

## Breathe, Baby, Breath: The Story of a Premie

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Dr. Annie Janvier shares her personal story of having her daughter Violette born at 23 weeks of gestation and spend some time in the NICU. Dr. Janvier discusses her book about what it was like to be a patient in the unit where she had long been an attending physician.



Featured Speaker:

**Annie Janvier, MD, PhD**

Annie Janvier, MD, PhD is a Professor of Pediatrics, University of Montreal.

### 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 to the Pediatrics Ethics Podcast. I'm John Lantos. We're coming to you from the Children's Mercy Hospital in Kansas City, Missouri and the Children's Mercy Bioethics Center. On these podcasts, we talk to experts in various aspects of pediatric bioethics and today, we are thrilled to have Dr. Annie Janvier who is an Associate Professor in the Department of Peds at the University of Montreal and a Neonatologist and Clinical Researcher at hospital Sainte Justine there. She's also the mother of Violette who was born very prematurely and she's written a remarkable book about the experience of being a Neonatologist and having a tiny premie in the NICU. The book is called *Breathe, Baby, Breathe!* It was published by the University of Toronto Press just last year. Welcome Annie.

Annie Janvier, MD, PhD (Guest): Hello, thank you for having me.

Host: Tell us a little bit about why you wrote this book.

Dr. Janvier: Well I decided to write a book that would have helped me as a parent and that could also help clinicians understand the parent perspective. When I had Violet, I was already a parent of a "normal term child." I was a Neonatologist and I was finishing my PhD in Bioethics. But I felt extremely lost as a parent as an NICU parent. I didn't feel like a parent. I didn't burst with love for my baby. I felt like I was in a totally alien world although I had spent hours in that same NICU. I mean I knew about the respirator, how Violette worked, the TPN but I really didn't know how to be the mother of a baby on a respirator.

Host: What do you think made it so strange and different?

Dr. Janvier: Well the world – I think it's a different disease to the NICU or a disease conditions because machines do what your body is supposed to do. I also had an incompetent cervix, but I was told not to feel guilty about that. And what really helped me is not my medical knowledge or any kind of facts that I knew very well. But the stories other parents had told me when I was a Neonatologist and I had

listened to how they felt and how they felt they were crazy and when is this going to end. And that really is what gave me faith that one day this tiny gelatinous blob would actually become a real child, my daughter. I mean I knew premies became real children, but I didn't feel it. And it's really the parents' stories that helped me.

So, I think by – I thought when I emptied my computer when I was changing institutions, I found that toxic shit folder that had many of the things I had written in these moments of distress, trauma or joy in the roller coaster and I realized this is what I used to help parents, some of these sentences. Some of them which had swear words and also stories of other parents. I didn't just want my story to be out there because it's a unique story and all stories are different, and all parents are different. So, I tried to have a blend of my stories, other stories and academic chapters.

Host: So, you were really keeping a journal while Violette was in the NICU, but you put it away for a while then came back to it years later?

Dr. Janvier: Yeah, I think I didn't really realize I was keeping a journal. I don't know I never saw myself like the Unicorn Diary with stickers at the end of the day. And I was actually writing to my computer and I actually don't remember writing most of the things I wrote. I think I was too much in shock or stress or distress and it was kind of I guess a release mechanism to speak about things I was afraid to speak about to others about.

Host: Yeah, that's pretty amazing. How long was it before you could open that folder again?

Dr. Janvier: I actually fell on it accidentally when I switched institutions and I was asked to empty my computer I found that Toxic Shit folder so that was three years later. A lot of it was written in English because my first language is French, but I think most of the things were too hard for me to say in English, I guess that's my interpretation. So, it wasn't even translated by me because it was too hard to relive some of these moments and some of the things, I said were very crude. So, it was kind of translated by somebody else and then readapted by me.

Host: What was the biggest surprise when you read what you had written and then forgotten about?

Dr. Janvier: Well some of the very raw and crude emotions, well some of the things are not published, it's just three pages of swear words so, some of the things were incomprehensible. Also what was hard to read is how I didn't love my daughter or the doubts I had that I loved her, how I didn't find her beautiful, how I didn't feel like a parent, how I didn't like to hold my daughter. Things we don't often speak about in the Neonatal world and that are very hard to actually speak about to say well I don't love my daughter is this normal. But when you actually tell parents it's normal not to feel like a parent, some of them will open up.

Host: Do you think that's because the NICU environment is so alienating, so foreign, so scary?

Dr. Janvier: Well I – that's what's funny is I didn't find it scary. I can intubate kids and I'm not scared of babies and I'm not scared of the NICU, it's my – where I work. But I think it's different. You kind of become a parent in a very abnormal way. You don't know your child yet. There's no relationship. It's very hard to bond. The child is not smiling, there's no reciprocity yet. And I think for other disease

processes that happens before a child has an accident but he's Thomas and he likes this and that and he likes to be soothed with that specific song and held in this manner and there's ways that you learn to be a parent with specific children that you become a parent of a baby who also looks strange because they are not very cute babies, the extreme preterm. And it's very hard to find yourself also in the situation where you know because of your body malfunction, your baby's there and now technology is playing the mother role. I think that's all important aspects.

Host: And in addition to writing the book, you've also done a bunch of research where you've talked to other parents. What have you discovered from that work?

Dr. Janvier: From the work of how they feel or the parental perspective?

Host: Yeah.

Dr. Janvier: Well what I've discovered is we're very factual in neonatology about describing – often describing the field and the children with deficits, death and disability as opposed to survival and quality of life. And what you ask parents about what is important; it's very different often to what doctors think parents think is important. For example, all the facts that we give parents wanting to help them in a standardized fashion; parents often want personalized information. What does that mean for them. So, for example, the percent risk of cerebral palsy is 8% when you are born less than 28 weeks. We'll try to tell this to parents using pictograms and but what does cerebral palsy mean for that family? And what family wants to know and what I wanted to know as a neonatologist and realized there's not many people who had examined that. There is Dr. Saroj Saigal who had examined that, is will she be happy? Will she have friends? Will she be independent? How can I be a parent of the disabled kid? What do other parents do? How can I prepare in a practical sense?

So, not just a tag of medical deficits but also the functionality, what it means for the baby and the family unit. In an optimistic fashion too as well as realistic to say you know it will be okay one day, you are stronger than you think, and you'll be able to rewrite your story. Because most of us are. But the way it works in neonatology is very pessimistic and scary. Even as a parent who knew all the statistics, it's always presented in a glass half empty kind of fashion.

Host: So, where do you start now when you are going in as the neonatologist talking to someone who is in labor at 23 or 24 weeks? What's your opening line?

Dr. Janvier: Well I say why I'm here. Most parents think they don't know what a neonatologist is. The think it's a kind of religion sometimes. Why I'm there doesn't mean that they'll deliver prematurely. Do they have a name? What do they know about why they are there? And why I'm here and what is important for them to know? And often with just these three questions we're able to have some kind of dialogue. But also what scares them the most? What can I do to help? And to actually personalize the consultation. Some parents want a lot of information. Other parents want just basic facts, what kind of parent are you and to personalize the decisions. I think we really rightly shun away from paternalism, hard core paternalism but many parents want us to be paternalistic and I think –

Host: In what way?

Dr. Janvier: Well many parents don't want, in my research for example, in trisomy 13 and 18 about half the parents didn't want to make life and death decisions.

Host: They wanted the doctor to make them?

Dr. Janvier: They wanted the doctor to make them or another family member or a religious representative or and generally the medical team. Though half the parents, the other parents some of them didn't want anything to do with shared decision making, they wanted to take the decisions on their own. And some of them wanted shared decision making but in fact, less than half parents wanted shared decision making, about 30%.

So, the way I engage with parents it's these decisions are very hard. It's normal to feel overwhelmed. Some parents say they can't take these decisions. They say it's for other persons to decide. Others say they want to make decisions on their own and others want us to make these decisions together. What kind of parent are you? And I think it's very – some parents other parents is important as opposed to do you want information. Or do you want to decide so that as a parent, you think okay what are they going to think if I say no, I don't want information and they are wanting to speak about my child, I look like a bad parent, so you say yes, then you don't listen to the information necessarily.

But by acknowledging parents are all different, and all the ways to decide or think are okay, and they are valid. Then parents feel like an opening, like oh if other parents take these decisions that way it's fine if I feel that way too.

Host: So, a lot more listening and trying to figure out what parents need rather than giving them percentages and numbers?

Dr. Janvier: Yeah and some parents want articles and data and websites, and these tools are I think important for these parents. But I find many parents don't want that. They also want to know what does that mean for me. One percent risk is deafness but what does it mean when you are deaf and what does it mean for a child and a family and a family unit and the school and the independence and these are really the questions that the functionality that comes about for parents as opposed to just the medical tag.

Host: Did you have any concerns about putting your story out there as a doctor? Knowing that maybe parents in the NICU would read about your own personal experiences and think of you differently?

Dr. Janvier: Well that's why I didn't put just – I thought it was unfair to put just my story because I don't want parents to think oh this is how I need to act to be a good parent. Because she's a doctor and she did this. Well and my husband is also a neonatologist so imagine like this is what you need to do. So, I thought it was important to put other stories for example the story of Gabrielle and EHUD and a lot of other stories that finish differently to balance just my story. What I found is interesting, yes, I was – I thought about that. Because it doesn't portray me always in a very good light or even as a mother and for my daughter too, I didn't want people at school to know all these things necessarily, so I waited for her to be older and to understand the book was coming out.

What I've realized is as that it for some people it increased my credibility and for many, it decreased it.

So, I'm now seen by a lot of pessimistic researchers as a very biased researcher who because I had a premature daughter, I'm unable to do unbiased research and to interpret it in an unbiased fashion. So, it has both helped and I guess perhaps harmed my reputation.

Host: Have you read the book to Violette?

Dr. Janvier: Yeah Violette actually read the book. At first, I told her about the book when it came out, she was too young to read it on her own. She has reread it since then. So, when she read it on her own, she was 13 and I remember her saying oh, geez Mom, this is intense and I'm like okay yeah. And what do you find intense about it? She said well at least I know that I'm living at the end so there's no surprises for me but imagine for others who read it. So, but she had heard about it before because we had questions about stopping the respirator, withdrawing the respirator and taking very hard decisions and insight there I say I don't love her at first and I don't enjoy being in the unit and holding her. But she knows I love her unconditionally now but she – I mean she – it was important to speak about it too before she read it.

Host: And that seems to be one of the main take home messages of the book that you go through a roller coaster of difficult emotions when you have a critically ill baby in the NICU, but they pass, and it doesn't mean you are a bad parent.

Dr. Janvier: Yeah, you're right. But it very hard to realize that when you are a parent in the NICU, and we can make it much harder as neonatologists of pointing out oh there's always a risk and there's a risk and oh your baby's fine today, but you know he can still be septic tomorrow. And we don't necessarily validate emotions of it's normal to feel crazy. Some parents feel crazy. You won't always feel disoriented like you do now for example. And out rigid care models can sometimes inadvertently harm parents. For example a nurse who says oh you'll take Violette in skin to skin, you'll love it. It will be so great. Parents they just find this is the best moment of their lives. Then you hold her, and you are like geez I hate this. I wish I wasn't here. I don't feel like a parent. Why don't I feel like this?

So, the whole world of for example the new parent integrated care can harm parents. I didn't want to present my daughter in rounds. I actually know how to present on rounds. I'm a neonatologist. I didn't want to give ASHBE to her. I know how to insert the tube. I'm a neonatologist. But I didn't feel that as a parent that was something I should do. But now we kind of format parents into knowing about CO2s and weight gain and empowering them to present their kid and be there at resuscitations and not all parents want to do that. A lot of them want to. But it's I think these rigid care models probably make many parents disappear like I did. I disappeared. I just showed up at change of shift for the first month of my daughter's life because I was afraid to be asked to do yet another thing I didn't want to do or be told that parents love to do whatever I didn't want to do.

Host: So, is that the main take home message here for doctors and nurses? Don't try to put parents in a box? Let them tell you what they need?

Dr. Janvier: Well that's one of the take home messages. Parents are all different and that's the sentence some parents, other parents is very important like some parents want a lot of information and others just want to know the crude numbers of the day and if this is normal for a 26 weeker, what kind of parent are you. Listening to parents, acknowledging emotions too and validating them.

Host: So important.

Dr. Janvier: And I think for clinicians, empowering parents into what they can do and how they can reorganize their routine to what they can control and what they can't control. And I think that was the most important thing as a parent is perhaps parents want to know all the facts as they feel they can control something, but the facts don't help you control if your baby will have a high CO2 or not. But you are able to control if you are there if you pump your milk, if you sing to your kid, if you change the diaper. When you go home, how you can have coping mechanisms that are healthy for you. There's a lot of things you can control, and I think empowering parents and recognizing their strong validating their emotions and making them realize what they can control can be very beneficial.

Host: Well thanks for those lessons and thanks for writing the book. The book is called Breathe, Baby, Breathe! It's published by University of Toronto Press. And we've been talking with Dr. Annie Janvier, a Neonatologist, Clinical Ethicist, Author and mother at the University of Montreal in Hospital Sainte Justine in Montreal. Annie, thanks so much for talking to us today.

Dr. Janvier: Thank you John. Thanks for having me.

Host: This is John Lantos from the Pediatric Ethics Podcast coming to you from Children's Mercy Hospital in Kansas City, Missouri and the Children's Mercy Bioethics Center. Thanks for listening.

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