PIERCE: I know we mentioned it in episode one that she has no known cure, and treatment is very limited, and research is very limited. There are a lot of research studies that I found that are going on all through the world, a lot of interesting ones. But treatment itself is usually multiple modalities, and they're going to be physical therapy, occupational therapy. A big one that they push for is cognitive behavioral therapy. And when we spent that month in Philadelphia, where Judah had to work on regaining so much of her function, learning how to walk barefoot again, how to run, how to go up and down stairs correctly, it was days of long sessions of physical therapy, occupational therapy, and then times with a therapist. So, when we came home, we only came back with cognitive behavioral therapy. But there's medications that they've tried. Gabapentin is a big one that they push for, but it didn't help Judah at all. So, after a round of Gabapentin, we pulled her off of that. We've tried holistic things. We have tried CBD oil, you know, she currently takes magnesium at night to go to bed. When our pain is really bad, we do a melatonin because pain medicine doesn't help. Opioids don't help. It's nerve pain. You know, sometimes you might see them use glucocorticoid steroids, but I really think that's only beneficial if you get an early, early diagnosis. In the beginning, had we known if we had tried that, would it have helped? I don't know. And really the research is very limited to say whether or not that's going to help. But usually what ends up happening is they have to learn how to regain functioning. So, you're getting that gait, strength, gait and strengthening and rebuilding the muscles. Let's see what else is there: coping skills and relaxation techniques. We've tried brain spotting and she did have a moment where her pain was gone for a brief second. But brain spotting and some psychotherapies that have to do with pain are new. So, there's again, limited research on whether or not those work. So, tens unit, she has a tens unit we use. But sometimes the tens unit hurts. Her biggest thing that she uses are heat, heating pad, pressure, and a compression sock. So honestly, treatment is whatever works for you. She's one of those rare people who her compression sock helps. But when we went to Philadelphia, they were very surprised that she was even wearing a compression sock because she still has severe allodynia.

MACLEAN: So, on hearing your story earlier in episode one about splint causing so much excruciating pain, that's that is really interesting.

PIERCE: So, where we're going?

MACLEAN: It makes getting treatment very complicated because, whatever works for you.

PIERCE: It does. And where we're going to be going for treatment soon. They have a whole list of things that they do that I find really interesting. So, we haven't done them yet, like oxygen therapy. I had to write some of them down, can't remember them all, but they're going to do vagus nerve stimulation, brain balancing, ionic therapy, lymphatic therapy, neuromuscular reeducation, neuromodulation, magnetic resonance therapy. So really, it's going to be a very interesting. It’s completely different than the treatments we've had before. And there's just not a lot of guidance and evidence-based practice, which also comes into play with insurance, because insurance will pay for the Band-Aids. Insurance will pay for the spinal cord stimulator, they'll pay for the ganglion blocks, they'll pay for opioids and pain drips, pain medication drips. But they will not pay for it, they'll pay for physical therapy, occupational therapy, and they'll pay for cognitive behavioral therapy. But for actual neurological treatments like what I was kind of talking about, insurance won't touch it, which again, is why a lot of people don't get the treatment that they need with this disease.

MACLEAN: Right. So as somebody who has had to navigate this, what's your biggest takeaway?

PIERCE: My biggest takeaway is if you have insurance or if you're a health care provider and that patient has insurance, the biggest champion that we have had has been a case manager through our insurance company.

MACLEAN: Interesting.

PIERCE: I didn't even know that those existed within insurance until we started this journey. But we were given a really good case manager through our insurance. And she has championed, she has helped our physicians rewrite referrals. She has really worked with us to help try to get Judah the treatment that she needs. She is the one person that feels like she's on our side.

MACLEAN: That’s amazing.

PIERCE: And all that insurance. Also, your physician's communication. We've emailed, they've given me everything that I've needed. They they've been there for me, but they've also admitted when they didn't know. And as a healthcare provider that's huge. Just, I don't know, and just be there for them. And I think the other thing that's important to realize is that when someone who's going through something like this comes in and they're yelling at you, which I try really hard not to get upset or to yell at anybody, but it's not you as a healthcare provider. It's the system. It's the system. It's the fear of the unknown. It's the frustration. And I think that when you're dealing with someone who's going through something like this, just remember that.

MACLEAN: Yes, that's really good insight because especially something like this that's so complex and so poorly understood and causes so much pain and trauma, honestly, remembering that this is the situation that Judah is in, and that you and your family are in is extreme. It's extreme.

PIERCE: And nobody tells you what to do next. We were given this diagnosis and then it was like, alright, appointments over, see you later. It's like you have this huge shock and now you have to figure out what to do next because you have no idea.

MACLEAN: No idea. And that's very different from other diagnoses, like when you get a cancer diagnosis, they're like, we're going to have this, this person's going to call you and this person call you. When my daughter was diagnosed with autism, here are some resources. Call these people. This is what you want to try next. I mean, there's always, so often there is path and you're getting nothing. So that's incredibly frustrating. Well, I would love to hear from Judah and get some of your thoughts if you're cool with that.

JUDAH: Yes, ma'am.

MACLEAN: It's really nice to meet you. I've heard so much about you, and I've heard a lot about your story, and I just think you're an incredible kid. So, I just have a couple questions for you. I would love to know, what did you think when you first got your CPRS diagnosis at that moment? What were your thoughts?

JUDAH: When I first got the CPRS diagnosis, I was kind of explained. They explained it to me in a way that just made me think they had no idea what was wrong with me. And so, that first time I was just like, they have no idea. We don't know what else to do. And then when I finally learned what it really was, and that it was something that for me was chronic and was continuing to stay and that it might stay forever. It was just this feeling of complete disbelief that there was something like this that I had gotten from merely tripping on a tree root. And it was just this feeling of disbelief. I wanted to laugh because I couldn't see how this was possible.

MACLEAN: That seems fair and completely legitimate. Tell me, how would you describe the pain that you feel?

JUDAH: It varies from day to day and, depending on what decides to make it angry that day, there are days where it feels like my foot's melting from the inside out. There're days when it feels like it's completely on fire or it's been stabbed in different areas of the leg. There are days where it’s just there, kind of constant and dull, and there's others where it's just throbbing like I can feel a heartbeat.

MACLEAN: And how does that affect the rest of your day? Like on a day when it's just kind of a dull, constant pain versus a day when it feels like your foot is melting from the inside? How does that impact your life on those different kind of pain days?

JUDAH: On days where it's just the dull constant, it's easier to kind of deal with because it feels more muted and it's not nearly as loud and angry as usual. And it's easier to continue throughout the day and just keep going with one foot in front of the other. Whereas when it's mad or when it feels like it's melting, it can cause me to have a really hard time focusing on everything that I'm trying to do. I get stressed about the littlest things that I probably shouldn't even be stressed about. I can get really a lot more emotional, a lot more irritated with everybody. And even though I know they're not doing anything wrong, it's just that snap of an instinct to get on to them because it hurts so much, and you don't know what else to do. And it really just kind of makes everything a lot more stressful, a lot more scary. It's a lot harder to get out of the bed those kind of days.

MACLEAN: I can imagine. Actually, I can't. And nobody should have to and least of all you. What do you find makes it worse and what do you find helps?

JUDAH: So, there's a lot of things that make it worse. Like literally almost doing anything makes it worse. Stepping out of bed in the morning hurts it, putting my sock on hurts it, going outside and just walking around hurts. The biggest main factor that has the most tremendous effect on it is cold. The temperature, if it's freezing, I can barely go outside because it hurts so much. It feels like I'm being stabbed in multiple places everywhere all at once, and it's not fun. I think the other one is there's been a kind of correlation between the weather and the air pressure of those days, days when it's more like rainy, thunderstorm, darker, it definitely hurts a lot worse than normal sunny days.

MACLEAN: Interesting. So, it sounds like you've kind of done some of your own research, that you've actually gotten to the point where you think the air pressure has an impact. And that tells me that you're paying really close attention to how external stimuli are impacting you. So, how much research have you actually done on your own?

JUDAH: When I first got diagnosed with CRPS, I looked it up, and I immediately went to my computer when I got home, and I'm like, what exactly is this? And I think the biggest thing that the first time I ever looked it up that got to me was the amount of people who had this. And it of kind of scared me to see the fact that I, of so many people, I had to be one of the few who had to get this condition just from literally tripping on a tree root and it was it was really kind of scary to see all this stuff and see all these people’s accounts. I will say when I first read research, there was a bit of hope. A lot of people said that after two years, their pain started to diminish. So, there was kind of a mindset of, if we don't know what else to do, maybe if I wait these two years, my pain might go down. Like some of these people’s did. And so there was a bit of that. I really do think a lot of other research came from when we we're looking for ways to put the pain in remission. And I think one of the biggest things is we found a book written by somebody, and there were a lot of different symptoms and things caused by it that I'd also been experiencing. It made me feel a bit less alone. And it also made me kind of wonder what other things were affecting it. And it's really helpful where you already kind of have an interest in how things work and the science of it. And so being able to look up the different factors that might affect it and being able to observe how the different changes with it is interesting, even though I would rather not have to do it in the first place.

MACLEAN: Right? You're put in a very difficult position. So, how do you find the strength to keep going every day when it hurts just to get out of bed?

JUDAH: I will admit that there have been times where it's got to the point where I just I want to get in bed, and I don't want to wake up the next day. I'm ready to completely give up. And I really think the biggest thing that has kept me from going down really down that road is the fact that if I gave up, I would have done all this for nothing. My mom and dad would be sad, my family would be sad, they'd be heartbroken. And what if the pain really did go away years later and I ended my life for nothing and I just gave up for nothing. And I wasn't really into risk that. And it's like, if I got given this, maybe there's a reason for it and maybe there's something I can do with it to help other people who might have the same problem. That's amazing.

MACLEAN: That's amazing. So, can we talk a little bit about some of the treatments that you've gone through so far?

JUDAH: Well, it was originally just treated as a sprain. It got wrapped. It was like treated with ice. And I would walk around on crutches for a while, but it kind of went down a downhill slope from there, actually getting worse. And so, before we ever really started any other treatments, there's a lot of discussion on the different conditions and the treatments are what happened. And I got scared because we had no idea what was wrong with me and hearing all these treatments that you would do for all these different conditions, I could possibly have is terrifying because I've never been good with doctors in the first place. When we finally kind of got the diagnosis, we started physical therapy a little bit. We would do it twice a week for an hour to help get the function back and to work on it. And it was extremely, extremely painful. I spent a lot of therapy crying half the time. And I will say one of the things that kept me going through therapy was the fact that they had a bowl of lifesavers on the counter. And every time before I started an activity, I would go over there, and I'd grab a lifesaver.
MACLEAN: Wait, the minty kind or the fruity kind? Because that's important.

JUDAH: Both, both, they had both. And I would get some of both. It was delicious. The next treatment we ended up going to was this program in Philadelphia and it was completely 3 hours of occupational therapy, 2 hours of physical therapy, and they didn't have lifesavers. So, it was a big jump. And it was really, really, really hard. I almost got kicked out for the fact that I had one treatment there that I hated with my entire heart that I was physically terrified of, and I almost got kicked out for it. It was a machine they called the shaker. And basically, there are two platforms. You would put one foot on each of the platforms and it would move those platforms up and down, up and down, up and down in an opposite rhythm to shake it really, really, really fast. And it hurt like heck. It was the worst experience I had the entire time, and they threatened to kick me out for it and that scared me so bad. Because I did not want to see my mom's face if I ended up getting kicked out of the program because I was terrified of this thing. So, I did end up doing it anyway. And we made it through three weeks of the program before they told me that I was ready to leave, and I was still in so much pain. I didn't feel ready to leave at all. Even though they got me back to the running, I still felt there were such ways that I still had to go, and the pain hadn't even gone down. And I'd been really hoping that this would have been the way that I could have gotten rid of it. And they sent me home and the pain started out kind of level. It was lesser than before, and then it went back on a downhill slope, and now we've gone back to doing 2 hours of physical therapy each week, Monday and Thursday.

PIERCE: But I just want to interject here because this particular program was really focused on her gaining her function back. And so, they told us that the pain should start to go down over months. So, we went back six weeks later for a checkup, and they were like, nope, you're good. You've maintained your function. And so, they released her and said she was a success.

MACLEAN: I remember this, and I remember how scared she was to leave because she didn't feel like she was ready.

PIERCE: Yes. So, they released us from the program. And again, it goes back to what do I do now? Her pain is still there. Her pain has continued to increase, so we have restarted physical therapy here while we were figuring out our next steps for treatment. And on Monday, they do a bilateral function and strengthening. And then on Thursday, it's just her left leg, and they only focus on that. And so, on her Thursdays, I think those are her worst days.

MACLEAN: Yes, it's really interesting how treatment is. You mentioned PT and OT are your two of the biggest treatment paths and those have pretty much nothing to do with pain. They're just about getting function. So basically, it's learning to function through the pain, not even learning to function through the pain, just having the physical capability to function, but still being.

PIERCE: But that's, that's the other thing that they focus on, cognitive behavioral therapy that is specifically about teaching your coping skills to cope with the pain, not getting rid of the pain, coping with the pain.

MACLEAN: Which seems wildly unfair because why, why, should you have to have that much pain? Judah, I would love to know from your perspective, what would you like healthcare providers to know?

JUDAH: I feel like the biggest thing healthcare providers kind of need to understand and the something you already kind of talked about, it's not made up. It's a real condition. The pain is completely real and there's something going on. It's not us wanting attention. I wouldn't be doing this for attention, because I'd rather keep the attention off myself. But just it's real. And sometimes you kind of need to understand that. And it's also something they need to understand is that it's scary. It's terrifying to be hearing all this stuff that they don't quite understand what's going on with you. And if the doctors don't know what's going on with you, what are you supposed do then?

MACLEAN: What's your best experience? What the healthcare provider knows? Your mom mentioned Dr. Wilson, but have there been any other moments that have stood out to you as being really positive and helpful?

JUDAH: I think the biggest ones were our doctor we have now, who has always kind of whenever we go for a checkup or something, he's always just kind of like, asked how I'm doing. He's made it really light and fun, a lot less stressful. Even though we were in the middle of the doctor's office. And so, it's definitely a lot more lighthearted than some of the other kinds of doctors we've experienced and been around with. And I'm just grateful that we have him now and that he's been such a great help getting us back in physical therapy. And this pharaoh

MACLEAN: That's great. And what are three things that you would like just anybody to know about CRPS?

JUDAH: I think the first thing is really, really, really big thing. It's not made up and it's not for attention because I have been told before, it's not real. Just pretend it's not real and you'll be fine. I've been told that those kind of things, and that it doesn't exist and that I'm fine. It really does hurt. And one of the biggest things is that, like in Philadelphia, one of the things the program was they told the adults to basically ignore your child's pain, completely flat out ignore it. And that terrified me because I thought if she's ignoring my pain, does that mean it's not it's not real anymore? And so those kind of things, if you can't just listen to something and you can't just flat out ignore the pain, it's there and it's going to be there for a while if you don't do something about it. And it really makes it worse to flat out ignore it, because then like, including me, you get the mindset. Maybe it really isn't real and maybe I'm doing something wrong and maybe it's all my fault.

And I think that leads into the third thing is when you are kind of suffering with something like this, you kind of get this mindset that it's your fault, that you did this to yourself that, like I struggle with. I'll apologize continuously to my mom for complaining, for continuously doing it even when it hurts because I feel guilty for feeling this pain, for complaining about it to her, that there's people who have it worse off than me and I shouldn't even be complaining or doing all this stuff.

MACLEAN: That's really, really hard. And I really appreciate you sharing this because this is incredible it's, it's actually hard to hear and you're so poised. And I've read some of the things you've written about your condition and you've go on my mind. And I really appreciate you taking the time to share your experience with us.

JUDAH: Thank you.

MACLEAN: Candace, before we close up shop, I think we don't have too much longer now on this episode, but can we talk a little bit quickly about navigating the system and what you've learned about navigating with the rare condition, a rare syndrome like this?

PIERCE: I have learned that you have to advocate for yourself, as you know, as a parent, as the parent of a patient with this rare disorder. When we got the diagnosis, nobody knew what to say. Nobody knew what to do. And we walked out of there with nothing. And so, you had to do a lot of your own research, and you had to bulldog a lot of things through. You had to figure out where your champions were going to be. And that's what I mentioned earlier.

We found our champion through a case manager, through our insurance, and she actually helped us get the entire program covered by our insurance, including airplane tickets. You know, I mean, everybody's insurance is going to be different. But had we not figured out where our champions were, we would not have known that. So really championing case managers and social workers who can help you with figuring out the next steps, because it's hard today to navigate insurance and to navigate the health care system as a whole. As health care providers being prepared for an unknown. You can't be prepared to know everything about every single rare diagnosis. But there are some generic steps that you can do to support and to help those who receive it so that when they walk out of there, they're not walking out of their shell shocked, wondering, what do I do now?

MACLEAN: And then finding the one website that says that this is also known as the suicide disease. How terrifying must that have been?

PIERCE: Yes. We actually told you not to research this when she came home, just to just turn it off her experience, we were like, please don't research it. Let us sit down and talk to you about this. But I can't control what she does at school. But yes, that's really the biggest thing is navigating the system.

There are no easy steps to doing it. It is not. There is no evidence based guidelines that break it down for you and break down what treatment is. Because like I said, when I found that the website for CPRS, the only treatment options they gave you were spinal cord stimulators, pain medication, drips and blocks. So, and that's really not all that there is that's out there.

You just got to figure out where to find it. So, there's not an easy way to navigate the health care system, to be honest, with a rare disorder. So, find your champion. That's my biggest advice that I have learned through this.

MACLEAN: Well, I wish that we could provide a lot more. She could provide all the information and resources and support. But we've really reached the end of this particular series on complex regional pain syndrome. I really appreciate you Candace and Judah, for sharing your personal experience and your insights. I have way more understanding of this, and I've been hearing about you, Judah. You know, for quite a while. I remember when you went to that program for three weeks because that was when your mom and I were really becoming friends. But I've learned a ton here today, and it's really helpful to hear about how much it's a challenge, but to also hear how amazing you are in handling it. And I thank you again for taking the time to educate us all today.

PIERCE: I do want to throw out some really quick support that you can look into for CRPS if you know of anybody battling it. There's the Reflex Sympathetic Dystrophy Syndrome Association, and they work to provide support and education and drive research to develop better treatments. And again, I'm sure there's the Burning Nights. It's a CRPS support group. I know they have virtual online and are the RSCSA also has in person around the country support groups listed as well. We have not found any government-funded help with treatment, but I do know CRPS is known worldwide and there are research studies that are ongoing right now from infrared imaging, prognostic factors, augmented reality mirror therapy, ketamine and midazolam infusion.

So, there's a lot of research that's going on worldwide. Even though it's rare, it is known and felt around the world. And then there are also some 501c3s that can help if you know somebody who is going through treatment that needs help with fundraising. And you can see those, some of them are the Burning Limb Foundation.

And I know for us being a military family, we're also using the Chek six Foundation. So, there is support to help out there. But as someone with a rare disorder, you have to do the research to find it.

MACLEAN: Well, thank you. This has been incredible. And to our listeners, I hope you've gotten a lot of insight into this topic, as much as I feel I have. We encourage you to learn more and also to explore many of the courses that we offer at EliteLearning.com to help you grow in your careers and earn CEs. But thank you again for joining us for this and thank you, Judah and Candice.

PIERCE: Thanks for having us.

JUDAH: Thanks for having us.