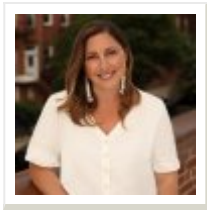


Premature Birth - What Does it Teach Us About Being Human

Sarah DiGregorio shares her personal story of going into premature labor, what she went through with a baby in the NICU, and what lead her into researching how NICU's came about.



Featured Speaker:

Sarah DiGregorio

Sarah DiGregorio is a Freelance writer/editor.

Transcription:

Welcome to the Peds Ethics podcast, where we talk to leaders in pediatric bioethics about a hot topic or a current controversy. Here's your host, John Lantos from the Children's Mercy Bioethics Center in Kansas City.

John Lantos, MD (Host): Hi. Welcome back. This is John Lantos from Children's Mercy Hospital in Kansas City, home of Super Bowl Champions Kansas City Chiefs coming to you with our Pediatric Ethics Podcast. A series that we do with interesting authors who write about interesting issues in pediatric bioethics. Today, we're thrilled to have Sarah DiGregorio with us. Sarah is the author of a book that just came out this week called *Early, An Intimate History of Premature Birth and What It Teaches Us About Being Human*. It's published by Harper and it's available on Amazon and we're going to talk a little bit about this book. You are not a doctor. You are not a bioethicist. How did you come to write a book about neonatal intensive care and premature birth?

Sarah DiGregorio (Guest): That's right, I'm definitely not a doctor, not a bioethicist. But very, very grateful to be here on your podcast and speaking to you today. I came to this topic actually because my daughter was born at 28 weeks and I – in the process of our NICU stay, and everything that came after it; realized that I had a lot of questions about how we have come to a moment in time when a baby like my daughter who was born as a result of intrauterine growth restriction so, she was a little bit smaller than average. She weighed 840 grams at birth and was at first in perhaps not good condition when she was born but quickly did very well.

I came to realize that babies like her are actually quite likely to do well now and from a parental point of view, it had seemed quite acute and very bad and of course it's not a good outcome but I was very curious about how we have arrived in this moment when it means that babies like my daughter are so overwhelmingly likely to survive and to do well. And in the process of that, I also had cause to think about the fact that I myself had been born prematurely. My grandfather was born prematurely and so it was this thread.

Host: How premature were you?

Sarah: I actually don't know exactly; I believe I was 32 weeks. Both of my parents passed away relatively young and I didn't have a chance to ask them about the details. I know that I was born very jaundiced and was brought to Woman and Infants in Providence and given an exchange transfusion. So,

I think that my parents must have had a lot of pain around that, that we actually never spoke about.

Host: And when you were – when your daughter was in the NICU; were there specific things that happened that made you worry or wonder or surprised you?

Sarah: I think at first the thing that really surprised me and scared me was just the way that she looked after giving birth quite suddenly and an emergency C-section to see a baby who is one pound 13 ounces, she was on a ventilator at first and on TPN and I had never seen a baby that looked like that. Our NICU was an open ward and so I was also sort of sitting next to her incubator but within arm's reach of three other incubators with babies in a similar situation. It was very overwhelming. It was like I mean I think a lot of parents speak to this, this sort of sense of being dropped into another planet with these human beings of a sort that you have never seen or imagined before. And it felt very powerful when I read actually parts of the Lazarus Case. It was the first time that I felt expressed me, the way that I had felt not only as a parent being afraid for my daughter but also the sense of like where are we? What are we doing here? This place is so powerful.

Host: NICUs are very bizarre places.

Sarah: Yeah and so and there were things about her stay. In general, we were very lucky. She had a relatively good stay. We were there for two months. At first, she continued to lose weight and that was a source of worry it seemed for the clinicians. But there were things that were routine about the NICU experience that I found terrifying and completely insane.

Host: Like what?

Sarah: Like bradycardia. It's like oh don't worry, that's normal. Your baby's heart will sort of slow to a stop and we'll kind of come over and be like, hmm can she handle this on her own, no, okay, we're going to just pat her chest now and get her heart going.

Host: Flick her feet and tickle her toes.

Sarah: Right and as a parent, that's crazy.

Host: Right? And the nurses are usually pretty casual.

Sarah: Yup, yup, your baby's heart is sort of coming to a stop. We're going to see how this goes now. This happens.

Host: Mira's your daughter's name?

Sarah: Yeah, Mira.

Host: And she was in the NICU for how long?

Sarah: For two months.

Host: Two months. And did she go home on medication or oxygen?

Sarah: Nope, she didn't go home on oxygen. It was an interesting experience going home. I struggle with anxiety in general and so this experience brought that out a bit.

Host: A bit?

Sarah: Yeah. When we went home, we were very lucky. She wasn't on oxygen. She was able to eat by mouth. We did discover subsequently that some of the challenges she was having was because she has hypotonia and so that's a challenge that has followed her. She's five now. She gets occupational and physical therapy for that but it's a very minor issue. It's really something that we've been able to manage with therapies. And subsequently, she was also diagnosed with asthma. Although at the time, it took us a while to figure that out.

Host: So, many parents who have had a baby in the NICU, once they get home, never want to think about NICUs again. And instead, you decided to write a book about it. Why did you do that?

Sarah: I think I wanted to maybe reassert some control over the situation. I had felt so confused and so very, very out of control of what was happening. I felt that there was a lot of context happening that I didn't understand. I felt that I was sort of dropped into a coloring book and it was all blank and I knew that there must be all this context around, and I didn't know any of it. Which I found very scary and it took me a while to want to revisit it. It maybe took me about eight months to sort of think like is this something that I could research and come to understand better.

Host: You're a writer?

Sarah: I'm a writer. A journalist, yeah. And I think I wanted – I wanted from the very beginning, to understand better but my attempts to understand better while we were in the NICU were often unsuccessful. Not necessarily because the clinicians didn't want to explain but also because I was having a hard time taking in information.

Host: A lot of parents say the way you think your baby is in the NICU is wildly different than the way you think the rest of your life. It's so emotionally overwhelming. Just short circuits. So, how did you decide to go about doing this research? Where did you start?

Sarah: I started by – I had written an essay about my experience and then realized that there were these – that really what my questions were, were generally how did we get here and what does it mean. And so I started sort of looking at as far back as I could find, I looked at the American Academy of Pediatrics interviews with pioneers of neonatology. I tried to call as many of them as I could find. And I wanted to understand where all this technology came from, who came up with it and people were in general, very open to speaking with me about it.

Once I started asking questions, more questions suggested themselves and I found myself going down rabbit hole after rabbit hole after rabbit hole and I really could have researched this book for the rest of my life probably.

Host: So, tell us about some of the more interesting people you met and what those discussions were like.

Sarah: So, I went to go see Dr. Maria Delivoria-Papadopoulos in Philadelphia, who is an amazing person and a fantastic conversation partner. I think one of my misconceptions was that especially as a lay person, I think maybe a lot of lay people might think this was an oh well researchers must come up with an intervention and then they test it. and then they are like oh it works, or it doesn't work and if it works then everyone starts to use it and the outcomes get better and then they do it again and that's how progress works. That's really what I thought.

Host: That's a beautiful story, yeah.

Sarah: And what was fascinating to me was to find out that it was just much more sort of lurching than that and the back and forth and the sort of disagreement about what should be done was very interesting and had more to do with culture and values and just all of our humanness than I thought it would.

Host: So, Dr. Delivoria-Papadopoulos was one of the pioneers, one of the first people to treat babies with positive pressure ventilation, mechanical ventilation. Did she tell you the stories with –

Sarah: Yes. So she told me – she started her training in Athens in a polio ward where she treated babies in iron lungs and so that was her background and so she had some background in treating in artificial respiration. When she got –

Host: For adults, right?

Sarah: I believe it was for children. It's was a children's polio ward, I believe. And when she got to Toronto to the Hospital for Sick Children, of course there were premature babies there and there was nothing really in the way of treatment for respiratory distress. And as she described it, at the time, positive pressure ventilation had just become available for adults undergoing surgery and she said, "Well why can't we use this for babies? They're having trouble breathing. This is being successfully used in other contexts, why can't we do it?"

And the people around her said no, that's crazy. It's completely untested. That would be experimenting on the babies. It's not going to work. And she just did not take no for an answer. And I was trying to think about how it came that she really just didn't give up. I think that she really felt like she could do more and that the babies were – that there was some kind of moral obligation she had to try these things.

So, they said to her, she told me, okay, you can try to intubate this baby, but you have to wait until five minutes after we declare death. So, she said, okay. So, she had gotten I think it was Bird, one of the early Bird ventilators and she had gotten a small tube from a friend who was a respiratory therapist. She sort of rigged it all up. She said okay fine, here I am with my machine. Call me when a baby dies. So, they called her when a baby died, she would wait five minutes and then she would intubate the baby and she had a couple instances where the baby would revive – and the heart would start beating again. Of course, those babies were too far gone, she didn't have any survivors, but she was proving to

the people around her that this was technically possible.

She kept doing it and doing it and doing it until finally, they said okay, at the moment of death, we'll let you do it. And so she did that until finally she had a survivor. And it was amazing to me to think about what that would be like to know that you are going to intubate this baby who has died and to know that you are doing it to prove something and for a greater purpose. But what that would take out of you.

Host: That is the whole ethical dilemma with medial research. You try desperate things on people who are dying, you don't know if they are going to work. Sometimes they have terrible consequences and you end up harming people or prolonging their dying and other times, you come up with a treatment that turns out to be beneficial and saves thousands of lives. It takes a lot of courage. Who else did you meet? Didn't you talk to Mellie Stallman?

Sarah: I did. I did talk to Dr. Stallman.

Host: Another pioneer.

Sarah: Another pioneer. She is 97 now and I went to the NICU that she founded. It was very, very wonderful to walk the halls there and have every single person say to me, oh my God you're going to go see Dr. Stallman. They have all these amazing stories about her, about her Christmas parties where she would have like spiced wine spiked with grain alcohol and then they'd go shoot mistletoe out of the trees. It sounded like a great place to work. But she was amazing. Because she was the first person to put a baby into a miniaturized iron lung and she is quite a character. She's known in Nashville as someone who left the trappings of her wealthy newspaper family behind. She was very single minded in her devotion to neonatology. And did a lot of research on sheep models and kept the pregnant ewes out on the courtyard, the hospital courtyard.

So, there were lots of great stories about her and I know she also really pushed forward the treatment of respiratory distress and I did go see her. And we had a short conversation but a good conversation. And she really was very much not interested in self-celebration. She said well someone else would have done it if I hadn't done it. I thought well nobody else was really doing that at that time.

Host: So, then in addition to talking to these pioneers, you talked to people who are working at the sort of cutting-edge of innovation today, right. I mean what is your sense of where the current controversies are in treatment?

Sarah: Well I thought about this a lot about where are the iconoclasts now. Who are the iconoclasts now? And I like to think of it less in terms of conflict because some of them are – all of them are moving in different directions but I think they – I'm not sure that they are necessarily in conflict. For instance, Dr. Bell in Iowa who runs a unit there, Ed Bell. He runs his unit there. Has made 22 and 23 week babies very low gestational age babies a focus of research and care. And they have reached a point where they can offer – the can recommend treatment to 22 week babies and they have a reasonable expectation of success. I find that really amazing and it's funny, because I actually was listening to one of Dr. Lantos's talks before, I went to go to Iowa to talk to Dr. Bell and one question I had was well how come? How come he can do this, and other people aren't?

And I think that there are lots of technical reasons for that. There are things that they told me that I'm probably less qualified to speak about with like high frequency ventilation and the way that they keep a very tight monitor on glucose and do a lot of – they take a lot of labs. But I think that the thing that really spoke to me and I found mind blowing was that they really believe that it's attitude and culture that is a big driver of their success. They believe that treatment for 22 week babies can be successful and so they proceed in that way. And that that has been just as important as their sort of clinical management.

Host: And in some ways, just as controversial as Maria Delivoria-Papadopoulos intubating a 36 weeker.

Sarah: Yeah, that real pushing of the envelope which some people find –

Host: Many other neonatologists say that they're crazy - we don't do that here. We don't want to do that, 22 weekers can't survive. Although my sense is the tide is turning and people are starting to accept that the Iowa results are generalizable, and the borderline of viability is starting to shift.

Sarah: Yeah, it does seem that way.

Host: Did you get to talk to the people who were doing the artificial placenta work?

Sarah: I talked to them one time and then they didn't want to talk to anymore. So I don't know if that was something about me or something about just coverage in general. It probably doesn't always cover artificial placenta technology and artificial technology in the most common deliberative way.

Host: That's a nice way of putting it.

Sarah: So, I did talk to Dr. Dysart at CHoP who sort of took me through some of their research and that was fascinating. And I do find a lot of echoes between the way that the incubator, the invention of the incubator was created to the way that the development of artificial womb technology is created. It makes people - clearly inspires some anxiety.

Host: So, knowing what you know now, do you think your way of being a parent of a baby in the NICU would be different today than it was?

Sarah: I would be much calmer.

Host: Yeah?

Sarah: Yeah.

Host: Because you would understand more?

Sarah: Yes. Because now I understand that I knew all the time that we were lucky. But now I truly understand how lucky we were to have made it to the point that we made it. I got two steroid shots. I know now in my bones, that premature babies do well. I also know that even when premature babies have challenges; that families do adapt. And that was something that I had very little understanding of

at the time. When someone tells you something like well you baby has a 50% chance of being disabled; what I heard was - what I imagined was not I think what the reality is. And so now I would have a much better handle on that.

Host: Say a little more about that, that Mira would be classified as having a disability?

Sarah: Right. Mira would be classified as having a disability and it's something that we need therapies for but it's not -

Host: Like you imagined?

Sarah: Yes and I know some people have a much harder road and I would never want to speak for their experience but I do think that generally speaking, what's important is that you are able to access the care that you need and the therapies that you need because families can really adapt to getting their children what they need and I was thinking the other day about would I want her to be different? Could I wish away her - do I wish away her challenges. I don't want her to have asthma. I don't want her to struggle with these things, but I don't want her to be different. I don't wish away anything about her. That was something that I learned.

Host: Do you have any advice for health professionals in the NICU? Doctors, or nurses?

Sarah: I think generally speaking, parents are very, very grateful to clinicians in the NICU because we know that you have save our babies lives. And so, we are intensely grateful for that. I think just to remember that the words that you use can sometimes stay with us for years and years and years. And so, what is your Tuesday afternoon, is the most intense moment of our lives. And so, when you say something like a 50% chance of disability; it would be very helpful either to not say that at all or especially when we are speaking hypothetically. Or to really say something like you know, let me tell you about outcomes for what a lot of premature - a lot of premature babies have motor delays. This is what that looks like. This is how their families handle it. And that would give you something to imagine and to hold on to that you know you can probably handle that.

Whereas if you just say she has a 50% chance of being disabled, your mind goes to these places where it's like what are we going to do. Will she have capacity for human relationship? And that's not at all what he meant. But I didn't know that.

Host: Yeah, maybe even just a little follow up conversation when I say disability, what you think about. Tell me your biggest fears. And let's talk about those. Well this has been a fascinating conversation. Thanks so much for dropping by to the Children's Mercy Bioethics Center to tell us about your wonderful new book; Early, an Intimate History of Premature Birth and What it Teaches us About Being Human. And it's available on Amazon, right?

Sarah: It is.

Host: And in bookstores everywhere. It is a great read, both for parents and families who have a baby in the NICU but also for doctors and nurses, many of whom I suspect do not know the history that you so beautifully explore and describe in this book.

Sarah: Thank you so much for having me. It has been an honor to be here and talk to you.

Host: Thank you for listening. I'm John Lantos, Director of the Children's Mercy Hospital Bioethics Center in Kansas City, Missouri. And this is the Pediatric Ethics Podcast.

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