

Health Equity Column: What is your Definition of Health Equity?

Jenné Johns, MPH, Selena Tisdale



What is your definition of health equity?

Basically, everyone, no matter race or ethnic background, having an equal opportunity to live healthy and receive the best healthcare there is.

What are your organizational priorities for addressing health and racial equity in perinatal and neonatal care?

“Basically, everyone, no matter race or ethnic background, having an equal opportunity to live healthy and receive the best healthcare there is.”

On an organizational level here, lately, we have been participating in a good bit of training, webinars, and classes in reference to this. So for my organization, I would look at it as just to ensure that we continue to advocate for the families that cannot speak for themselves or choose not to speak for themselves because a lot of people have to look at, I guess, risk on their behalf. You know you can't say everything you want to, so sometimes it takes someone else to speak for you. So, in that case, being that we're in a better position to actually speak on these matters, that's what I feel our priority should be. Speaking about it on every avenue possible that we can to get it out there to let them know that, look, it exists. We are all for that. We are about making change. We either want to come together as one to make this happen or want to continuously hear from us every day, every week. However, it has to go in order to make this happen and make this change because it's sad to say it still exists, and I am a victim of that.

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What personal and professional experiences led you to focus on health equity in perinatal and neonatal care?

Well, for one, my personal experience as a mother of a preemie and now as an owner and the founder of my organization. It's kind

of like it's a must-do. I must do this. There are absolutely no questions about it. In my experience, I would not wish that on anyone else because, honestly speaking, you don't know people's mental state when they're going through their journey at that time. It is not just about the NICU. They have homes to go back to also, so you don't know what they're experiencing at home and some of them may still be employed, so that's work, home, and the NICU. That's a lot on someone. And in my case, it was just one particular doctor that I had an issue with, to the point where it was, though, I didn't even want any more interactions with him. He really did not know how to speak to me. He spoke to me as if I was illiterate and the sad thing about it is, I have several degrees, but I had to let him know that later on. I didn't let him know anything. I would allow him to speak to me however he felt it at that moment because I wanted to be the one to let him know to stop judging me just by looking at me. I don't have time to dress nicely when I come in here when I'm coming straight forward.

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You don't know what kind of work I actually do, and I may only have time to come straight to the NICU after I get off work, but he was very, very, very judgmental. Everyone else was excellent. I loved them, but he was very harsh. He came to me, and he had some paperwork on the clipboard, and he said, “Good morning. You need to sign this DNR.” I had to look around like, “You're talking to me?” and he was like, “Yes, because I mean we've tried everything that we can possibly try, and I don't see the reason why he should suffer any longer” or this and that, and he just went, and he was very short, and that is just how he was. And then I would see how he interacted with other families and it was nothing like how he interacted with me. I was like, okay, that's it all right. So I looked at him and I told him my exact words. I say I don't mean no harm, no disrespect, because, at the end of the day, he is still in

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a unit with my son. He still has access to my son. So I had to be very careful of the words I chose to give him, so I told him I said: "I don't mean any disrespect to you, but can I please speak to the head doctor in charge of this unit, and I need to also speak with the actual director over the NICU."

"So I had to call a meeting, and we sat around the table, and I was not playing with them at all. And that doctor, to this day, I can tell you he still works there, but his attitude is a 360. Everything. I mean it's a complete 360. I'm not there yet being so social with him at this point, but on a business level, when I do go to the NICU, of course, yes, you know, speak with him, but it's very, very brief, but I could see the change in him."

And he was like, "What do you need that for, I'm trying to tell you..." I said, "Don't worry about that. Thank you for your services, to thank you for everything you have done this far, but I need to speak with them." So really, how he was thinking of me, that wasn't the way he expected me to respond. So when the head doctor came out and the actual director over the NICU and, as I explained to them, I do not want any interactions with him. I don't want him to have any more doings with my child as long as he is here. Nothing, period. And for them to respond to me the way they did, I wasn't the first person he did that to. So that was an issue for me. So I had to call a meeting, and we sat around the table, and I was not playing with them at all. And that doctor, to this day, I can tell you he still works there, but his attitude is a 360. Everything. I mean it's a complete 360. I'm not there yet being so social with him at this point, but on a business level, when I do go to the NICU, of course, yes, you know, speak with him, but it's very, very brief, but I could see the change in him. He had several trainings, and from my understanding, he's still going through more training. Anything that comes up, he's placed in there to take it, and he needs that because I told them I could have been someone else that actually took this a little further, and it would not have been nice. But I wanted to give them the opportunity to fix the issue internally before it gets out of hand.

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Mandatory training and classes. That is the call of action. No questions. No way around that. They need more patients to do surveys and feedback. If a doctor or nurse's name is mentioned in this feedback, they need to get them and put them in a class immediately. Let them know why they are put in this class. They can't know the patient that named them because that can cause

problems also, but once it is listed, the specific employee needs to enroll in the training. They need to be monitored at least for a few weeks, not just for one week because anyone can put on a show for just one week. If they don't do these surveys or feedback, nobody is going to say anything. For the people that do not have a voice or are afraid to express their feelings, that would be a way they can get how they are feeling out, it would be anonymous, but they can get the names out, and that is the only way it can be fixed.

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Disclosure: The authors have no disclosures.

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About the Author: Jenné Johns, MPH:



Title: President and Founder

Organization: President, Once Upon A Premie www.onceuponapremie.com and Founder, Once Upon A Premie Academy www.onceuponapremieacademy.com

Jenné Johns, MPH is President of Once Upon A Premie, Founder of Once Upon A Premie Academy, mother of a micropreemie, author, speaker, advocate, and national senior health equity leader. Once Upon A Premie is a non-profit organization with a two-part mission: 1.) to donate Once Upon A Premie books to NICU families in under resourced communities, and 2.) lead virtual health and racial ethnic training programs and solutions to the neonatal and perinatal community through the Once Upon A Premie Academy. Jenné provides speaking, strategic planning and consultation services for fortune 500 companies focused on preemie parent needs from a cultural lens and reading as a tool for growth, development, and bonding. Jenné is also a national senior health equity thought leader and has led solutions-oriented health equity and quality improvement portfolios for the nations' largest health insurance and managed care companies.

About the Author: Selena Tisdale-Shaw



Title: Executive Director/Founder

Organization: Eli Collins Foundation for Premature Babies

Short Bio: I am Selena Tisdale-Shaw, the Executive Director/Founder of Eli Collins for Premature Babies. I am married to a very supportive and loving husband, and I have two daughters and a granddaughter. I founded this organization in May 2016, after the death of my son Eli who was a micro preemie. He was born at 23 weeks 6 days, weighing 1 pound 3 oz. He lived for five months. He died due to complications with his lungs. After several months of grieving and trying to get myself together, I established this non-profit organization to assist the families traveling on this journey.