From: Emilie Bishop [mailto:emilie@bishop.be]
Sent: Thursday, February 01, 2018 5:50 PM
To: Kaeser, Lisa (NIH/NICHD) [E] <kaeserl@mail.nih.gov>
Subject: Written Comments for February 26 PRGLAC Meeting

My name is Emilie Bishop. I am 34 years old and the stay-at-home mom of my three-year-old son, Jonathan. We live in Bellevue, Washington, a suburb of Seattle, and Jonathan was delivered vaginally at full term at Evergreen Hospital Medical Center in neighboring Kirkland, Washington. Evergreen has the distinction of being the first hospital in the country to earn the WHO's "Baby-Friendly" designation, based on their adherence to a ten-step protocol designed to promote breastfeeding among mothers who give birth there. There are many reasons to promote breastfeeding in parts of the world where, very regrettably, clean water and nutritious formula may be hard to come by. I would like to share the story of how such policies hurt me and my son, who are privileged to have a six-figure household income and access to clean water, formula, medical care, and a growing awareness that breastmilk is a food, not the magic elixir our prenatal classes and postpartum care team claimed.

As previously stated, my son was born vaginally and full-term, on January 20, 2015. He was on the small side at 6'12'', but with no complications or concerns. He was, however, born to parents who had suffered a miscarriage in September 2010 and were unable to conceive again until April 2014. In that time, I was diagnosed with endometriosis and underwent two laparoscopic surgeries as well as numerous other tests and treatments, sometimes in an attempt to conceive again, sometimes just to try to stop the unrelenting pelvic pain. We conceived naturally after failed fertility treatments and a discouraging attempt at adoption. To say our son was wanted and that I wanted him to have the best of everything was an understatement.

At the time of my pregnancy, Evergreen was our closest hospital and the home of the ob/gyn practice I'd used since 2006. Several local friends had delivered babies at Evergreen and had great things to say. Most of them breastfed at least part-time and were grateful for the extra support they found at Evergreen. I wanted to breastfeed, and our prenatal classes and paperwork made it sound like the only proper way to feed a baby. I knew from preparations we'd made for the possibility of becoming parents through adoption and from my own well-being that formula was fine, but I believed the hospital that breast milk had everything short of actual super powers. Why would I doubt my doctor and hospital staff when they had been to medical school and read scientific papers?

All was not roses and sunshine for us, despite the La Leche League video we watched in prenatal class. Every latch attempt required multiple people to assist us and often resulted in me screaming in pain. Within hours, I had one nipple bruised from my son needing to be pulled off because his nose got covered and he was suffocating, as well as another nipple bleeding from being scratched by his finger nail. My son was very sleepy that first day and had a bout of low body temperature. I was given a nipple shield and cream for comfort, as well as a pump to stimulate milk production. Neither helped. He was down four percent of his body weight in less than twenty-four hours, but because he'd had one wet diaper, we were discharged with a follow-up appointment two days later with a lactation consultant at the hospital's breastfeeding center. We were told to only breastfeed at home. By the time we got to that follow-up appointment, we'd spent two nights on the phone with various nurse lines, asking if 12 hours was too long between wet diapers, if he should still have meconium every few hours, if I should still have such intense pain with every latch. Always the advice was the same: keep breastfeeding. It's normal, he's fine, keep breastfeeding, they'll check him out at the appointment. When we got there, he was down eleven percent (74 hours after birth), weighing only 5'9'' and so dehydrated he was peeing

every 23 hours (24 was the cut-off to go to the ER, we'd been told). A weighted feeding showed he was only getting an ounce between both breasts over twenty minutes, even with the LC correcting position. He gagged up his first few swallows of formula. We were readmitted for the night.

That night, we were taught how to "triple-feed," or nurse, bottle-feed with formula, then pump for additional stimulation and/or to add to the formula at the next feeding. It took an hour each time, and we were told to do that every 2-3 hours round the clock to build up my milk supply. I was asked if my breasts had changed during pregnancy. Since I bought extender hooks for my bras, I said, "I think so? A little at least." No one told me that wasn't enough.

The next six weeks are a blur of lactation consultant appointments, pediatrician appointments, exhaustion from the triple-feeding schedule, and self-loathing for not doing the one thing I had been told a "good" mother did for her baby. I felt like a complete failure for not recognizing my son was starving and then for not being able to increase my milk supply. By two months I'd weaned completely and was only feeding him formula from a bottle. I felt horribly guilty, but I couldn't keep up with the schedule that was doing nothing to increase my supply.

I learned later that my breasts have the hallmark features of insufficient glandular tissue, or IGT. They are wide-spaced, tube-shaped, and have changed very little since I was eleven years old, including when I was pregnant. For reasons unknown to me and the larger medical world, my breasts are not equipped to make enough milk and nothing will change that. No one in the entire hospital told me this. When I saw our charts 2.5 years later, though, I saw the very first nurse/LC who visited us wrote "Mom has wide-spaced breasts that is sometimes consistent with low supply (I will not discuss this with mom at this time)." In other words, better to boost our breastfeeding numbers than to prevent a newborn's starvation and a mom's mental breakdown.

The Baby-Friendly Hospital Initiative makes actions like this nurse's justifiable. One of their ten steps is to give no food or drink other than breastmilk except when medically indicated. Another is that hospitals will track the number of mother/infant dyads who have exclusively breastfed during their hospital stay. At my particular hospital, we were told that if we chose to formula-feed from the start, we would need to bring our own formula and bottles, and that we were responsible for preparation and cleaning. But as a first-time mother who wanted the best for my long-awaited baby, I had no reason to think I would need formula, so I didn't bring it. Hospital staff are taught that newborns don't need much to eat in the first few days, that weight loss is expected, and that medical indicators are things like unresponsiveness or seizures, not the more subtle steps leading to such a crisis. And if the only number that the BFHI tracks to ensure its program's "success" is the rate of exclusively breastfed babies at discharge, what's to stop women like my first nurse from lying to a clueless new mom so that she meets this arbitrary standard long enough to check the right box? No one cares about what comes later.

The NIH needs to start taking stories like this one seriously, because it isn't an anomaly. Data from a major hospital system in Utah and a national study recently published in Academic Pediatrics both found that newborns who are readmitted to the hospital are much more likely to be exclusively breastfed than formula- or combo-fed. The WHO, which created the BFHI, has admitted to a world-wide rise in newborn jaundice due to exclusive breastfeeding practices. All of these are preventable by being honest with mothers about general risk factors and their own personal risk factors associated with exclusive breastfeeding, closer monitoring to ensure babies aren't losing excessive amounts of weight, and making formula available without shame or additional hoops for an exhausted new mother to jump through. No family should have to suffer because ideologically-based lies when alternative and perfectly

adequate food is readily available. If the BFHI won't allow for that, then it's time to let it go. Ireland has banned it entirely, citing it as an unnecessary expense that doesn't live up to its promises. The US could do the same, or at least add humanity and common sense back into the equation.

Thank you for your concern.

Sincerely,

Emilie Bishop