

- Kelly Cervantes: 00:00 I'm Kelly Cervantes, and this is *Seizing Life*, a weekly podcast produced by Citizens United for Research in Epilepsy: CURE.
- Kelly Cervantes: 00:18 On today's episode, we speak with Wendy Katten and Laurel Henson about the current nursing shortage within Chicago Public Schools. This shortage has a dramatic effect on the quality of care for students with epilepsy. Wendy is the founder and board member of Raise Your Hand Action. This group is leading the fight for higher-quality nursing care for Chicago public school students. Laurel Henson is the mother of a six-year-old child with epilepsy who attends a Chicago public school. She is also an advocate with Raise Your Hand.
- Kelly Cervantes: 00:48 Wendy, Laurel, thank you so much for joining us today. What is the nursing shortage that you're currently seeing in the public-school system?
- Wendy Katten: 01:00 Right now, I lead a grassroots parent organization, and we've been hearing from parents on a weekly basis who have no nursing coverage in their school for their children. We've been meeting with the district, and we've found that they're just way understaffed for the number of positions that they need.
- Kelly Cervantes: 01:22 Is this for the nurse that's full-time in the school, in the nurse's office, where a kid goes when he/she has a fever?
- Wendy Katten: 01:30 The days of having a full-time nurse in each school are long gone. We have parents whose kids have daily medical needs, which require medical intervention or the administration of emergency medications, and there is no nurse there to handle these functions. In our district, there are only 104 school-certified nurses out of a total of 500 needed. The district is filling a lot of the vacant positions, but not all, with nurses from a temp agency. That's causing a lot of problems because of the nature of temp agencies with a rotating crop of untrained people who oftentimes don't show up. So, you have parents who are being called lucky to even have a nurse in the school.
- Kelly Cervantes: 02:23 I think it's important, first, just to go back. I think a lot of people are unaware that there isn't a full-time nurse in many of these schools. Talking about the statistic that you gave, of 100 certified nurses for 500 schools. That's 20% of the schools have nurses, and the other 80% do not.
- Kelly Cervantes: 02:44 In terms of the temp nurses, it's awesome that you can get someone in there if it's just students who don't feel well that

day or vomit. But when you're talking about chronic medical conditions, like epilepsy, you really need that nurse to know what this student's seizure looks like. You hope, as a parent, that you can go in and talk to that medical professional and give them parameters. But if it's a different person every day, every week, then you can't have that conversation with a new person every single time to educate them on your child. Laurel, how have you seen this impact you? Tell us about your son.

- Laurel Henson: 03:27 My son is six years old, and he has periventricular leukomalacia, which also causes his cerebral palsy, epilepsy, and hemiplegia. His seizures started when he was two years old. In his school setting this year, in first grade, he's no longer getting naps. We had put a nap into his school day last year. Without the nap this year, the seizures have gotten increasingly stronger and stronger.
- Laurel Henson: 03:54 The nurse that is assigned to my son's school actually rotates among five other schools. One day she's at my son's school, the next day she's at a different school, and so on. But that's just that nurse. My son's school is an off-shoot, called a primary center. CPS is renting a Lutheran school from this church for kindergarten and first grade. The nurse that's assigned to my son's school, per se, never goes at all to my son's school. Because it's off-campus, at a different site from the regular school. So, when she's rotating, she only goes to the actual ...
- Kelly Cervantes: 04:36 The main building.
- Laurel Henson: 04:36 ... the main building. The nurses aren't there for headaches, or fevers, or anything like that. The nurses that are there have been assigned to that school because of an [IEP requirement](#). The nurse is not there to help all the other kids, but rather is there from an agency that has been required by an IEP.
- Laurel Henson: 05:02 So what I've been requesting is for them to addend my son's IEP. I have four letters from four different physicians, three epileptologists in his primary care, saying there has to be a nurse here who is able to triage. Because they're making me jump through hoops, they still haven't ... This has been two years now. Two years I've been requesting a nurse, and they haven't done it because I didn't use the term "to addend" on to the IEP. I didn't know I had to.
- Kelly Cervantes: 05:29 So they're finding different ways ...

Laurel Henson:	05:30	They're finding ways to get around it.
Kelly Cervantes:	05:31	... to get around it.
Laurel Henson:	05:31	Then, as soon as I said, "I want an emergency IEP. I want this addended to this," all this stuff started moving. I requested the emergency IEP in June. They said, "Sorry, it's the end of the school year. You'll have to wait until the new school year." I requested again three weeks prior to the new school year. It got pushed and pushed and pushed, trying to coordinate with everybody, until November 11th.
Laurel Henson:	05:56	It took from June to November. I finally had my meeting. I had to get an attorney involved. I said, "I'm not asking for a one-on-one. I'm asking for you to have a nurse on staff in case there's a problem." My son has an emergency rescue medication that has to be administered rectally. They have no one there now to administer it. So, their resolution was, "Well, we'll call 911." I said, "Well, the closest ambulance center is 2.4 miles from this school. There's no way they can get here in five minutes." "Then we'll send the nurse from the other school over," was their response.
Kelly Cervantes:	06:25	Not to mention that calling an ambulance into the school is not only expensive for you, based on whatever your insurance provides, it's also disruptive to every other child in that school. Also, the potential awareness and embarrassment for your son to be the center of that much attention and that much focus.
Laurel Henson:	06:51	And he's six.
Kelly Cervantes:	06:51	Yeah.
Laurel Henson:	06:52	He's starting to understand. He's still, because of his delay from ... Like with speaking, he's still a little immature on certain things, but he's starting to understand the dynamic of, "I'm different."
Kelly Cervantes:	07:08	Now, is he integrated into a mainstream classroom?
Laurel Henson:	07:11	Yeah, he has no cognitive delay. He reads at a third-grade level. He's quite brilliant.
Kelly Cervantes:	07:17	Wow.

- Laurel Henson: 07:17 But he's got the seizures. And I think that's also part of the problem. Because he's high-functioning, they disregard a lot of my concerns, saying, "Well, he can speak." I say, "Did you read his IEP? He didn't actually speak until he was three years old." He looks like a normal kid. Unless you're really focusing, you can't tell that, when he gets tired, he starts to fist and his eye starts to droop. You know, that kind of stuff.
- Laurel Henson: 07:42 Since his injuries don't look egregious enough, I think that's a lot of the problem, being taken seriously, and that's why I'm having to fight as hard as I am. Because it's, "Well, no. You're looking at how hard I've fought to make sure that he got the therapies he's needed because I've literally pushed and fought and pushed and fought." But I still say, "Listen, guys. My whole goal is that by the time he's eight or nine years old, he doesn't have to do all this stuff, that he doesn't have to have all these therapies."
- Kelly Cervantes: 08:05 What is the district legally required to provide?
- Wendy Katten: 08:10 By law, laws that were passed in the '70s, students have a right to a free and appropriate education despite any disability. Schools are not required by law to provide a nurse. That's not mentioned in federal law. They are required to provide the care that a student, like Mason and all these other kids that we know of, can get. That's up to the district. There are a lot of issues at the state level around the Nurse Practices Act, a kind of in-fighting among adults, I would say, around who's going to take the lead.
- Wendy Katten: 08:48 What we're seeing is parents are left to sit at the school or, in your case, just have no one trained, while you have to be at work, to provide the care. We have so many parents who, whether it's a daily intervention, an insulin shot or an emergency medication, or something more extreme like a ventilator, where there's just no one trained. We're saying CPS needs to change their design system. Other districts have done that, so they're not relying mainly on these temp agencies who don't have the training. So, they are required to provide care. Again, it's not stated that it must be a nurse.
- Kelly Cervantes: 09:30 Even if it is not legally stated that they require a nurse there, there does have to be someone skilled and trained to allow them to get the same education as the child next to them who doesn't require the insulin shot, or the emergency med, or so be it. Does it seem like the district is aware that this is an issue? Have they discussed a plan? Is there something they want to do

aside from just temporary nursing services to remedy the situation?

- Wendy Katten: 10:07 Our group of parents has met with the district four times this year, and they acknowledge that this is a major issue. They told us that they were going to come up with a plan by December. Yet their plan was really only to triple-down on the temporary nursing services. At the meetings, we brought parents whose children had been double-dosed on insulin. Four meetings determined that the absolute wrong path to take was to just increase the use of temp nurses.
- Wendy Katten: 10:43 The real issues here are continuity of care and competency of care. Students need someone who knows them, who doesn't come in every day and not know their care plan, not know their needs. Or have no one. I think our district, because there are so many kids who require daily intervention, hasn't figured that part out yet, and they're scrambling and redeploying the full-time nurses that they have to cover schools. They're in a whack-a-mole sort of crisis mode.
- Wendy Katten: 11:18 They're looking at students like Mason, and the many others who do have "call 911" in their care plan, which is incredibly unsafe. It's the bottom of the priority list. In our meetings with them, they've sort of said they know they need to address the complex medical issues, the very fragile cases. They know they need to do better with the daily medical needs. Those are cases where students may absolutely have to have a medical intervention like insulin. Then they've got the emergency medicines. My son had one too, called Glucagon, when he was a student at CPS. It just wasn't even on their radar.
- Laurel Henson: 11:57 I actually went ... I'm sorry.
- Wendy Katten: 11:59 No, go ahead.
- Laurel Henson: 11:59 I went and spoke in front of the school board. I said, "You guys have to do something. I'm a single mom. I have absolutely no help here. I own my own company, but I'm having to leave work. I'm having to do all this stuff. It's affecting my entire life."
- Kelly Cervantes: 12:15 I can't even imagine. You get the call from school ...
- Laurel Henson: 12:17 I have to go.

- Kelly Cervantes: 12:19 ... and you have to go. You have to drop everything. That means that you cannot be far from the school during the day.
- Laurel Henson: 12:21 I drop everything, and I go. I've been at night. I've been in meetings where I'm at lunch with one of my clients, and I have to go. I've got to leave. We went back and forth about this in November. One of the people from CPS said, "Well, he wasn't having seizures during the day last year." I said, "Well, that's impossible because we did this EEG for 23 hours, which was during the day, and he was having seizures on this EEG. That means you're proving my point, that the people in this facility are not trained, they're not capable, they don't know what they're looking for."
- Laurel Henson: 12:55 Then I sat down with CPS and said, "You guys need to understand what the kind of seizures are because Mason has a type that's extremely rare." That's the one that causes brain damage. And still, I have no idea if they've had the training, but I get multiple calls, saying, "Hey, Mason's having seizures, he's acting weird. This is what's going on, he's saying this." We just did a new EEG in December, and it's showing that his seizures are even stronger now than they were back then. Because they keep getting stronger and stronger, he went from maybe one or two a day to eight or nine a day. They're just getting more and more frequent.
- Laurel Henson: 13:28 I have this system in place to have this emergency medication administered, but it has to be a certified person to do it because it has to be done rectally. And there's nobody. So, I'm saying, "Hey, his seizures are getting stronger, you guys need to do something. This needs to happen."
- Laurel Henson: 13:44 The other side of it is, you know, for the teacher. I honestly kind of feel bad for the teacher, too, because it's like ... She's trying to educate these kids, and my son's yelling, "Alert! Alert! Alert!" Whenever he has his seizures, I've told him, "You need to alert her. You need to know because I have to start keeping track of these." So, this was another phone call today, and I had to rush to the school to give him his rescue medication. Then after I gave him one of his rescue medications, I said, "Okay, he should be good. These are myoclonics, they shouldn't be causing any brain damage. If there's anything weird, call me. If he has anything, if his face turns purple, you call me immediately, call 911 immediately. Don't even mess around at this point. Don't wait the five minutes. Call."

Kelly Cervantes:	14:23	Right.
Laurel Henson:	14:23	And they call me back, saying, "He's saying, 'Alert, alert,' a bunch of times." I said, "Oh, yeah, that's our new system. So, he's going to be doing this." Now it's disruptive to the class as well because my son is yelling "Alert!" every time he's having a seizure. But I don't care at this point because I need to be able to keep track of it. But it's not fair to the other kids that are, in a sense, normally-functioning.
Kelly Cervantes:	14:46	But it wouldn't be an issue if they had ...
Laurel Henson:	14:48	A nurse on staff.
Kelly Cervantes:	14:48	... a proper nurse on staff in the school.
Laurel Henson:	14:50	She would be able to triage it. She would be able to sit with him. She would be able to administer that rescue medication.
Kelly Cervantes:	14:56	It shouldn't be the responsibility of the teacher to try and have to ...
Laurel Henson:	14:59	To be able to figure out, is he having one? They've moved him closer to her. It's just ... it's a lot. It's a lot for him too. When he comes home, he's exhausted. He goes to bed at six o'clock at night. He's not like a normal kid who's going to bed at his age at 8 o'clock at night. He's done at six o'clock. It's tough.
Kelly Cervantes:	15:23	Parents who are in a similar situation, who are facing these nursing shortages in the school, who are having to run back to the school to administer meds, what services, what advocacy organizations, what resources are available to these parents?
Wendy Katten:	15:44	First of all, they should absolutely file a complaint with the Office of Civil Rights. The problem is many parents don't know that's an option. Some of the parents that I know who have filed a federal complaint have had their situation resolved. That's a first step.
Wendy Katten:	16:04	Another thing is there are other disability rights organizations, advocacy groups, and parent groups working together right now. We can always refer parents to some of these groups, like Equip for Equality, Access Living, or Legal Health Justice. My group is a parent group called Raise Your Hand for Illinois Public Education, and we're constantly referring parents to these

organizations where they can get further help for their situation.

- Wendy Katten: 16:36 For some reason, sometimes they are not yet getting resolved. It's outrageous the stress this is putting on parents and children, who deserve an advocate, an adult in the school, and shouldn't have this stress of being alone and lost in a school where there's no one for them. I mean, it's against the law, and it's also immoral to do this to our kids.
- Wendy Katten: 17:03 I would start with the Office of Civil Rights complaint. If you have a child who needs services, medical services, and no one's providing the care, and you've tried to work it out with your school, it's just a simple complaint form. Then they can contact us at info@ilraiseyourhand.org, and we can always put people in touch with some of the advocacy groups. There are people, there are free resources to help parents. This is also an equity issue. In Chicago, CPS is a district that's 85% low-income. I think sometimes districts are banking on the fact that low-income people are not going to fight, and no one should have to be in that place, right?
- Kelly Cervantes: 17:56 I imagine in an urban school district, this is probably something that's seen across the country.
- Laurel Henson: 18:02 It's terrible.
- Wendy Katten: 18:02 Yes!
- Laurel Henson: 18:02 It's frustrating.
- Kelly Cervantes: 18:03 To that end, is there a gold standard out there? Do you know of any cities or districts who are doing this well?
- Laurel Henson: 18:13 There are districts that do this much better than CPS. In our meetings, we've given CPS job descriptions and sort of design systems. I know, in Nevada, where my sister-in-law's a principal, it's a low-funded district like CPS, but they've managed to hire a health clerk for every school. Those are lower-paid jobs, but they can do a number of medical tasks to off-set what those hundred full-time nurses are doing and allow them to do the medical intervention. Again, these are lower-paid, non-nursing positions where they can cover a range of tasks. There are other creative solutions, and we've put some of them in the hands of the highest levels of CPS. The problem, I believe, is there's not a real urgency and sense of responsibility to make all kids a

priority and to get this done. That's what we're continuing to push for.

- Kelly Cervantes: 19:17 Ladies, thank you so much for coming on, for your passion, for sharing your stories. I think that this is just so important to shed light on these issues, that these problems do exist. It is not just the issues of the students with the additional medical needs, but this does have ramifications on the entire school, and the entire classroom. Just because someone's child may not have a medical condition today that requires this assistance, they could tomorrow, and we need to stand strong as a community. I just thank you both so much, thank you for fighting for all our kids, we appreciate it. Thank you for taking time to be with us today.
- Laurel Henson: 19:59 Thanks for doing this.
- Wendy Katten: 20:01 Thanks for having us.
- Kelly Cervantes: 20:04 Thank you so much, Wendy and Laurel, for discussing this critical issue affecting students in the Chicago public school system. I have to admit that learning about nursing deficiencies in public school systems does not necessarily surprise me. But that does not make it any less unacceptable. Students have a right to adequate resources and proper care so that they can attend school and learn in an environment that is safe for them. To help shine a light on this issue, we want to ask you to share this episode on Facebook, Twitter, and Instagram. Thank you so much.
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