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Introducing Lauren Reimer-Etheridge 00:51

We met Lauren at the [HealthVoices](#) Conference in Dallas sponsored and paid in full by Janssen Pharmaceuticals with three hundred forty patient advocate participants selected by lottery, half newbies to the conference and half previous attendees. I was a newbie. A conference planned by patient advocates; sessions led by patient advocates. The amazing part of the HealthVoices conference was hearing everybody being matter-of-fact and appreciative of the craziness of their particular brand of ways the body can go off the rails. If stories about this insanity appeal to you, I recommend listening to the podcast, [Sick Boys](#). Again, find a link in the show notes. Lauren is 26 and has [chronic intestinal pseudo-obstruction](#), which means that she doesn't have peristalsis in her small intestines. Peristalsis is the worm-like movement that pushes food down from the stomach to the bowel. Not only that, but her intestines don't do their job – absorbing nutrition from the food. We'll be talking about the lines, tubes, ports, and feedings that Lauren needs to survive. I'll explain some of the terms here, but they will be in the show notes as well. IV's are intravenous lines – sticking a needle in a vein and instead of drawing blood for a test, fluids go into the vein. When a person needs to be stuck frequently, a central line is put in with a port on the end of it just under the skin. A central line is a large line put into a major vein closer to the heart. Lauren talks about ports in her chest. The port is stuck every day rather than her skin. Parenteral feeding is liquid going through venous lines, and enteral feeding is through the gut. There are G-tubes and J-tubes. G-tubes go into the stomach. G is for gastric, the stomach. J is for jejunum, the small intestines. TPN is Total Parenteral Nutrition. That's all the nutrition a person needs going through a line into a vein. It's a milky looking substance. Crystal Harper joined us for the conversation. You'll hear Crystal's voice near the end.

**Health Hats:** Hi. I'm sitting here with Lauren Reimer Etheridge. Hi Lauren. Thanks for joining me. And Crystal Harper's sitting in with us too and she may or may not join us.

**Health Hats:** Tell me a little bit about yourself. How did you come to be at the HealtheVoices Conference?

**Lauren:** I advocate for folks who rely on nutrition support whether that be IV nutrition or that they're tube-fed - parenteral or enteral nutrition. While I was in that community, I saw another fellow IV nutrition advocate who had come to the conference a couple of years ago. So, I decided to check it out.

**Health Hats:** Do you use different methods of getting nutrition?

**Lauren:** Yes. I'm on IV nutrition and have been for the past 13 years.

**Health Hats:** So, starting when you were 13?

**Lauren:** When I was 13, I was diagnosed with chronic intestinal pseudo-obstruction. My small bowel doesn't have the peristalsis to move things through, and it doesn't absorb nutrients. I had been sick for a lot of years before that diagnosis happened. I was told it was all in my head for a lot of years and then I ate too much cheese. A lot of different ideas that came across. Finally, I was diagnosed with a small bowel full-thickness biopsy. And so that's how that diagnosis came about. I was 13, in seventh grade and I still weighed between 60 and 65 pounds. You're supposed to be growing at that point and doing stuff I wasn't doing. It took me getting to that age, and they were like, "oh, there may be something going on here because you're not doing what people do when they're this age."

Self-care 0 to 60 at age 13 06:05

**Health Hats:** How did they tell you about what you had? What was that like?

**Lauren:** Unfortunately, in pediatric hospitals - I know I can't speak for everybody's experience - but for mine, I wasn't a part of that conversation. I know that my parents were pulled to some sort of conference room. I guess that's probably a big thing at children's hospital because they want to tell the parents the things that are going on. So, I don't have distinct memories of a day that I got that diagnosis, but when I did get the diagnosis it was a relief to have a name for the thing that was causing chaos. That's really all I remember feeling.

**Health Hats:** Then, it was your parents that were informed, and it was your parents who would learn about treatment and what needed to happen and then they told you?

**Lauren:** There's not really treatment. It's mostly symptom management. When I was diagnosed nothing big happened. It wasn't like here's this medication that's going to do this or that. It didn't take too much

time after the diagnosis that I was put on the IV nutrition known as TPN. I'll probably continue to use that term.

**Health Hats:** Total Parenteral Nutrition.

**Lauren:** Yes. Of course, my parents were kind of involved. But when it came to that part of my life, they were very hands-off. It's kind of interesting as an adult now. I've asked them both, "why was that your approach?" And honestly, I haven't asked my mom that question, because I don't know if I'd love the answer. But I have talked a lot about it with my dad. My parents are separated. They separated about that time. It was interesting seeing how they handled it. But my dad's very valid reason is that he wanted it to be my thing and not be dependent on my parents. He wanted me to live my life as much as I could and not depend on him.

**Health Hats:** So, did that mean that you learn to set up the IV bag and you had a portal?

**Lauren:** Yeah, I've had a central line for the past, you know forever. But yeah, I did all that myself. My parents don't even know how to do it.

**Health Hats:** Wow. So, you took control, right away, not necessarily by design?

**Lauren:** I coordinated all my home health nurse visits. I did all of it.

**Health Hats:** Oh, you did. Did you feel kind of like a freak? This is so weird. Nobody else has to deal with this?

**Lauren:** Not really. My central lines now are more visible than they were then. They would place my central lines on my lower chest. So even when I went to school, I was open about it. I didn't not talk about it, but it wasn't visible to people. Of course, when you miss a lot of school and my belly was always really distended. And like that stuff is visible. But yeah, the TPN part - unless you were at my house at like 9:00 p.m., you didn't know.

**Health Hats:** Okay. You had the TPN infusion when you were at home?

**Lauren:** Yes, so I've always run TPN overnight. I'm just running fluids to keep me energized. Typically, it's just at night.

**Health Hats:** So, you find out when you're 13. Then you almost immediately are managing your own care. And you're in a children's hospital and with pediatricians outpatient for your medical care? And you're doing the arranging of all that?

**Lauren:** It's funny when looking at a 13-year-old. People say "you can't do it." But you can.

**Health Hats:** But you can. Which is interesting to me: I've seen quite a range of development. You're certainly on an extreme. 0-60 mph managing yourself. And the other extreme being, "look you're 30, and it's time to start ordering your own medication, right? But one of the things that is just normal teenager: you're starting to feel your oats, feeling your agency, trying to run your own life and having tension with your parents or guardians. But this must have really changed the dynamic, because you're managing such a significant part of your life, or did you still have normal everyday teenage angst?

Independent agent transitions off a cliff 11:14

**Lauren:** Yeah, not a lot with my parent. The typical like parents' stuff. I had my teenage angst moments, but I was an artsy person, and so that's that comes with that. Gotta have angst to make art.

**Health Hats:** You do, don't you? So, then you're 18, 19, and it's time to shift from the pediatric world to the adult world. And I'm assuming and correct me if I'm wrong, that you didn't just see one doctor, you maybe saw six. It wasn't like you're making one transition from a pediatrician to an internal medicine doc, but you were making a transition to many? Is that true? How did that go?

**Lauren:** Honestly, when I went from the pediatric world, my GI [gastrointestinal] doctor handled pretty much everything for me. It was kind of interesting. Whenever I did transition to the adult world, they almost seem more specialized, in that they're like, "No, I don't deal with that. You got to go see this person."

**Health Hats:** Wow. So, here you are independent in your equipment and all that, but it's another matter to be independent and audition physicians or find physicians and so how does that go?

**Lauren:** I move right out of high school to Portland, Oregon. I've lived in the Dallas area and moved to Portland, Oregon.

**Health Hats:** You need to find a new system as well as the doctors.

**Lauren:** I was all by myself. This is when of my angst happened. This time I was like, "I don't need support." I didn't say that I didn't need a support system but in a way. More like I can do this by myself. I came across the country to handle full-time school. Handle it? I don't even know. But that's kind of when my angst - like I don't have to deal with this; 'I'm going to get over this' attitude happened. Yeah, it was an interesting time for that to happen. But I did go to doctors there.

**Health Hats:** Through the school system?

**Lauren:** No, I went to a very small art school. So no.

**Health Hats:** You had to go into the community and find....

**Lauren:** I had my pediatric GI doctor. I think she told me of somebody that I went to. I can't even remember. It was only nine months.

**Health Hats:** Nine months is nine months. OK, then you got ill?

**Lauren:** Yeah. So, then I came back down to Dallas and then my old pediatric GI referred me to another adult GI. I really liked that person, and I think they did a good job. But the transition piece: I wish that they had some communication. Like the pediatric doctor would somehow ease you into it. Not just "Bye. Hello."

**Health Hats:** Like dropping off a cliff. There wasn't anything gradual about it?

**Lauren:** No, it was very hot then cold.

**Health Hats:** That was disconcerting. You had a routine, and you were comfortable with the routine. But as in normal life, let alone having a chronic illness, shit happens. You get sick and sick means out of equilibrium. That's what I mean by it. Here you were, an independent woman managing this disequilibrium. So how did that go? Did you have cronies that you could help you? Is this into adult medicine or just in general? Let's go back to pediatrics. When you were young, there was your family? Then you went off on your own, and your family is available by phone, which is good but not the same. Then you're in Portland, and something happens and you need a little more help.

**Lauren:** The perk of being at the small school was that people knew who you were. I recall one of my friends that I went to school with rode with me to the hospital on the bus because none of us had cars. There's like one girl with a car. This friend rode with me on the public bus to the ER. So, that's support, I guess. I wasn't by myself on the bus. And then there were some administrative people at the school that knew what was going on and they knew I was having a hard time. After all, I dropped from five full-time classes to two in three weeks.

**Health Hats:** So, they knew, but not necessarily stepping up to help you out? Were you comfortable asking for help? You were not. Then you come back to Dallas. Did you go back to your family home? Or did you have an independent life?

Self-care with flexibility for disequilibrium 17:09

**Lauren:** No, I just wanted to be independent and figure out what I could do for the rest of my life. So, I decided I was going to be a live-in nanny. Okay, surprise, what a great idea.

**Health Hats:** Oh, that's so interesting.

**Lauren:** Yes, I was a live-in nanny for a single mom who traveled at least one week out of every month.

**Health Hats:** Did she know the whole story?

**Lauren:** Not that I didn't tell her. Clearly, I had medications that were a whole thing and so she knew, but maybe not to the extent. But I was only able to handle that for about four months. Then I just job hopped. I got this opportunity to be an insurance agent. Okay. Let me try that. Yeah, I not a great time.

**Health Hats:** So, there were factors that you needed flexibility in your schedule so that you could both take care of yourself on a day-to-day basis and flexibility for disequilibrium.

**Lauren:** Yes. Because my body hates waking up early. I've actually figured that out since graduating high school. I missed so much school because I was ill a lot. Now I don't have to get up at six o'clock in the morning. I have more good days than bad days now. I think that that's huge.

See the show notes or my website [www.health-hats.com](http://www.health-hats.com) for more information, to subscribe or contribute. If you like it, share it. Thanks.

Advocacy for the practicalities 18:59

**Health Hats:** You're here at the conference because you're an advocate. Again, correct me if I'm wrong, but my perceptions about advocacy are that there comes the point where you've taken whatever it is you're dealing with in stride, and there's enough brain space to be thinking outside of others. And brain space and desire are the two pieces necessary for advocacy - interest. So, how did that transition happen that you got into advocacy?

**Lauren:** Well, my dad got me involved in the children's hospital. They wanted to hear from teenager patients. "How are we doing for you?" So, that was something I was very fine talking about. A lot of children's hospitals treat you like how they told my parents about my diagnosis in a separate room. But I was 13. I was old enough. It was my body. I wouldn't consider that my doing. But when I say, honestly, I didn't know that there was a community of people on TPN. Because when you're diagnosed with a rare disease, you're constantly told that you're rare and weird. Why would you think to go try to find others like you with that being circulating in your brain? But when I finally found that there were so many people just starting this world of nutrition support; getting these tubes and these central lines, or whatever else, I was like, "oh my goodness, I have so many things that took me years to learn that these people are just now trying to figure out. How amazing would it have been for me to find a blog that told me how to cover a central line to shower?" When I first got my central line, I had a port at the time. It was accessed seven days a week. I didn't know how to shower. Doctors don't; nurses don't know how to tell you how to do that. They don't have to deal with that. So, my mom would wash my hair in the kitchen sink. How annoying, right? So, one day a week that the dressing was changed and got to shower. Like wow, what a day! I've like come up with these - it took years for me to figure out how can I do this.

**Health Hats:** So now, you have a toolbox of things to do. Are the people that you are communicating with are they young, are they older?

**Lauren:** A lot of them are young.

**Health Hats:** Okay. So, you went through a transition from being 13 to now 26. Now you're hosting some people who are crossing the threshold themselves. How does that feel? Again, correct me if I have a wrong impression, but my impression often of young people, myself included when I was young, is that I was just really full of myself. I thought I knew a lot more than I did. It can be really hard to hear from people but having somebody who says I've done it. That is totally different. Did you feel like you had all this to offer, but there was a lot of variation in how ready people were to hear it or did they self select you? I'm ready, here she is. Do you know what I mean?

**Lauren:** Do you mean the younger demographic kind of thing? I think that's probably an any age thing.

**Health Hats:** But I'm interested in how you experienced being a helping person. It's a mixed bag.

**Lauren:** Yeah, I get what you're saying. Go back to the showering example. I think people are totally ready for that information. Always. Because that's practical, everyday stuff. I would love to know how to shower again. Now when it comes to a new TPN person that doesn't quite understand the risks and long-term side effects of that therapy. Those things are really hard to talk about. I don't even know that I'm actively talking about that yet. I'll talk to people about it if we're in a conversation and getting to that point. But in my content creation, I'm not saying, 'hey, some days I'm really scared my liver's gonna be real bad.' I guess I am kind of in a phase where I am mostly like practical, how to live with this life.

Sex, drugs, and rock and roll 23:16

**Health Hats:** That makes sense. Being practical I'm thinking, somebody in their teens and 20s. There's normal every day, sex and drugs. Do you find that your advocacy ever gets into those realms because those are practical every day. There are certainly the risks of getting stoned or getting drunk and unprotected sex. Those same things that happen to anybody, but it's a different problem. There's additional dimensions to the problem with somebody who's dealing with what you're dealing with.

**Lauren:** I think a lot of people in my crew don't feel like they can partake in any of those things. They feel like they're missing out.

**Health Hats:** Totally. They can't partake because it's so awkward and do I really want to show my body with this weirdness?

**Lauren:** That's huge. I think people assume that with TPN use... and not to say that you know anything you see that's on TV and don't go drink all the alcohol, right. But doctors don't really say, "no you're not allowed to drink." It's kind of a weird nobody's really giving direction on that with our liver situation. And so that's hard.

**Health Hats:** Which is amazing to me. I'm a nurse and know enough to be dangerous, but it seems to me that lifelong TPN has vascular, kidney and liver risk, infection risk. So that compounds drugs and alcohol sex and then just activities of daily living, exercise.

**Lauren:** Yes, people ask me about that all the time. There's a girl that has a feeding tube fitness program. [Shout out.] She's trying to make working out accessible to people with IV and feeding tubes. I've been showing these videos of myself doing her little workout. How nice that I work out with my central line. I've never been told not to.

**Health Hats:** Why not?

**Lauren:** So hard, as people don't even know, and when you only have 10 minutes with your doctor to ask all these, "Can I do this?" They probably don't even really know the answer.

Warm hand-offs, extreme hand-offs, slow hand-offs 26:52

**Health Hats:** If you wanted to leave a couple of pearls of advice either about transitioning from pediatric to adult care or self-care. What would they be? Let's start with advice you'd give to clinicians. What advice would you give to clinicians as their patients are in these situations that you wished you had heard or you would have learned?

**Lauren:** To the clinician?

**Health Hats:** Yeah, let's start with the clinician, then we'll talk about lay people.

**Lauren:** I would say that it would be so helpful to go into a new care team situation with them knowing what's going on?

**Health Hats:** Like a warm handoff?

**Lauren:** Not just here's a thousand records that is more than a person can handle. "I've known them this long and they're this is how they learn. This is how they whatever."

**Health Hats:** Right and in a 15-minute conversation. Wouldn't that be great? What would be your words of wisdom to parents?

**Lauren:** That's a really good question. I've thought about this a lot because I, of course, had this extreme hands-off situation and I'm very good friends with a girl who is in a very hands-on situation with her parents. There's gotta be some sort of middle moments, but I don't know what that looks like. I think you know when I talk to moms that have kids on TPN and I tell them that I was doing my care at 13 and they're just like, "oh my stars. When?" Then they start thinking how will that look for us? They have a baby on TPN since birth. That's a conversation to be had. If I was a parent of someone on TPN and maybe I would have some more insight.

**Health Hats:** Maybe some of it is just a normal parent thing. My wife and I homeschooled. Our kids did their laundry from the time they were six. You can do this stuff and cook.

**Lauren:** My dad didn't know how to do TPN. But he did my laundry until the day I moved out.

**Health Hats:** That's funny. Love that. I love that there are different ways to do it. Parents themselves have such varying abilities. There's the "helicopter parent" that does everything and hovers. You just wonder, when is this kid going to learn how to troubleshoot anything, right? For parents could be mindful that there's a transition coming and start as soon as you can at some level.

**Lauren:** The person that's dealing with the illness starts showing that they could change their ostomy. I don't have an ostomy, but when does that become uncomfortable for the child? Right? When do they want to start doing that themselves? Maybe even try to do it before it becomes uncomfortable?

**Health Hats:** You're right. There's a certain age: maybe at ten you don't care, and at 12 it's ugly. If you start at 12, you're dealing with, "oh my God, this is disgusting," versus "this is sort of fun." Crystal, anything you'd like to ask?

A Pretty Couch Potato 30:55

**Crystal:** Do you have any motivational quote or saying that you live by?

**Lauren:** Yes, and my blog is based around it. It's okay to be a [pretty couch potato](#). It came to me while I was really ill. I was in my room, and I couldn't do anything but play with some art stuff. I just made this little thing and then that's what it said and then it hung by my bed for years. And every time I saw it, I thought I should start a blog. The pretty part is that I'm launching this whole thing. I'm not the pretty Couch Potato, but it's validating because Couch Potato just has a negative connotation. I want to spread that the feeling is valid. Being able to do something productive is not what makes you valid. You can lay there all day and feel valid because your body is doing so many things that no one can see. We're doing a lot that we don't even think about.

**Crystal:** I think that's such an important message system. And I think that's such an important message to spread to other people in your exact situation because you never know how somebody else is feeling.

**Lauren:** Yeah, and in all disease states. I love that like that covers a lot of people. We all have our couch potato day.

**Crystal:** What's your blog?

**Lauren:** [prettycouchpotato.com](#) and on Instagram

What do you have again? 32:54

**Health Hats:** Would you like to tell us a little bit of more about what it is that's going on with you medically?

**Lauren:** Chronic intestinal pseudo-obstruction. My guts act like they're obstructed, but they're not. They don't know why. It has something to do with my muscles. We really don't have many details past that. They don't have the peristalsis and they don't absorb nutrients. Stuff just hangs out in there for however long it decides to which leads to bacterial overgrowth of the gut. I've spent I spent a lot of my life throwing. Thankfully now I have a G-tube which is typically used for feeding into the stomach and like bypassing the mouth and throat and esophagus and stuff. But I use mine so that I can eat for fun. Thankfully my doctor sees quality of life as being really important. Not being able to eat is not fun. So I'm able to eat for fun. But I have to be careful about what it is. I can't eat most things that people eat to be healthy. Most of those things are not for me. So that's an uncomfortable situation whenever somebody's like I didn't get salad today. The guy that worked at the hotel came up and said, "Do you have questions?" I just had my empty plate and I until I got to the risotto. He said, "do you have questions about the food?" I was like, "Nah, I'm just waiting to get to the carbs."

**Health Hats:** Well, thank you. I appreciate you taking the time.

Reflections 35:06

In the news, we hear about six-year-old refugees caring for three-year-old refugees at our southern border. We can do a lot when we have to. A theme throughout these episodes has been the variable pace that young people take control of their care, their health, each other. As I look around me in my privileged, first world life, I see parents walking their kids five blocks to school and carrying their packs and instruments for them. Or driving them five blocks. Learning that Lauren managed her own IV nutrition since age 13, reminded me that young adult agency (self-direction) is cultural, idiosyncratic, opportunistic, and quite variable. I still hear physicians say, what if the patient doesn't do what you tell them and hurts themselves? Parents have a variation on that theme. Seldom do I hear, how can we best support those that want to be the captain of their own ship within the parameters of safety? How can we promote creativity, experimentation, and resilience? Sounds like another podcasting series. Thank you, Lauren, for inspiring us to love and care for ourselves no matter our genetics and circumstances.