Clinical Lactation

Official Journal of the
United States Lactation Consultant Association
USLCA
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Hope From Ashes

The Creation of the NEC Society—An Interview With Jennifer Canvasser

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Jennifer Canvasser has served on the Ecology Center's children's health, first food, and environmental health campaigns since 2010. She completed University of California, San Francisco's Reach the Decision Makers Fellowship program in 2011, with a focus on reform of the Toxic Substances Control Act. In 2014, Jennifer founded the NEC Society, a nonprofit organization, after losing her son, Micah, to necrotizing enterocolitis. She is a regular contributor to The Huffington Post *on parenting, health, and food justice issues. Jennifer completed her undergraduate studies at University of California, Los Angeles and earned her Master of Social Work from the University of Southern California with a focus on community organizing. This interview with Jennifer Canvasser was conducted in May of 2015 by Barbara D. Robertson and Barb Demske (Barbara Robertson's intern). Barbara Robertson has a podcast, "All Things Breastfeeding," available on iTunes or her website, bfcaa.com.*

Keywords: necrotizing enterocolitis (NEC), human milk, breastfeeding, preterm infants

BD: Do you feel that mothers of premature infants get adequate support and information on the importance of human milk?

JC: That's a great question. Just to share my story a little bit, my twin boys, Micah and Zachary were born 3 months early in January 2012. They were born emergency C-section and I immediately, when I was in the recovery room, asked for a breast pump. I had never even seen a breast pump before. I didn't know what to do with it. But I knew I needed to start pumping milk for these teeny, tiny babies. They were born weighing just about 2 to 2.5 pounds each. My nurse said no. She refused to bring me a pump. I was crying and begging at this point, "Please bring me a pump, so I can start making milk for these babies." About 3 hours later, they finally brought me a breast pump. They didn't show me how to use it. So my husband and I had to figure it out . . . About 24 to 36 hours go by and I am pumping around the clock, every 2 hours, trying to get this milk going . . . The babies were born at 27 weeks and 5 days, so very prematurely . . . and my milk wasn't coming in . . . I was told they had to be fed my milk or formula, and if you don't have milk, this is what we will be feeding them . . . I didn't know anything else. I didn't know there was a HMBANA (Human Milk Banking Association of North America; https://www.hmbana.org). I didn't know other mothers could donate their breast milk for fragile babies just like mine . . . That was very troubling. (Later, I found out this was an option as I went online and started doing some research.) Obviously, I didn't plan on having premature babies, so I didn't know what to expect and how to prepare myself for this situation.

BR: The babies needed some formula to start, and you were working on your supply. What happened after that?

JC: It is really interesting because I somehow intuitively knew that my babies needed my milk. It's not because I knew they were at risk for some type of disease or infection, like necrotizing enterocolitis. I had no idea what that was. I just knew they needed my milk. But no one told me they could die from not receiving my milk.

BR: NEC, or necrotizing enterocolitis, that is a disease that babies, especially immature babies, ones whose guts aren't very well formed, can get. Tell us what happens with that disease.

JC: Tragically, it actually happened to my son, Micah. When premature babies are born, their immune system, and their intestines, their guts, and their entire systems are not mature, so they cannot properly metabolize and digest formula and things other than human milk. It puts them at risk of severe inflammation, and pieces of the intestines and the gut can die. That's what happens with NEC. It's a severe, severe, inflammatory process that can cause intestinal death and disease. That's what happened to Micah. He developed NEC when he was about 6 weeks old, and from there developed many different life-threatening complications as a result from this very severe infection from the disease.

BR: And sadly, research and best practice shows that either the use of mother's own fresh milk, which is ideal, or mother's own pumped milk, which is our second

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Clinical Lactation, 2015, 6(4), http://dx.doi.org/10.1891/2158-0782.6.4.156

choice, but then the third choice is not artificial baby milk, formula, but it is actually banked human milk, and we know from research when we use this, the odds of the babies developing NEC are much lower.

JC: Right, researchers actually show that an exclusive human-milk diet and human milk can reduce the odds of NEC by 80%.

BD: I would like to hear a little about why NEC is so devastating. Most people don't know what it is. Can you tell us about how Micah was diagnosed and what you were told what happened?

JC: Necrotizing enterocolitis is actually the 10th leading causes of overall infant mortality in the United States. It claims the lives of about 500 infants every year the U.S., and it impacts thousands more. So the thousands of babies who don't die from NEC suffer from life-long complications. That's through short-bowel syndrome and many other complications that can result from having NEC.

BR: It not only takes an emotional and physical toll on families and babies but it's also incredibly expensive for hospitals. Research shows that spending the money on banked milk will save them money on care.

JC: Absolutely.

BR: So tell us a little bit more about your experience. What actually happened?

JC: Micah started to develop some feeding intolerance. He was receiving my milk. Fortunately, I was able to build up a supply to support both Micah and Zachary but [the hospital] insisted on fortifying it. Fortifying sounds very benign, so a mom in the NICU, like myself, I didn't know what it meant to fortify my milk. I thought it meant just adding a few vitamins or something. When I started to ask more questions, when I saw Micah and Zachary were just on my milk, their bowel movements were different, their breathing was different. When they added this "fortifier," things changed. They were breathing differently. They were acting differently. Their bowel movements were different. And I asked, "What is this fortifier that you're adding to my milk?" And they showed me and it was this little packet of Similac. It's formula! It's formula they are adding to my milk!

BR: Right. And their justification is that babies need extra minerals, babies need extra calories. They want the babies to grow. Their main focus is grow, grow, grow. But there are also different kinds of human milk fortifiers aren't there? It's deceiving. When you hear "human milk fortifier," you think, "Oh, it's made from human milk." But in fact, that's not usually the case.

JC: You really touched on it right there. I was shocked when they called it human milk fortifier. Then come to find out, it's not made out of anything from human milk. It's a bovine-based formula feed being added to my breast milk. It's incredibly deceiving.

BR: But there's also an option of human milk, human milk fortifier, but it's very expensive.

JC: Absolutely. That would provide babies with an exclusive human milk diet. So, yes. Some babies do need more nutrition and calories than human milk alone. Although my babies were growing on just my breast milk, before they started fortifying it. Nevertheless, if babies do need to be fortified, there is an option of human-milk-based fortifier.

BR: And so Micah, he was not looking good and he was struggling.

JC: Yes, to get back to Micah, and his story . . . in my eyes, was not tolerating this fortifier that they were adding to his milk, and he exhibited feeding intolerance, which consisted of breathing issues. He wasn't breathing well. He wasn't having bowel movements. He was very irritated, agitated, and very quickly, he went downhill and developed NEC within a matter of hours of his most recent feeding. He went from being this 5 pounds—small, but perfectly healthy baby. By later that evening, he was intubated, hooked up to an incredible number of wires, medications, basically fighting for his life, and then was in the OR less than 48 hours later to look at his bowels.

BR: They suspected something was happening now with the bowels? And they were going to investigate this?

JC: Exactly. They took x-rays of his belly and they saw some inflammation in his bowels. Micah did end up having a piece of his bowel removed. Just as much life threatening, perhaps even more, then he went into renal failure.

BR: This is such a tragic story. And it went on and on.

JC: One thing leads into another.

BR: How many days did this go on?

JC: Micah was hospitalized for 10 months. He was able to come home at 10 months. We had him home for a month. He did need to go back to the hospital every day for dialysis. I wanted to note, too, during this whole time, he was getting my breast milk. I was pumping for him. Feeding him through a feeding tube. And he was not getting any more bovine-based, cow-based fortifier. Or anything like this.

BR: That was a family decision, wasn't it?

JC: Yes, we were adamant that he not be placed back on formula or any kind of bovine-based fortifier. But tragically, he developed pneumonia and that sent him back to the hospital. He had a very high fever and an infection. He had been through so much. He passed away when he was nearly 11 months old, in December of 2012.

BD: I am so sorry for your loss. Can you tell a little bit about what happened after and what have you done because of this experience?

JC: In the days and weeks, even the first couple of months after Micah's passing, it was really a matter of figuring out how to live. To breathe and eat and sleep without your child. It was just tragic. It was a devastating loss. Even though we knew Micah was going to have a long road, we didn't think we would lose him. It was still just a tragic loss. So once I figured out how to live and be without Micah in my arms, I really needed to find ways to stay connected to him, keep him integrated into my life. So one of the things I did, this was about a year after we lost Micah, I founded a nonprofit organization called the NEC Society. This organization is dedicated to protecting fragile and preterm infants from NEC. A major strategy we put forward is advocating for exclusive human-milk diets for these fragile infants.

BR: Micah was born so early and we know those guts are so immature and we get the argument that it costs too much and all that, but when you think about the emotional loss and social loss, and the financial loss, it just doesn't make sense not to use human-milk human milk fortifier.

JC: No, absolutely not, and the financial argument falls apart very quickly. Micah's care was multi-millions of dollars. And I understand that donor milk and human-milk human milk fortifiers are very expensive, but they do not even come close to the cost of surgical NEC, if babies need surgery to help them. And the months of hospitalization and the care they need to receive. Months, years, even a lifetime of care after this diagnoses.

BR: Let's talk a little bit about the Human Milk Banking Association of North America (HMBANA). What is the difference between banked human milk and moms just sharing their milk. Why is banked milk important for these little babies when mothers cannot provide their own?

JC: When these babies are so fragile and premature, like mine were, they are at incredible risk of infection, and disease, and all types of struggles. HMBANA makes sure the milk they can receive is pasteurized, and is safe for these premature babies. They make sure the milk has been screened. That the mom has been screened and checked out by her doctors. I've actually has the benefit of donating to a HMBANA milk bank before . . . There are moms who milk share, and that's a wonderful thing, as long as you're not throwing that milk away! Milk sharing to an adoptive family, or family and friends, that's a wonderful thing. But you can actually save a baby's life by donating to a HMBANA milk bank.

BR: Milk sharing, mother-to-mother sharing for a healthy term baby from a healthy mom, is usually low risk. But when you have a fragile baby, the mom could appear to be healthy, but she could have CMV, and that can be a threat to one of these early babies. At a HMBANA milk bank, they test the milk for bacteria before they pasteurize it to really make sure it's as safe as possible.

BD: We know that human milk is vital for these infants. Even the AAP (American Academy of Pediatrics) says these babies need a human milk diet. But we also know many hospitals across the country don't provide this, or educate parents about this. Can you tell me what some of those barriers are?

JC: Well, the barriers are multifaceted and seemingly endless. One would be lack of awareness and lack of appreciation of the power of human milk from clinicians and the care teams. Yes, the AAP has come out and said this, yet human milk is not valued as it should be in NICUs. Number two is it's not valued as a lifesaving prevention. Micah and Zachary needed blood transfusions when they were in the NICU, and no one blinks an eye when you need a blood transfusion. Everyone says, the baby needs it, of course they are going to give it. But why do we blink an eye when a baby needs human milk or donor milk if the mother can't provide that? And so I think we need to be framing human milk as a lifesaving intervention. This is a critical component for the health of these fragile infants.

BR: Do you think that it has something to do with the formula companies and the money they spend on "educating" doctors? Because they spend a lot of money educating doctors and nurses on their products? HMBANA is a nonprofit and they don't have money to go out there and be really promoting human milk for human babies. So, do you feel like that plays into it?

JC: Absolutely. Especially when physicians are in training, they get little to no adequate training around the power of human milk, and that it is critical for all babies, especially these premature babies. And usually no training what so ever. And many hospitals have deep ties with the formula industry, and they're getting free products and samples. Some babies get free goodie bags. It's horrible.

BR: Education, money for their staff.

JC: Yeah, it's pretty sickening.

BR: It's a conflict of interest. In Europe, they've banned all the pharmaceutical companies. And the people who make formula are often owned by pharmaceutical companies. They've banned them from entering the doctor's offices and hospitals, and doing this advertising, where here in the U.S., this practice is still very legal and very supported.

JC: I know that some hospitals have gone with the Baby-Friendly Hospital Initiative and there has been some components brought over to the NICUs, for Baby-Friendly NICUs. And that's the exact same thing you're talking about. Where NICUs who won't accept free products from the formula industry because it negatively affects their population.

BD: I was actually on your society's website, the NEC Society. I read an interesting article that highlighted a NICU that was NEC-free for one year in another country. Do you see that as a possibility here or something that would ever happen?

JC: I am a hopeful, optimistic person, so I would have to say yes to that question! I think the more people who become aware of the power of human milk, engaging parents, and keeping moms involved in their babies care, yes, I hope it's sooner, rather than later.

BR: We have a hospital in Michigan, Bronson Hospital in Kalamazoo, and for whatever reason, their NICU team, their pediatric neonatologists, asked that they establish a milk bank (in their hospital). That's our only milk bank associated with HMBANA here. Cindy Duff, an IBCLC who is in charge of that milk bank, got it started. She's an inspiration to us all. But in their hospital, they only use banked milk to supplement all their babies unless the parents refuse, and so here in Michigan, we have a model. And she says it saves them money because the babies are less sick. She did some research herself. I don't know if it's been published, but she noticed that not only did their NEC rates drop tremendously, but so did the respiratory complications that run through NICUs.

BD: Let's get back to your society. Can you tell me what your society is doing and what type of help is it giving to families?

JC: We really pride ourselves on being a collaborative. We are a collaborative nonprofit organization between families who have been impacted by NEC, clinicians who are concerned and want to help provide better care to these babies, and researchers—anyone really. But it's really between researchers, clinicians, and families members that have been impacted. We strive to provide awareness. Educate families. Empower families. And one of our main goals is to ensure that more babies are receiving the lifesaving power of human milk.

BR: What are some things people can do if they are interested in helping support your organization?

JC: First, you can visit us on our website. It's www.necsociety.org, and from there, you can learn a little bit more about NEC. You can follow us on Facebook and Twitter. One of the main things we are working on is awareness about NEC and how to prevent it, because again, most people do not plan on a premature birth. No one plans on their baby being at risk of developing NEC. So we really want to get families before they are in the situation that we found ourselves in. To give them this information and empower them.

BR: Tell us a little bit about what kinds of things you could envision that an IBCLC could have helped you with because you felt like you didn't have quite enough help.

JC: I would have loved to have had earlier, consistent support. It would have been amazing if someone could have come and seen me within the first hour, 2 hours, or 3 hours, or just that evening. My boys were born via C-section around 7:30 p.m. Of course no one came to see me that night, or even the next day. So just as early as possible, coming to make sure that these moms of the fragile babies understand how critical their milk is to their baby's health. And also explaining that you need to work really hard, but if your milk doesn't come in right away, there is donor milk available. Getting that information. Because I had no idea.

BR: I think our hospitals are getting a bit better with this, valuing mom's own milk anyway, but there's still some protocols and things that are not research-based on that. So, getting a pump right away would have been good, getting good information right away, the importance of this milk. What other kinds of things?

JC: When the baby's in the NICU, there's such a horrible separation between mom and the baby. So I couldn't hold them. I couldn't sleep next to them. It was horrible. This really impacted our ability to breastfeed in a negative way. So my babies were receiving my milk through a feeding tube. But when I wasn't there, you know I couldn't be there 24 hours around the clock, they were being bottle fed, and unfortunately, that really impacted our ability to breastfeed negatively. I didn't have the support. So when Zachary came home, he wasn't breastfeeding. So, I was exclusively pumping for both Micah and Zachary, and I continued to exclusively pump milk for over two years but, my point is, I would have loved to have the support to ensure that Zachary did come home nursing from the breast instead of just being reliant on my milk from a bottle.

BR: I think that often NICUs get really wrapped up in the use of human milk, rather than breastfeeding. So having support with latching and positioning, having support as to how to bottle-feed in a breastfeeding-friendly way, pacing the bottle-feed. Well, my goodness! What a story! But what a wonderful organization you have created from this tragedy. The phoenix is rising from the ashes. We know you are expecting a new little one.

JC: I sure am! It's incredible! And this baby's already full term. This baby's name is Elisha Micah, after his brother, and I'm looking forward to having a long, breastfeeding at the breast, relationship with this baby!

BR: Thank you so much, Jennifer, for doing this interview. Awareness is key, information is power. Thank you for spreading the word about this.

JC: Thank you. It's an honor.

Barbara Robertson is the owner of The Breastfeeding Center of Ann Arbor.

Barbara's professional experience includes

- More than 15 years' experience working with mothers and babies, helping them resolve breastfeeding issues
- Current IBCLC since 2004
- More than 25 years' teaching experience with all ages, newborn to adult
- Director of Professional Development for the United States Lactation Consultant Association 2009–2014
- Associate editor *Clinical Lactation* 2010–present
- Grant awarded from the Michigan Breastfeeding Network 2010
- Co-chair of the Washtenaw County Breastfeeding Coalition from 2005 to 2009
- Master's degree in Curriculum Development in Education
- Bachelor of Arts in Education, Communication, and Children's Literature

Barbara has been involved in education for more than 25 years. She received a bachelor's degree in Elementary Education in 1988 and her master's in Education in 1995. Barbara left teaching elementary students in 1995 to raise her two children. Her children spurred her to become involved in La Leche League, and in 1998, she became a La Leche Leader. She enjoyed this work so much that she decided to sit for the International Lactation Consultant Exam and became a board-certified lactation consultant. Barbara is the director of The Breastfeeding Center of Ann Arbor, on site at the Center for the Childbearing Year. She teaches breastfeeding classes for parents, runs support groups, trains professionals, and is in private practice as a lactation consultant. Barbara has developed a 90-hour professional lactation training and a 20-hour course, which fulfills the "Baby-Friendly" education requirements. Barbara volunteers for the United States Lactation Consultation Association as the Director of Professional Development. Her responsibilities include coordinating educational opportunities for IBCLCs across the country. She loves working with mothers and babies, helping them with breastfeeding problems in whatever way she can.