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A NICU Parent's Passion and Perseverance

Developed by Jennifer Degl and Jenn Bhatla for PedsCases.com.

November 1, 2020

Introduction:

Jenn: Hi everyone, my name is Jenn Bhatla and I'm a third-year medical student at the University of Alberta. This podcast was developed with Jennifer Degl, who is a parent of an NICU baby and an important advocate for maternal and neonatal health. She has spoken at many international conferences and sits on the board of directors of the NICU parent network, among many others. We are really lucky to have Jennifer with us here today.

This isn't our typical PedsCases podcast as we are going to be talking about the NICU from Jennifer's perspective as a patient and a parent. We are really lucky to have her here to share her story with us.

Our learning objectives for this podcast are to:

- 1) Gain an appreciation of the parents' perspective on NICU.
- 2) Identify challenges the family may face with a child in NICU and on discharge from the NICU.
- 3) Identify some resources parents can access while the child is in NICU.

Jennifer, I'm so excited to have you with us here today. Let's start with getting to know you a little more. Could you tell us more about yourself and your family?

Jennifer: Sure. Thanks for having me today, I really do appreciate it. I'm a mom of four. My oldest son is 14. I have a 13-year-old, a 10-year-old and a seven-year-old. My seven-year-old was my premature baby. I am a full-time science teacher at my local high school. I teach mostly science and biology courses. My husband runs a gym, a wrestling school inside the gym, and we recently got two dogs.

So, it's a little bit crazy at our house. We had our three boys and then we had decided to have a fourth child, and that's where our story began.

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After I had my daughter, and we'll get into all those complications and our journey from there, was a few months after she was home from the NICU, most parents are questioning why did this happen to me?

Why did my daughter have to suffer so much pain? You know why, why, why? And I realized that I had this calling inside me. All of that happened to us to help others. So, I started to write, and I wrote one book at first called from hope to joy. And after that a whole other world opened up to me.

It was pretty well received, and I started getting invitations to talk and share my story. And then I realized that it's so important to have a parent's voice almost everywhere. I'm happy to share my perspective to advocate for maternal health issues and inequalities, but also to advocate for neonatal health and particularly family centered care.

Jenn: Thanks, Jennifer. It's amazing how much advocacy you do. That's wonderful. And it sounds like you have a really nice family. I'm excited to learn more about your family and all your experiences. Let's start with before your daughter was born, what was your pregnancy like and when did you know it wasn't going to be an uncomplicated pregnancy?

Jennifer: You know, it's interesting because it was almost immediate. I didn't realize it would be as complicated as it was, but I did ask the question after I had my third child, how is my uterus? We wanted to have another child eventually and after three C-sections, all I was told was it was a little bit thin and I really didn't know what that meant having no medical training. So, we just decided we were going to have another baby.

Almost immediately, to get back to your question, I was spotting, and I was spotting a little bit more than I was with my other pregnancies. I had gone to the doctor, at first they told me it was going to be an unsuccessful pregnancy, but it didn't end. And then they told me that, maybe it was a touch of placenta previa and they could resolve, but that didn't happen.

I was on a field trip with my students. I hadn't been put on bed rest. I wasn't given any orders to modify any of my activities, and it was an overnight field trip, to these mountains. We were in cabins and that night, in the middle of the night around 1:00 AM when I had these 14 freshmen girls sleeping in a cabin with me, I felt liquid. And I thought something was obviously going wrong, but there wasn't any pain. And I turned on a flashlight and saw that I had been hemorrhaging.

And that was very scary because I wasn't near any health centers or friends or family or medical professionals. I did wake up one of the girls, told her I had to go to the hospital and I had to walk to my car. There was no cell phone signal, so I couldn't call

another adult in another cabin, and I couldn't walk to another cabin without banging on the door in the middle of the night and wake up a bunch of probably frightened children. So I went to my car and I went to the hospital and that was the first of four hemorrhages that I had. And that's where it started. And then we got a lot of bad news on that first hospital stay.

Jenn: That would have been a really scary experience.

Jennifer: Yes. It was beyond frightening. And I was in shock too, because I think a normal clear-headed person would stop as soon as they could get a cell phone signal and make calls. But I had lost so much blood and I wasn't thinking, and I just drove myself 40 minutes to a hospital. I did eventually call my husband on the way and he came. It was very frightening.

At that point I knew it was very serious because it took days in the hospital to stop the bleeding and some blood transfusions, just a few this first time. That's when I got the really dire news that this pregnancy either wouldn't last very long or could take my life.

And that started a very fearful six weeks. My daughter was born at 23 weeks. It was terrible.

Jenn: That sounds very scary. Thank you for sharing with us everything that's happened. What was it like for the rest of your pregnancy? You mentioned earlier being on bedrest, what was that like?

Jennifer: That was terrible. I've written about it several times. I call bed rest my enemy. It was excruciating, especially for a person who is always on the go. You can't do anything from your bed, but talk, perhaps watch movies. But I was in a state of depression from that. Because my life was in danger, it might be a little bit more heightened than other pregnancies on bedrest.

I really had a hard time. I was depressed. I didn't want to talk to anybody on the phone, I'll fully admit that. I didn't want to see anybody. I wouldn't let my husband let anybody in the house, except for my children who I would allow. Part of the time I was home and part of the time I was in the hospital. When I was in the hospital, I would only let my children come once or twice because it was a lot on them. They were so little, they were three, five, and seven. And my three-year-old is quite rambunctious. And he would be the one pulling out everybody's wires and running around yelling and whatnot. But it was hard. I was put on bed rest after that three day stay in the hospital at 17 weeks, and a few bags of blood.

Jenn: That sounds like a really challenging experience, I can't imagine. And for six weeks with little kids, that sounds very hard.

Jennifer : It was. It was.

Jenn: Do you have any recommendations for a mom who's on bedrest?

Jennifer: I do. It's difficult depending on who you can have around you. I wrote a second book about being on bed rest. It's called stuck in bed, and it's a children's book, and every page has a different activity you can do with your kids in the bed. That's what really struck me, more than anything else, was missing them. So, we did a lot of watching movies in the bed we would eat special snacks. I had my husband or my parents buy one of their favorite things they could only have if they were doing time with me in the bed. We did a lot of arts and crafts. We would try to do homework. I would have the kids do little exercises on the edge of the bed. I had asked the kids to write little journals of what they did every day with me in the bed and kind of keep them active.

You know, luckily now more than even seven years ago, it's so easy to have video so you can have the kids even doing things on their own or outside or in other parts of the house and sharing video with you so you still feel connected. And now we have zoom and all of these things that we didn't even have.

Jenn: Thanks. Those sound like really good suggestions. Our technology now is great. You mentioned your daughter being born at 23 weeks. What was that like for you and what was delivery like?

Jennifer: I was able to get the steroid shots at exactly 23 weeks. And then my daughter was born two days later. I went into labor and I was really in a place of emotional shock. I didn't even call my husband until a few hours in labor, after the magnesium, after all the things they were doing to try to stop the contractions. They finally said, we have to deliver the baby. I didn't want that because 23 weeks is way too early and I kind of refused at the moment. And then they kept coming back and saying, we have to, we have to. The last thing I remember is them calling for blood. I heard them calling, "we need more blood, we need more blood". And then, they strap your arms down and then they put a mask on me. And that was it. I didn't wake up for a few days, so a lot had transpired by the time.

It turns out that I had what they call placenta percreta. My daughter had perfectly implanted herself on my scar tissue, from my previous three C-sections. And the placenta grew right through it. Just kind of used it as an opening and grew right through the scar tissue and the entire placenta had attached to my bowels and my bladder. After her delivery and about 35 units of blood, they had separated the placenta from my bowels and my bladder and then put them back.

During that time my husband was able to go see my daughter in the NICU. She was born at 575 grams. So that's about one pound, four ounces. She was 11 and $\frac{3}{4}$ inches

long. When I tell her story, I say she was not even as long as a typical ruler. She was intubated fairly quickly and taken off. There she spent 121 days. They saved my life, and they were able to help her grow and thrive. And we're so very lucky. When she ended up coming home, she was seven pounds, eight ounces. After those four months, the first two being very critical.

Jenn: That would have been such a scary experience. Thank you for sharing all of this with us. What was it like for you and your family to go through that time with her in NICU and you recovering as well at the same time?

Jennifer: It was really challenging, and we did have a lot of help. My parents and my in-laws live in the same town, but it was very hard. The younger kids had already been dealing with me being primarily in the hospital a little bit at home. But even when I was home, I was in a bed and that went on for six weeks. Then you have to be there in order to be the best advocate you can be for your baby. And it's so important to participate in any of the care activities that you can or that you're allowed to be in. There's things parents notice, because they're with their babies every day. Slightest change in color or behavior and all those things really are important.

My daughter was born in May. In school we finish mid-June. For the first couple of weeks, I couldn't drive. I had to rely on other people to drive me 40 minutes to the hospital and that was really hard because I don't like having to do that to other people or be on their schedules. And after that, I signed up the other three kids for camp. I would bring them, Monday, Wednesdays, and Fridays, spend a day in the NICU with my daughter. Then I would pick them up and give them dinner, a bath, put them to bed and have one of my parents or my in-laws come back at around seven and go back to the NICU until one or two in the morning. Tuesdays and Thursdays I would spend the day with the boys until maybe two or three in the afternoon and then leave and then stay in the NICU until one or two in the morning. She was more stable at that time, but it was really hard on them. There are days we tried to make it as normal as possible, but of course it's not. And they notice mommy's not there and daddy's not there and everybody is stressed, and everybody's upset.

There were a lot of close calls for my daughter, especially in the first four weeks. And everybody is having an emotional response that we come in contact with. And that I think is really hard for kids. My son, who was three, he's now just turned 11 a few days ago. He still remembers it.

We made it work as best as we could. What's also very hard for most moms, if they can, is pumping all the time because it's important to have breast milk, particularly for premature babies. That is very time consuming, especially if you're somebody who doesn't make a lot of milk. I really was terrible at it with my other three kids, but it was so important for my daughter. Every two hours I would have to stop whatever I was doing with the kids and sit and go and pump and try to get whatever I could get to go

bring her for her feeding tube. So even when you're doing something fun with them, you have to stop and interrupt it to go and pump. And they remember that too. And forget about relationships. I am still married, but it was really hard to manage all of that stress. And I think everybody handles it differently.

Jenn: Thank you for sharing all this with us, that sounds like a very hard balance with three kids at home. During that four-month period while Joy was in the NICU, what kind of procedures did she go through?

Jennifer: She was septic twice, that was early on. The first or second day that I could drive to see her, I had turned around to come home and within like two or three minutes, I had gotten called to come back. We are super lucky. She did not have a brain bleed that was detected. We think she did have a smaller one, and I'll talk about that in a minute. She never had necrotizing enterocolitis, which is amazing, and I do attribute that to being able to give her breast milk. There was a feeding tube, for three and a half months, and then she started to grow and eat more. She had a PDA but it did close with the second dose of indomethacin. And she did have retinopathy or prematurity. She still has effects of that today, with glasses. But she didn't need eye surgery.

She needed a lot of blood transfusions. She was on a ventilator for almost three months. Which is a lot of the reason why today she is living with bronchopulmonary dysplasia. She has a lot of lung issues, but she was on a ventilator for quite some time. She did self-extubate accidentally and had to be re intubated. And that was really very scary. And in fact, the first time that happened, I will never forget, because they kept coming out saying they were having a hard time reintubating her for whatever the reason it would be. She also needed, I'm forgetting what it is, but it is a like a central line near her heart. And they had a very hard time with that. That took about five different people to get that in. I remember that they saying they had to give her more fentanyl. She was reacting to that. She had so many x-rays, many rounds of antibiotics. We thought the first time that she would die from this blood infection. They couldn't get it under control for several days. but she did turn the corner on that, thankfully, and that was, that was very, very scary.

She never really mastered the art of eating. We had feeding therapists for years and speech therapists and occupational therapists. I don't know if a lot of her issues with feeding, she still has them with textures and whatnot, is from the intubation and extubation. There might be some scar tissue in there. She had lines in her stomach at one point too which seems to have affected her abdominal area and her muscles. She's got a very weak core. So a lot of these things we weren't even aware of that there would be effects until later on.

I think if NICU parents or our neonatologists listen to this, is that it doesn't end when the baby is discharged. Yes, that's a milestone and it's amazing. But once you're

home, there are complications that follow each and every baby and they're all different and it goes on for many years. Hopefully, eventually things all catch up and sometimes they don't.

Jenn: It sounds like you have an amazing, really strong family and really strong daughter.

Jennifer: She's very tough. She is definitely the toughest little girl I know. Still to this day.

Jenn: Definitely a tough little girl! As a medical student or as other healthcare providers, is there anything we can do to support parents and the babies in the NICU?

Jennifer: You know, there is, I mean, family centered care was always important and it's coming up now, in the last two or three years as something that should be encouraged, but it's so important. It's not only important for the baby, you could find research on how babies have a shorter NICU stay and they're developmentally ahead when they have a lot of parent contact and participation. But it also helps the entire family.

To go back a bit, and I didn't mention before, I did not get to hold my daughter until she was over one month old. She was that critical. And I was that mom that would stand on the side of her plastic box, that I call it, and just look at her and I could stick a finger in, you know, a freshly sanitized finger on occasion when they would let me, and she could hold my hand and I could talk to her. But I wasn't able to even touch her for one month. And that really is a problem for a lot of reasons because it really prevents the bonding. I didn't feel like her mother, I didn't feel like her mother because I wasn't doing anything motherly other than pumping for her, which was important, but it wasn't enough. You have all of these other people in the hospital and staff that do everything and take care of your child. You are your child's mother and you can't do it yourself. And it really does slow down the bonding between a mother and a child. And the same for the other spouse that maybe can't be there enough. So I think it's really important for the staff to understand that you need to involve the families as much as you can. If the parent, in irregular times but not non-health crisis, can change the diaper, or just participate. I'm a big proponent of giving the parent a job, every day, look at their baby's color. Look at the baby's behavior. If you just ask them, what do you notice today about your baby? Is he or she more active, a little bit less active? It may mean nothing and you might not write it down, but you're then asking the parent to be involved in something and they feel that they are involved and contributing. And sometimes just that feeling is enough to help the bonding of the family.

I never will forget the first time I got to hold her. It only lasted a few minutes because she started de-satting and things were beeping, but that was the first moment I actually felt like her mom, and it's so important.

Jenn: Jennifer, thank you for sharing all that. It's good for us to know. I really appreciate your advice. Once your time in the NICU was over, you mentioned things not being over when you go home. What was it like to be discharged and go home?

Jennifer: Oh, it's very frightening and happy at the same time, you're happy because your baby's healthy enough to come home. You get to take your baby home, and of course you feel that, but quite honestly, it is very frightening. For four months, for me, but it could be weeks or more months for other families, you have the knowledge that other people are keeping your baby safe, that they are looking out for changes in breathing. They can see everything that's going on with your baby, and then you're sent home. Some families are sent home with equipment. Some are not. Even if you have your own equipment, it is now your sole responsibility to care for your baby. And after such a traumatic experience, you really are in heightened alert and you don't relax. I actually put a bed in my daughter's nursery and I slept in her room for eight months, every single night. I was so afraid to leave her. She did have a lot of complications and a lot of reflux, and she would gag. She had aspirated. I had her sleeping on an incline, but I would stare at her almost the entire night and then kind of not even sleep until the next day when somebody could be with her and I could take a nap.

You're not having people over, and if you're going into the fall and winter season of illness, you're even more afraid. You're isolated. You don't take your baby out unless you absolutely have to. Nobody touches your baby. You have sanitizer in every room. If one of your kids, or your husband or your wife sneezes, they can clean their hands immediately. You have signs at the door, leave package here. You don't show up to birthday parties or whatever holiday you celebrate, because if somebody's ill, your baby can catch the cold, which could give them pneumonia. My children never had a play date in our home up until like two years ago. It's really isolating.

My children would change their clothes when they came home from any place, doesn't matter where they were. Wash their hands. If one of my kids were sick, then my daughter would just stay in her bedroom and never come out until the other kid was better. And we cleaned the house. We didn't have visitors. In my opinion, we did everything we could do and she still has had pneumonia eight times in her little short life.

The first time she had pneumonia, she was eight months old. She was back in the hospital for two weeks in a pediatric ICU and she almost lost her life. I mean, talk about trauma coming in, PTSD. Then here I am back in there again for two weeks, not leaving her side. And then she catches another virus, or fever spikes the day we're supposed to go home. And she had gotten the rhino virus in the hospital and then we were there for another week, so three weeks at a time. And that happened a few other times. It doesn't end. That's just the medical aspect and the mental part of it. Most

babies have to see specialists. We were very lucky. We had the interventions come to our home.

Right away she had a physical therapist, we had a visiting nurse right away that would come. It was the first three days a week. They would listen to her lungs. We had speech therapists, occupational therapists, we were seeing a physiatrist, which I had never heard of until I had my daughter. She never crawled, she wasn't really walking and when she would sit up in a chair, her right hand would be halfway up in the air, like she was leaning on a table, but she wasn't. She was like that until she was almost two when she walked. Finally, the hand went down. The physiatrist and the physical therapist said that it's probably because of all the stomach tubes that she had. She has such a weak core.

That's how she was balancing herself when she was sitting, until she could walk. We had the fear that she would never walk because she was almost two. For years, we are dealing with delays. In the grand scheme of things, everything does happen eventually, I guess it did for her. What is excruciating as a parent, she's not talking, she's not crawling. She's not walking. She's still choking. She can't swallow different foods. You have all these interventions and people coming in and out of your home. And we're so lucky, but it goes on for years. And I think that's important to know. It never would hurt to ask the family. How they're coping with interventions and if they need help. Let them know, it's quite normal to have these babies take longer to catch up.

And it's quite normal to be upset about the life your family once had that you no longer have for a while because you have to make these concessions.

Jenn: Thanks Jennifer. That is really good for us to know. That sounds very challenging How's she doing now?

Jennifer: Now, she's doing great. We did hold her back in school because of her delays now. If you were to see her, she's quite tiny, but you know, genetically she did not have a lot going for her anyway because I'm only five, three. She's probably the height of a four to five-year-old and she's actually turning eight in May, so she's quite tiny. She also is still behind in her academics, which is fine. We're catching her up. She's just starting to learn how to read two, three letter words now. She should be in second grade. We have her in first grade. Socially, she's also on the younger side, it could be because of her premature birth and all of that, or also could be because she really, unfortunately doesn't socialize in a large class. She goes to dance when it's nice weather and there's no flu going around or anything else. She goes to a small school of only six kids in her class. We tried a bigger school and she was sick like twice for a very long time, so I had to switch her schools to a private school where the teacher will call me and let me know if another student is ill. Then I just keep her home. Everybody's life has been modified and it's, you know, 1000000% worth it

health wise, it's really just her lungs that are still quite compromised. She has bronchopulmonary dysplasia, which will never go away. We have the rescue inhaler, but she still does have every day a regular two doses of inhaled steroids. She does have some issues with her core still. She can't do sit ups, she runs differently. I'll put it that way. If she can run, it just looks a little bit different than the average runner but she loves everything. She loves to run around. She loves to take ballet. She just gets very short of breath with any exertion. Considering all that's happened to her, I think that's fine. She compensates, she learns to deal with it. She doesn't even think twice about her inhaler anymore.

So she's quite strong and she's the boss. She bosses everybody around in this house. So her personality is fine.

Jenn: That's great. Even with three big brothers, she's the boss of your house?

Jennifer: She bosses them around and they listened to her, which is crazy.

Jenn: That is crazy. She sounds like one amazing girl.

Jennifer: She is.

Jenn: Thank you so much, Jennifer. I think you and your family are incredibly strong and I really appreciate you sharing your experiences with us and answering all our questions, and I think hearing your perspective as a parent, it's also just so valuable for us as learners, to appreciate it a little bit more, what people go through.

Thank you for coming today.

Jennifer: If you're looking for more information, you can always visit my website, speakingformomsandbabies.com. And I'll have some of my writing pieces and other current information on what's going on in maternal and neonatal health on there.

Jenn: You can also find the script to the podcast and links to some of the resource Jennifer mentioned on our website as well. Thank you for listening and stay tuned for more great podcasts.