Sarita and Kareem Edwards

Transcript

**Lower Third**

Sarita and Kareem, parents of Jeff, Rian, Josiah, Jeremiah and Elijah.
Elijah, age 6, has Trisomy 18.

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| 1 | Title: *A diagnosis in-utero of Trisomy 18: Being told, Don’t get too attached. He is going to die. We wanted a different conversation.*<https://youtu.be/uQ2qUbIaBSI>Parents of a child with Trisomy 18 talk about how clinicians set their expectations that their son would not live; and how it left only them as parents to advocate for him to live. "When you try to keep hope, and they keep trying to keep it away from you because of the statistics, it is hard. We wanted a different conversation. . .Were there opportunities to think differently?" Mom share that it made her feel angry to suddenly feel abandoned by the medical community. "I didn't know you could refuse care to a family because of a diagnosis. It blew my mind."TC: 00:50I am Sarita Edwards. This is my husband Kareem. Kareem and I have been married almost 20 years. We have five children. Our eldest is Jeff. He is a college graduate and outside of the house. We have four other kids at home. Ryan and Josiah, Jeremiah and Elijah. And Elijah is what introduced us to the rare disease space. We received his diagnosis in utero. And that started our journey of advocacy [0:01:00:02] and education and public policy.so Elijah has Edward syndrome, or Trisomy 18 is a more common name for it. We did receive his diagnosis around 22-23 weeks pregnant. Edwards’s syndrome is when you have the presence of a third 18th chromosome, and Elijah has full or complete Trisomy 18, which means he has that extra 18 chromosome on all of his cells. We were told in utero that Elijah could pass away, that he would pass away during the delivery process or shortly after birth. [0:03:00:03] We were told that he was missing three fourths of his brain, that his esophagus was offline, that he only had one working kidney, he had heart issues, clenched hands, rocker bottom feet. Everything that you find, if you were to Google search this diagnosis, we were told that Elijah actually suffered from it. I think having had four other children before we knew what to expect when it came to being pregnant, and post-delivery and after receiving that Elijah's diagnosis everything kind of changed, you know, our doctor's visits changed, we went in and they would listen for a heartbeat and check for activity, and then we will just follow up, you know. It was just different for him [0:04:00:02] after we got the diagnosis. I guess it was around 30-31 weeks, our local OB transitioned us to a different facility, two hours one way, they felt that that facility could better accommodate what we were dealing with, and so we started prenatal care somewhere else at 31 weeks, and so we did that. And they gave us the same narrative. /Elijah was born alive. We spent the first seven months of his life in hospice care, you know, honestly, a lot of resources were withheld from us, I think just because of the high mortality rate of the diagnosis, we were told to enjoy our time with him, he would pass away soon. And so that's kind of what they prepared us for, [0:05:00:00] and I think initially, that's what I expected. I expected him to pass away any day, because, you know, that was the only narrative that was being shared with us.**Kareem Edwards:**  Well, two, I think the hindsight being 2020, after the diagnosis, it seemed or it felt like we were the only ones that cared about Elijah, like Sarita said, we've gone through this process four other times, and it looked completely different than what it did this time, and it just felt like nobody but us cares, almost like we were -- it was almost like that was the beginning of our advocacy, not after he was born, right, like, we began advocating first for ourselves [0:06:00:04] to transition into the birth, and so on and so forth. But yeah.**Sarita Edwards:**  Yeah, it was really difficult, I think, you know, I think because all you have is what they tell you, especially when it's a diagnosis that they have seen, but you haven't seen or heard of, and all you have is Google, which they told us not to do. And so you really rest on the information that you find and the information that you're told. And the challenge with that is when you try to keep hope, and they keep trying to take it away from you, because of the statistics. And so that's where we found ourselves a lot, just really fighting for a different conversation before he was ever even born into the world. [0:07:00:06]We just wanted to know, you know, what we were dealing with. And is there something other than prepare for him to die, you know, I mean, because we understand that this is the science, we understand this is what you've seen, but are there opportunities for something different? Is there room for conversation to do something different? You know, is hospice our only choice, you know, do we have to not pursue interventions? You know, like [0:08:00:01] is that our only out, and that was just the only conversation that we were being told.**Kareem Edwards:**  You know, he's going to die, don't waste your time.**Sarita Edwards:**  Don’t waste your time.it all came across the same way, don't get too attached to this kid because he's going to die, those weren’t the words used, but that was the narrative in place for everybody.**Blyth Lord:**  How did it make you feel when this was the very two dimensional [0:11:00:07] uncurious, unhopeful presentation of the facts or the expectations or just the nature of the care, how did that make you guys feel?**Sarita Edwards:**  I think I felt angry a lot. And I think my anger was -- I had such a high regard for the healthcare system, because [0:14:00:05] I had worked in health care for 20 years, a little over 20 years. And so I had such a high regard for the health care system, a high regard for medicine and science, and physicians. And so to find myself in a situation where the healthcare system was telling me, we're not going to give you care, we're not going to respond to your living child because of a diagnosis, I was angry, I was very, very angry. I was frustrated, and I was disappointed, because I never ever thought that could happen, I never expected it to happen, I didn't think it was something that could happen, you know, I didn’t know [0:15:00:04] that you could refuse care to a family because of a diagnosis, it blew my mind. And so you have this roller coaster of emotions, you know, you're angry, you're upset, and then we started getting this -- we started this journey at 22 weeks pregnant, so every doctor's visit, it was like pulling the scale off of a wound, you're having to relive this reality that they're giving you over and over and over and over again. And in between those doctor's visits, you're still feeling the movement, you know, you're still having symptoms, and so you still feel pregnant, but the moment you go to the doctor's appointment, they take it all away from you all over again. And so I stayed very, very aggravated, I stayed very, very aggravated for [0:16:00:00] many, many weeks. And I think we still find ourselves aggravated sometimes, you know, we've been refused care as recent as 2021. Our doctor told us, you know, for a kid who would never walk, why should we do anything? Why would you want to do anything? And so we still have those moments where we are disappointed in the healthcare system, and how they choose to respond to a child with a rare diagnosis like this. |
| 2 | Title: *We just want a conversation about options: “Are we going to get somebody that cares or somebody that just wants to talk about diagnosis and prognosis.”*<https://youtu.be/brVG2qhEiSg>Parents of a young boy with Trisomy 18 tell the story of how a doctor would only discuss treating their son's hip dysplasia in the context of his Trisomy diagnosis and that he would likely never walk. They want doctors who will explore options, show curiosity, and have the conversation. "We need physicians who show care"TC: 17:05Elijah, he has chronic GI issues, and he had had a flare up, and we found ourselves at the pediatrician’s office. They wanted to do an ultrasound, we did. The ultrasound revealed hip dysplasia that we didn't even know existed. When they called to give us the results from the ultrasound, the pediatrician’s office said, so who's following hip dysplasia, I don't see anything in the chart. I said, we didn't even know he had hip dysplasia, they connected us with an orthopedic physician, we made the appointment, and when the doctor walked into the room, he had the results from the ultrasound. They also wanted to do an x-ray at that appointment. [0:18:00:00] He came in with the report and he never acknowledged the report, the first thing out of his mouth behind, hello was, so Elijah has Trisomy 18, I said yes. And he says, okay, and then he started asking me about, you know, mobility, and how does he get around? And, you know, and I told him, I was like, well, he uses a wheelchair, we also have a gait trainer. And he says, okay, and then he began to look at the x-rays. And he started talking about, you know, typically for a child with hip dysplasia, you know, what we could do is, you know, this, this, this, in some instances we could break the bone, some instances we could cast and all this type of stuff. You know, [0:19:00:03] but for a child who would never walk, that may be a little extensive, you know, I don't think we should, you know, I don't think we should consider that, I think we would be better off if we would just let him continue on the path that he's on using his wheelchair, you know, using the gait trainer, I mean, don't you think that makes sense a little bit mom. And so he threw it back on me. I had spoken with our physical therapist prior to the appointment, and she said, you know, ask for AFOs and see what other options are available. She kind of gave me some things to take to that appointment in terms of conversation. So I started to mention all of those things, and he said, well, I mean, I don't think any of that is necessary, again you have to look at the [0:20:00:04] facts, you know, for a child who would never walk. That was his second time saying that, for a child who would never walk, I mean, is it really necessary to put him through that. And I'm looking at Elijah, who is at the time pushing his wheelchair not wailed, but enough to where he can, you know, move a little bit in the room that we're in. And Kareem actually was not at the appointment. And so I text him after and I told him, I was like, so we probably won't be going back to this doctor because he disregarded everything, you know, everything that the PT had prepped me for to ignite conversation, he completely disregarded. When I specifically asked for braces and different things that she said, you know, let's see if this this this this this will work. He was like, [0:21:00:03] well, I mean, I don't think we need any of that either, I think we just wait, see what he'll do, that was the extent of our conversation. Needless to say, that was our first and only visit, we decided never to go back to him. I think for us, we just wanted the conversation, you know, what does hip dysplasia mean for Elijah? What does it mean in terms of his mobility? We did end up connecting with an orthopedic who said that we should not do surgery, who said that braces were not necessary, but we have a plan. That's all we wanted from the other guy. You know, we just wanted the conversation. We talk about Elijah's mobility, we talk about the things that he's doing. He actually takes Elijah out of his wheelchair, and let him walk across the room in our appointments. The other guy, Elijah never [0:22:00:03] got out of the wheelchair, he was in the wheelchair the entire time. And so it was just, you know, it's the same diagnosis for both physicians, one just has a little bit more concern than the other one, and he acknowledges Elijah's Trisomy 18, but he doesn't allow it to prevent him from providing Elijah care based on Elijah's needs. And those are the doctors that we're looking for.**Kareem Edwards:**  Yeah. And it's in the name health care. Right. So, at the heart of it, that is all that we ask.**Sarita Edwards:**  That’s it.**Kareem Edwards:**  Is that we come into a physician's office, and they care.**Sarita Edwards:**  They care**Kareem Edwards:**  Kind enough to address the issue, and not talk about the diagnosis or [0:23:00:05] their response be in relation to the diagnosis and not the issue.**Sarita Edwards:**  Right. Don't dismiss us.**Kareem Edwards:**  Because Elijah has a multitude of issues from kidney developmental delay, etcetera, so on, so forth, but we need physicians to care. And I think that would solve 99% of the issue that we have coming into a doctor's office, because that's the first thing that we think -- I don't know, maybe it's PTSD, but going into a visit, it's always a new one, a new visit, right? So if we have to see somebody new, it's always oh, boy. So we're going to get somebody that cares, or we're going to get somebody that wants to talk about diagnosis.**Sarita Edwards:**  Well, and it's the defense mechanism, you know, a new physician, we walk in defensive, you know, I do, [0:24:00:07] I walk in, ready to shut down anything that they're going to say regarding his diagnosis. One of so many diagnosis, you know, we could very easily be going in for hip dysplasia, and we spend the entire visit talking about Trisomy 18 and why because of Trisomy 18, we shouldn't do anything for the hip dysplasia, like we never really address the hip dysplasia and the impact of it on Elijah. And those are the conversations that we want, we are not dismissing Trisomy 18, that's the cause of his hip dysplasia. But we want to talk about what those diagnoses, those individual comorbidities, what do they mean [0:25:00:04] for Elijah, and how can we give him the best quality of life with the diagnosis that we know he has because of the Trisomy 18.**Kareem Edwards:**  We have zero false expectations for this young man. Like, do we expect him to leave the house, get a job, get married? Probably not, we'll be excited if he does, absolutely, but that's not what we expect, what we expect from him is what he can do aside from the limitations placed on him.**Sarita Edwards:**  Yeah, and I think that's the greatest challenge, you know, just as a parent being hopeful for the best quality of life, and someone else determining that the [0:26:00:04] best quality of life is to do nothing, and that's not okay. Because to me, quality of life is responding to whatever is presented, not dismissing it, because he's doing better than expected, still responding, you know, we still have to respond because he keeps defying the odds. And so we want to celebrate that and give him the best opportunity to keep doing so, not act like -- because he is you should be grateful for that and not do something else. |
| 3 | Title: *We look for physicians who will be champions for our son, and who will offer us options.*<https://youtu.be/CmAFIBiQKw4>Parents of a boy with Trisomy 18 recount their evolution as their son's advocate in the face of a medical system that does not expect their son to live. "I have no reservations or hesitations about finding another physician. My entire outlook on being a patient has changed. . . We give new physicians the chance to be champions for Elijah. I go in ready, because we have been shot down so many times when it comes to providing care for him, that we’re just ready for whatever they bring." They give an example of a G-Tube.Sarita: initially, I was going in, you know, what brings you in and I kind of give the backstory about what brings us in and then I'll wait for them to give me what they think. Yeah, I don't do that anymore. Elijah, he literally has transcended the way that I approach probably everything, you know, I walk into appointments now very -- I walk in almost as an advocate, before a mom, you know, I walk in ready to say, you know, this is what -- you know, this is why we're here, you know, this is what we're thinking, this is why we were told to come to you, I give them the opportunity to respond, [0:30:00:04] but now I am very much okay with that being my only visit, I have no hesitations or reservations about finding a different physician. You know, we are fortunate enough to where we can commute two hours one way as much of an inconvenience as that could be sometimes, having to drive two hours one way for a specialist, we're willing to do that. You know it's just -- my entire outlook on being a patient has changed, because I feel like for Elijah, there is a different level of advocacy, you know, you advocate for your kids just as a parent, you know, my kid is sick, I think we need medicine, oh, you don't need medicine. [0:31:00:04] well, we do, we've had this symptom for three days, that's advocacy. Before Elijah, we really literally had to kick doors down to receive treatment for him. And so when it comes to a new physician, we give them the chance to be a champion for Elijah, because that's what we're looking for, he has 20 specialists. So we are looking for those champions that will speak up on his behalf if we ever needed that. But we recognize that everybody isn't a champion, and that's okay, that just means they're not the physician, they're not the medical team for Elijah. So yeah, you know, sometimes I have to go in and say, well, let's give him a chance to read it, because I go in ready. And, you know, I recognize that sometimes that's not the best [0:32:00:05], you know, attitude to have, but I go in ready, because we have been shot down so many times when it comes to providing care for him, that we’re just ready for whatever they bring.**Kareem Edwards:**  Right. And we've learned to not settle, right. So we're not going to go, oh, well, if the doctor said, whatever, if we don't as parents feel as if this is the right path to take for our child, again, we're professional parents we got four other children, so we kind of know a thing or two about parenting. So if we don't feel like it's the right path, if this physician is not the champion, then we're okay with moving on to the next. So for example, we're told what he was maybe six months old that he needed a G-tube. And so [0:33:00:04] our question was, or mine specific, my wife may have had more medical termed questions, but mine was why does he need a G-tube? And the answer was, so that it would be easier to feed him. So my question to that was, okay, so why does he need a G-tube? Because yes, it would make it more convenient to feed him, and maybe my greedy kicked in with this one, because I can't imagine my stomach being filled, and not being able to taste that just seems like torture to me.**Sarita Edwards:**  And let me just interject quickly, I think just to provide context, Elijah was being orally fed up until that point.**Kareem Edwards:**  Right. That’s a good point.**Sarita Edwards:**  Right, like, I mean, he was eating foods by mouth, and then all of a sudden, the G-tube was [0:34:00:04] offered.**Kareem Edwards:**  Right. So it's not like he was having problem for being feeding, right. It was, well, he's not big enough. Well, like every other child, he's different, he didn't grow that fast, right, so he's a small kid, but feeding him through a G-tube to make it more convenient for me is a disservice to him. So we're in the wrong space. So we're not going to do a G-tube. Are you sure your doctor sent you over here? Well, I get that but to the point, we're okay with saying, we're not doing that, we're going to try something different.**Sarita Edwards:**  And for us it becomes in that specific example, you know, the very next question now becomes what are the goals, right. You know, if you are offering us, he's being orally fed, you're offering us a G-tube, because he's small, what are the goals that the G-tube will achieve, give us those goals and let us [0:35:00:03] try before we do something as innovative as this, and so we ultimately, we got the goals and achieved and even surpass them. And Elijah, he never had to get the G-tube, he continued to be orally fed. But I think prior to a lot of the experiences that we had had up until just those six, seven months old, I think we would have strongly considered the G-tube because it was recommended. But having had a lot of those challenges, if you will, up until that point, we could just become very, very okay with questioning the process, and asking for an alternative solution, we [0:36:00:01] understand this is what you recommend, why do you recommend it? And we don't really like it. What's another alternative? And we're okay with saying that now. |
| 4 | Title: *How we advocate for our son. “We are over the system telling us the best plan of care. We are going to do this together or we are not going to do it with you.”*<https://youtu.be/JoVaIiTq2J0>"If you're advocating, you're not complaining, you're fighting for a better conversation. . . We're not going to just make a decision for Elijah’s health because you the physician feels like that's what we need to do. I need more than that; we need more conversation than that."TC: 44:15Sarita: I mean this as humbly and respectfully as I can, we are over having the health care system refuse us care, tell us the best plan of care, we are going to do this together, or we are not going to do it with you, it's just that simple, when it comes to Elijah, we want a team of people who want him at his best. And if that's not who we are speaking to in that moment, that's totally fine, we are okay with shutting down that conversation and moving on to a physician [0:45:00:03] who's willing to have that conversation with us. I think I just, I don't know, I feel like I sound so antagonistic, but we're over it, because we've experienced it too much, you find yourself where they're patting you on the head, we're not going to do anything, he's going to die soon. Why do you want to do that? You know, do you want to put him through that? Like they put all of this burden on you as a parent, making you second guess your choices. And you feel this heaviness, am I really putting him through a lot if I choose this? Is that fair as a mom? Am I being selfish? Because I'm doing this because I want him to live, but, you know, should I just be letting him slowly passed away? We're all slowly passing away, you know, [0:46:00:03] I don't know, I'm over it.**Kareem Edwards:**  Additionally, I think advocacy is that not being a complainer, I think a lot of people confuse the two or [muddy #[46:16] the line between. And if you're advocating, you're not complaining, you're fighting for a better result, or what did you say earlier a better conversation.**Sarita Edwards:**  A different conversation.**Kareem Edwards:**  A different conversation.**Sarita Edwards:**  And I think that's the -- I think that's the gray area that's often skew, I think a lot of times we think advocacy is speaking --**Kareem Edwards:**  Making demands.**Sarita Edwards:**  Right, or complaining about or speaking up, but still accepting. Well, advocacy is a conversation, you're talking about the goals that you want for your child, for yourself if you're the patient you're talking about those goals together with your healthcare team, they're not making [0:47:00:00] the decisions, and you just have to accept it. I'm spitting, sorry. Advocacy it's a conversation, is talking about what those goals are for your health, and if it ends up being exactly what they recommended, I think that's totally fine, but you have to feel good about that decision, I think we're over walking into a conversation. And then second guessing ourselves, when we leave out of the room, we're going to talk about it while we're here, if we need another appointment, that's fine, but we're not going to just make a decision for Elijah’s health, because you the physician feels like that's what we need to do, I need more than that, because it's life or death for him. Yeah, we need more conversation than that. |
| 5 | Title: *A Black couple reflects on unconscious bias in medicine: “I shouldn’t have to start flashing all these badges in order for you to respond.”*<https://youtu.be/zJYsKCAqmiM>Black parents a boy with Trisomy 18 reflect on impact of their race and his diagnosis on this care.Black parents of a boy with Trisomy 18 reflect on their experience from his in-utero diagnosis onwards and the possibility that their race impacted the care and conversations the medical system was having with them. Mom felt that they thought she didn't understand the prognosis, that she was ignorant. "I find myself having to show our education and who we are . . . I shouldn't have to wear a college degree on my shoulder. I shouldn't have to change the way I speak in order for you to listen to me. You shouldn't have to google us to listen to me." They also note their perception/vibe that the clinicians don't assume the father is actually the father. They eventually found the right team to be their son's champions and pave the way so that race and the diagnosis are less of a factor, 'opening the door for us and making it easier for us to walk in.'TC: 49:50I think initially, I don't think I [0:50:00.4] ever thought race played an issue, I think initially, we thought it was the diagnosis itself. You know, I think race slowly became something for us to think about, because you know, being given the diagnosis, it went from this is what we're dealing with, this is 99% to the very matter of fact, you know, shaking a sheet of paper in front of us, this is 99%, it was almost like they were treating us as if we were being resistant or noncompliant, because we were asking questions, because we wanted to know, you know, [0:51:00:08] what does this mean for our families, because we chose not to aboard. It seemed like, it was very much, it felt like they were treating -- it felt like they were treating me, I'm going to speak for myself as the patient, the one carrying the kid, the child, I felt like they were treating me like, I wasn't understanding what they were telling me. I felt like they were treating me like, I was having challenges making a decision, not because of the diagnosis that they had given me, but because intellectually, I wasn't comprehending what they were saying. And that's how they made me feel. And I was very much [0:52:00:04] aware of what they were saying. I was very much aware of the diagnosis, but that doesn't mean I don't have questions. But I did feel like they were treating me like I was ignorant, you know, I find myself often letting professionals feel like they're telling me something. And then I think we both show our education, we show, you know, we show who we are, you know, I think there's this automatic assumption, I think. And you shouldn't have to wear your college degree on your shoulder, [0:53:00:04] you shouldn't have to -- you shouldn't have to be anybody about who you are, just your authentic self, we live in the south, you're going to hear that Southern, I shouldn't have to change the way I speak in order for you to listen to me, I shouldn't have to send you to our website for you to find value in what I say, you know, you shouldn't have to Google us and see that, you know, you shouldn't have to do all of that, you should listen to me because we're a family, we are parents, we have a kid with a illness that we want care for. And so it shouldn't have to -- I shouldn't have to start flashing all these different badges in order for you to respond.**Kareem Edwards:**  It's almost like you receive care based on some sort of social or educational status, right. If you're ignorant then you get [0:54:00:07] this much care, if you're a little educated you get that much, and then if you're black then you get this care right, so you're probably a single mom that's got a bunch of kids, oh well and then I get, are you the uncle or are you the uncle**Sarita Edwards:**  Brother.**Kareem Edwards:**  Or brother.**Blyth Lord:**  Have you had that happen? Have you had that happen?**Kareem Edwards:**  Not literally, but you couldn't get the vibe, it's the vibe for me.**Sarita Edwards:**  Well, we have had people walking to the room and, you know, and, I mean, you can look at a glass half empty glass half full, right, they walk into the room and I get maybe not wanting to assume who he is, but it's very much okay, now I'm sorry, who is this, who is this [0:55:00:05] like there's no assumption that he's the father or my husband, you know, it's just the I'm sorry, now who is this, it's very, I mean it -- And again, it feels like a shock factor.**Kareem Edwards:**  And it could be some level of objectivity. I'm a black man, so I feel like they're treating me a certain way, right, but you can't dismiss the vibe that comes with even one or the other that oh, you get a total dismissal, of all right, mom, all right, mom, all right, mom, all right, mom.**Sarita Edwards:**  And he's right there.**Kareem Edwards:**  I'm right here.**Sarita Edwards:**  I mean, if I'm completely honest, I do think [0:56:00:07] our race, you know, I do think being black played some part in a lot of Elijah's care. I think once we found a medical team that was willing to see him, a medical team who was willing to look past the Trisomy 18 diagnosis, and have those conversations with us, I think once we found those physicians, it really was having a lot of that champion infused care, you know, they were able to connect you, you know, to another doctor, oh, you know what, I think we need to see this person, and so they were able to speak on our behalf. And I think that did open up the door for us to have the medical team that we currently have, I don't know if we would have been able to accomplish that without those medical champions, you know, having a diagnosis like [0:57:00:09] Edward syndrome, because of the high mortality rate associated with it, a lot of times doctors will refuse you care before you're ever there. And so I think having a medical champion has played a huge part in the care that we have received, because somebody is speaking for us, before we ever get there. They're talking about Elijah and saying, you know, no, you need to see this kid, you know, you need to see what he's doing, what he's capable of, I see him and this is what I see, so they're opening up that door for us, making it easier for us to walk in. Without that, I do think race will play a part, I do think the diagnosis will play a part. And the two together without a medical champion, I do believe will be difficult.**Kareem Edwards:**  Lose, lose for us. |
| 6 | Title: *Our son’s team of medical champions (Trisomy 18).*<https://youtu.be/O5VD2pEAX18>Parents of a boy with Trisomy 18 describe his team of medical champions: the pediatrician, the plastic surgeon from his cleft palette who connected them with so many other specialists, the nephrologist, rehab specialists. The champions are those who connect them with other champions who really care and work it out for them. "They are ready to fight for him ... they help us know things that we wouldn't know, you know, watch for things that we wouldn't know to look for."TC: 58:20**Sarita Edwards:**  Our very first champion is our pediatrician, just because he was willing to confirm the diagnosis, he was willing to support whatever we wanted to do. You know, in all of his years of medicine at the time, it was 30 years, I think 35 years, and all of his years of medicine. He had had a couple other Trisomy 18 patients and Elijah was completely different. And so he was very much open to supporting any [0:59:00:02] conversations that we wanted to have. So he was our very, very first champion. And then we were connected with a plastic surgeon, a cranial facial specialist for his bilateral cleft lip and palate, who became the ultimate champion. We were connected with him because of an urgent, it was an acute situation, and it was one conversation with him. And he said, have you seen a geneticists, no, we haven't. You have a genetic condition and you haven't seen a geneticists he made a phone call, connected us with genetics, that connected us to ENT and audiology and speech and we were denied newborn screening, we were told that newborn screening was unnecessary for Elijah. [1:00:00:01] But after being connected with all these other doctors, we began to uncover diagnoses that newborn screening could have found from hearing loss and all these different things, it was that one doctor, our plastic surgeon, he connected us with so many other people, and that led us to nephrology for Elijah's kidney, he has one working kidney, Cholestasis just a bunch of different things. Our nephrologist, champion, she connected us with rehab medicine, she connected us, and is those champions who connect us to other champions who really care about Elijah's care. And now we have a team of people they will work it out, you know, for us to see several of them on the same day, because we make a [1:01:00:01] two hour drive, they will work with each other and say, okay, so I see you're coming this day for this, and I see you're coming this day for this, you know, let's put those appointments together, it'll be a long day mom. And I'm like, you know, what, if it's going to keep me from having to make multiple trips, let's do it. And we of course make sure not to overexert Elijah, but it really all started with aside from the pediatrician, it started with our plastic surgeon, our cranial facial doctor, and he just slowly just kept plugging us into people, plugging us into people. And to this day, he is a huge, huge champion and advocate for Elijah. They are ready to fight for him if we ever need it, you know, with one working kidney, we were concerned, if he ever needed a kidney, you know, they're going to shut us down because of this diagnosis [1:02:00:02]. And they're like, no we’ll fight, we’ll fight it, like just very -- not, we'll fight it. Those are the folks that we want to work with. So yeah, we've got some amazing people now who really, really root for him. And root for us as a, you know, as a family, they help us know things that we wouldn't know, you know, watch for things that we wouldn't know to look for, because we've not had a child with a special health need before. And so they prepare us if this happens, let's do this, if this happens, watch for this, is he doing this, simple things like sounds beat bah, bah, and da, da from his cleft repair, you know, things that we would just probably dismiss, they help us be on top of that. They ask us questions, we ask them questions, we have conversations. |
| 7 | Title: A little brother with Trisomy 18 and how the siblings cope.https://youtu.be/gRZ1ygTvE0IParents of a 6-year old with Trisomy 18 talk about his older siblings' adjustment, how they keep an eye on the siblings, and the siblings' protectiveness.TC: 1:05:50**Sarita Edwards:**  I think it started out really, really scary, especially for the three older ones, because they had experience being an older sibling before. For number four, this was a new experience for him. And so to know, oh, I'm about to be an older brother, but this is what's going on, you know, that's a lot to have to help him understand. And at the time, he was eight years old. I think our eldest kid was actually headed off to college, when we found out about Elijah. He was a freshman [1:06:00:07] in college. And I think for us, it was really trying to let him know what we were dealing with, because he knew that we were pregnant, we found out the day before we took him for tour. So he knew that we were pregnant, but to let him know what we were experiencing, you know, just in case something did happen, we didn't want everybody caught off guard. We did wait a little while before we shared, you know, what we were dealing with, but with our eldest kid, being a freshman in college, he was five hours away from home, six hours away from home. He was an athlete, you know, so Kareem actually reached out to the coaches, and told them, you know, this is what we're dealing with, you know, we need you to help keep an eye [1:07:00:06] on him because we're going to share this news with him. If he starts to behave differently or whatever, just keep an eye out and let us know because we're sharing this news. And now when he comes home to visit, you know, they have their own little big brother, little brother, you know, he's the oldest, Elijah is the baby, they have their own little conversation, he does a lot of snuggling with him, just because he doesn't live at home anymore. Our daughter is the only girl, it's four boys and one girl, so I think she's just an automatic nurturer. I think for her it's really, really important that Elijah is included, you know, if they have movie night or music or something, you know, she's very intentional about asking Elijah what he wants to watch, she'll even go through the trouble of, you know, letting him touch or if she's using [1:08:00:07] DVDs or something, she'll put a bunch of them down and let him pick something. She's just very, very intentional about him being a part of whatever they do.**Kareem Edwards:**  She reads books to him.**Sarita Edwards:**  She reads to him. She'll let him turn the page and, you know, she'll act like he's reading back when it's his turn to read. The other two boys, they are very much attached, I think one, I think they're both very protective, but the baby right before Elijah, he's like the bodyguard, he is very much, you know, he cares, if we're out and about and he noticed that somebody's looking [1:09:00:04] or if he feels like somebody is saying something, he is very on guard.**Kareem Edwards:**  He is ready to beat them up.**Sarita Edwards:**  He is ready to handle them. He is very much -- he is very much -- I think they talking about Elijah, you know, but I think for him, he's just very protective, because again, it's his first time being a big brother, you know, he was the baby.**Kareem Edwards:**  That was his first response, wait mom you having a baby, so that means I don't have to be a baby anymore, he was excited about it.**Sarita Edwards:**  Very excited. But I think I think for them, I think they appreciate each other more, you know, they’re siblings, they still go back and forth with each other, they'll talk trash to Elijah, you know, and let him be a part of it. But they try to respond, you know, if they're tossing the ball or something [1:10:00:06] Elijah will make gestures and make coos and different things. And, you know, we have to help them notice sometimes, hey, Elijah is trying to play, and so they're throw him the football or whatever they're doing to make sure he's apart, I think it's really, really helped them better understand inclusion, and the importance of making sure everybody is a part, I think it's raised awareness for them about differences and what it means to be different. And even though you're different, you might look different, you may sound different, but that doesn't mean you can't play, that doesn't mean you don't want to play, it doesn't mean that you don't want to be a part of the conversation.**Kareem Edwards:**  And moreover, that doesn't make you less of an individual as well, like, it's okay to be [1:11:00:06] different.**Sarita Edwards:**  It's okay. I mean, Elijah started crawling, and, you know, he would crawl to their room, and they would be -- you know, they would jump up Elijah, like, where are you going? It's the normal of, it's our normal, you know, and I think it's just giving them a better appreciation of each other, you know, we try to communicate at the level we think they can understand, you know, we don't try to withhold things from them, they know that Elijah has a list of challenges, if he has a doctor's appointment, they're asking questions, you know, what the doctor say, you know, did the doctor go -- did the visit go good, but they also know, you know, they know that we have to fight for care. Like, we don't keep anything from them, they know, that is a challenge, because we want them [1:12:00:08] to appreciate the journey, and the process of what it takes to be a family and to care for Elijah, and we want them to know that it's okay to speak up for him. You know, it's okay to speak up for yourself, but its okay to speak up for your little brother who's different. Especially being in the school system now and other kids are there, it's okay to help somebody understand the differences that Elijah has. And then, of course, tell the little guy you can't beat everybody up. |
| 8 | Title: *Finding support and the limits of disease-specific support groups.*<https://youtu.be/IU10vtRnGj8>Parents of a child with Trisomy-18 talk about why they did not find the Trisomy-18 group helpful and encourage parents to find people, in a group or otherwise, that helps them feel understood and supported, not judged or marginalized.TC: 1:13:50**Sarita Edwards:**  You know, I think I started out with a Google search. I did find some, you know, online Facebook groups, they were not for me, you know, they were not for me, you know, the conversations that were being [1:14:00:05] had, it wasn't what I was looking for at the time. And I remained in the group but I wasn't active. And then when I circled back as Elijah got older, you know, it still just wasn't for me. I found that even trying to respond to questions, there was this sense, it felt like anyways, this sense of competition, you know, I responded to a question that someone asked, and they wanted to, you know, follow up privately, and they were asking about purees and me, I'm thinking, oh, well, we puree Elijah's food, maybe I can be helpful. And they just completely disregarded me after they learned Elijah’s food were pureed for [1:15:00:05] oral feeds, and they were looking for purees for a GT. And that was never clear in their question, I was just trying to be helpful, completely disregarding me after they learned that Elijah was orally fed. I don't know, it was just this, it felt like I was putting up a lot of effort to be supported by a group that needed support. And so it just, yeah, so I'm not active at all in it. We found support from each other. And, you know, when we chose to start talking about it, we found support just from our church family, from our family, and, you know, our closest of friends. [1:16:00:06] Because we talked to the schools, we wanted all hands on deck, you know, so counselors at the school were very supportive, because we wanted them to be on top of if the kids were, you know, acting out at all. So we found support from them. That was our support. I think in terms of now, just as the foundation, we do try to offer that support, you know, that peer to peer support was already present in the Trisomy 18 space, so, you know, we're not trying to reinvent something, but if someone reaches out to us specifically, then we are more than happy to be that shoulder, we have been that shoulder, and whatever support looks like for them, we try to do that. But for ourselves, [1:17:00:05] we really just found it with each other, I think.And that's still our support system now, you know, just our faith and family. I mean, we have some really, really great, you know, family members and friends who support our journey. And, you know, if you ever need those moments to vent or something, you're having a rough day, and all that kind of stuff, you know, we do have, you know, folks that we can reach out to and talk to. You know, I'm the very first to say, I think it's said, and I say this, because of my experience, but then also from experience [1:21:00:00] that I've heard from other families with other rare diseases, other diagnosis, I think it's sad to have a community where you don't feel supported, you know, but I think it's great to have support from other sources, because I think it's human nature to have a diagnosis and want to find people with that same diagnosis, I think that makes total sense. But I think if you're not finding what you need in those communities, I think it's important to keep looking and find it somewhere else, it could very well be right there in your house, it could very well be, you know, another family, that mom who had the same experience as me with a totally different disease group, you know, she and I have connected to where, you know, we'll takes from time to time [1:22:00:07] to kind of check in on each other. And so, you know, I think that's just -- that's something that specific disease groups and organizations and communities can consider, our families feeling supported when they reach out to you or is it just an opportunity to say, you know, we have a community, we have a group, because it wasn't just me, it's happening.**Kareem Edwards:**  And think it's important to find, or to define support for yourself, and not allow somebody else to dictate what support looks like to you.**Sarita Edwards:**  Right.**Kareem Edwards:**  Yes. So like, this is a Trisomy 18 group, so I'm supposed to be in this Trisomy 18 group, for example. But I don't feel like the other people in the Trisomy 18 group are supporting me, [1:23:00:09] I feel like because my situation doesn't look like your situation, you're judging me. Like, for example, we've had a oh, well, your kid didn't have the kind of Trisomy 18 that my kid has, well, there is three different types [with this but #[1:23:25].**Sarita Edwards:**  My kid had the --**Kareem Edwards:**  The severe kind.**Sarita Edwards:**  My kid had the severe kind --**Kareem Edwards:**  Like what is that. They have full Trisomy 18, or you have partial mosaic, right. And so, in this case, both had full Trisomy 18, but because my kid --**Sarita Edwards:**  Responds differently.**Kareem Edwards:**  Looks different than your kid, oh, well, my kid, you can't relate to me because my kid had the worked up the bad kind, right, he had the bad Trisomy 18, you got the good kind.**Sarita Edwards:**  But I think that's, you know, just like, you know, [1:24:00:05] we talk to physicians and practitioners and, you know, we talk to health care spaces, but, you know, it's also room to talk to communities, because I think people think they're providing a service, and that could very well be the goal. But when you have a community of personalities, there's going to be some clash, and if nobody is monitoring, the conversations that are being had, it's easy for families to walk in and feel like yeah, this is not the space for me, because that's how I feel. And so I created, we through the organization, we created a space for the family who may be looking for something different, and if they find us, fantastic, you know, we'll be that support. But it's not to [1:25:00:08] dismantle what's already there, that's not our goal, it's just to be something different for the person who's looking for something different. |
| 9 | Title: *The EWE Foundation*: *Raising awareness about Trisomy 18 and offering support to Rare families*<https://youtu.be/75t5hW_MpM8>Sarita and Kareem Edwards describe the foundation they started to support families and children living with Rare disease in their community. https://theewefoundation.org/programs/TC: 1:25:10**Sarita Edwards:**  So our organization is the EWE Foundation, the Elijah Wayne Edwards Foundation, our goal is to just bridge the gap between diagnosis, delivery and care coordination. We do a lot of that by just raising awareness about Trisomy 18. We have grown so fast and so unexpectedly, we host community conversations through webinars, we actually got started during the pandemic, or right before the pandemic. And so we have been in the [1:26:00:03] virtual space, and it's been good for us, so we've kind of stayed there. But we do host webinars and conversations to kind of raise awareness about Trisomy 18 to really talk about advocacy and what that looks like, what it means. We do have some focus areas, child abuse and neglect prevention, you know, to just kind of speak to the reality that children with special health needs are more likely to be abused and neglected than their peers who are not. So we have different campaigns that we push and promote. We have our comfort care, which is a form of support for the family who may be looking for some one on one conversation, you know, not necessarily a group setting, we can provide those conversations, we have mental health support. You know, well, we just really go out into the community, we have a partnership with our local [1:27:00:06] school district to just raise awareness about mental health, our goal is to highlight the additional burden of mental health challenges that can arise and families with special health needs, especially when siblings are at play, because a lot of times parents are spending all of their time on the child with special health needs, and so it's very easy to miss something that one of your other children may be going through. So we really push mental health awareness and just normalizing those conversations, especially among youth. And then we have our financial support system for families with Trisomy 18, is really to just try to remove some of the financial hardship, the financial burden that comes with the diagnosis, we know that insurance doesn't cover everything, everybody doesn't have secondary insurance like Medicaid or another secondary policy. So we do try to offset some of the cost [1:28:00:04] that families may experience whether that's durable medical equipment, or, you know, a utility bill, because you're just struggling this month or something. And so those are a lot of -- those are the core programs that we have, we do have a few other initiatives that we do, know your family history, kind of like Kareem said, when we got our diagnosis, we started trying to question, you know, who in the family may have had something and we didn't know about it, so we do have a know your family history campaign as well, that just really promotes talking about family history, not being afraid to ask those questions about diagnosis that you heard, you know, your grandma talking about, or somebody talking about, but you didn't explore. And so that's really the premise. Then, of course we really building relationships with the healthcare system. We want to change the narrative about Trisomy 18, we want to use our story [1:29:00:04] for the healthcare system to see Trisomy 18 in action. And so we do raise awareness about Trisomy 18 in the healthcare space as well. we started out specifically for Trisomy 18. And, you know, just over the course of, we just celebrated our fourth year, just over the course of four years, we have found ourselves helping Trisomy 18 families, but also helping families with other special needs, rare diseases, or not, helping families, you know, navigate the IEP process through the school system. And that's [1:31:00:07] really how we build our program. And we look at where we are with Elijah, and, you know, this may be a resource that a family could appreciate, you know, understanding the IEP process, for example. And so we put that into the information that we share, and then that's just another community of people who find your resources valuable. And so we still are a rare disease organization, but we are providing support to anyone who needs it. |
| 10 | Title: *A couple’s advice to fellow parents: “Don’t do anything you’re not comfortable with; It’s OK to say to the doctor, ‘I don’t know, can you please give me a list of things to consider.’”*<https://youtu.be/twJgGrrFBQE>TC: 1:33:30hold on to your, I guess, in a parent's instinct, and not just follow, this is a medical professional, he knows what he's doing, and she knows what she's doing. So let's just do everything they say. But allow your parental instincts to kick in and advocate for your child.**Sarita Edwards:**  Because it's okay to do what they say if that's what you [1:34:00:07] want to do.**Kareem Edwards:**  Exactly.**Sarita Edwards:**  You know, and I think that's the, we're not forcing you to do it their way, we're not forcing you to be combative and demand something different, we're trying to help you know what your goals are, what do you want.**Kareem Edwards:**  Make sure you’re comfortable.**Sarita Edwards:**  And that’s what you communicate.**Kareem Edwards:**  Don’t do anything you're not comfortable with**Sarita Edwards:**  Know what your goal, and if you don't know what those goals are, it's okay to say, I have no idea what I want in this, tell me what my options are, you know, just helping parents know how to ask how to ask those questions, how to say I have no idea, you know, because sometimes doctors, if you push back, they do want to know well, what do you want us to do? And so just helping [1:35:00:01] families know that it's okay if you have no idea, you're not a medical professional, but it's okay to say, I don't know, can you give me a list of things to consider? And so just really helping families understand what advocacy really is, and helping them feel empowered to push back if they feel like this is not the outcome that we're looking for.**Kareem Edwards:**  Being effective in the conversation.**Sarita Edwards:**  Being effective, right. Because if you start yelling, and, you know, and sometimes you have to, but if you go in, in the right headspace, which is something our mental health speaks to, you know, go in in the right headspace, so you can deliver the conversation that you want to have, and you will get a response that you feel was beneficial to the conversation. You don't want to go in and just talk and they're not listening to you, you're not listening to them, because then the child suffers. So just go in in the right space [1:36:00:01] and be ready to have a valid conversation. |