



Culture Matters in the NICU

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About the author:

Jenné Johns, MPH is the mother of a micro-preemie, author, speaker, and award-winning health equity leader. Her son was born 26 weeks prematurely and spent nearly three months in the NICU before coming home. As an advocate for reducing healthcare disparities, Jenné found herself advocating for the needs of her son, as his survival depended on it. She also learned the power of reading to her son daily. Jenné wrote, “Once Upon a Premie” one month after her son’s discharge from the NICU as a reflection on their journey home.

Currently, Jenné is a member of the Premie Parent Alliance, and a board member with Pebbles of Hope. Jenné was featured in Premie World, Heart and Soul Magazine, Tom Joyner Morning Show, CBS Philly News Radio, Disruptive Women in Healthcare Blog, and Women of a New Sisterhood.

In her professional capacity, Jenné holds a Masters Degree in Public Health from Temple University, and a Bachelors Degree from The University of Maryland Eastern Shore. Jenné currently leads health equity initiatives for one of the largest health insurance organizations in the US and serves on health equity advisory committees. She was recognized as a 40 Under 40 By The Network Journal, Top Diverse Leader Under 50 by Diversity MBA Magazine, and Leader on the Move by the Philadelphia Business Journal.

About Once Upon A Premie: Once Upon a Premie is the only children’s book written for the parents of premies while they are in the NICU. This bedside companion motivates, encourages and inspires preemie babies and families until they go home. For more information visit: www.onceuponapremie.org

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In recognition of National Minority Health Month, BabyFirst introduced resources for multicultural families. Nationally, premature births impact African-American and Hispanic families significantly more than non-minority families. Jenné Johns, micro preemie mother, author of Once Upon A Premie, and speaker, reflects on her family’s NICU journey and offers navigation tips for multicultural families.

As the mother of a micropreemie, I know firsthand the realities, joys, and struggles of parenting in the Neonatal Intensive Care Unit. My son was born 14 weeks prematurely and had a three-month hospital stay before coming home. Like most preemie families in the NICU, this overwhelming introduction to your newborn baby is, at best, nothing short of a rollercoaster ride. Depending on your preemie’s length of stay, medical conditions, and growth, there are many highs, lows, twists, turns, and moments of uncertainty about the future. The NICU experience is a true test of any parent’s hope, trust, patience, advocacy, and love.

For preemie families from multicultural backgrounds, this experience may be different due to cultural norms, race, ethnicity, and language needs. These cultural factors impact how a family interacts with the NICU overall, and how NICU staff respond. It is important for NICU professionals and families to establish a relationship based on trust, mutual respect, and positive consistent communication.

But what happens when you, as the parent of your fragile preemie baby, don’t have this harmonious relationship? What happens when health professionals do not understand your culture, traditions, and practices, leaving you feeling isolated and alone? What do you do? How do you cope?

You are not alone. I, like many families around the country from diverse backgrounds had this experience in the NICU.

Here are a few tips based on my reflections and lessons learned during our NICU journey:

- **Acknowledge the cultural differences in the room:** During my sons NICU stay, over half of the families and babies reflected my cultural background. Yet only one of my sons NICU care team members shared that background. She was a rotational respiratory therapist who cared for my son two weekends of every month. The lack of cultural diversity among the hospital staff was very clear among us preemie families, yet there was very little acknowledgement of this from the hospital staff. I remember looking forward to the weekends, as I knew this particular staff member would be on call, and I could talk to her. I could let my guard down a little bit. I often shared with her some of my frustrations with being in the NICU and some of the communication challenges I faced with a few of the hospital staff. She often offered comfort, suggestions on how to request different resources that I was not aware we had access to, and laughed with

me about funny things she'd observed my son doing that showed his personality early on. It felt great having a culturally concordant member of the NICU team to just connect with on things specific to our NICU stay, and spiritual areas because we shared the same religious background. There is power in having a professional in the NICU who shares your cultural values. Don't be afraid to acknowledge this elephant in the room. Express your need for professionals from your cultural background to interact with you and your baby. It could be a NICU parent graduate, support group members, nurse, lactation consultant, a community health worker, promotora, or other specialists in the hospital. The NICU is a microcosm of the larger hospital, and parents from multicultural backgrounds are affected most by the lack of diversity. While our 99% Caucasian care team did their best to provide the highest quality of service to my son, there were just some things we were unable to address.

- **Speak up and ask questions often:** It's important to be open and transparent about your needs during this time. A life in the NICU is confusing, emotionally draining, and painful. During our time in the NICU, I asked questions around the clock about every aspect of my son's care such as changes with his care team feeding schedule, body temperature, medication dosage. Although I'm no

medical professional, I took great comfort in knowing the same details of my son's progress or setbacks as the NICU staff. There were times when I'd think of a question at midnight and I needed to call the NICU for an answer. For some of the NICU staff, I felt like a burden, and others, I felt as if being a proactive preemie mom was appreciated. In hindsight, no parent in the NICU should feel like a burden to staff who are responsible for your baby and their health. This burdensome feeling also made me wonder if stereotyping, or implicit bias was at play here. In addition, people with limited English proficiency (LEP) are often embarrassed to ask questions for fear of being thought ignorant. A multilingual professional that shares the patient's background can address cultural issues without being asked. The fact is, an activated parent should be celebrated in the NICU, they are, after all, their babies first and best advocate! "Ask Me 3", is a great resource for NICU families, as it encourages patients to use three questions to better understand your health (or the health of a loved one). Although, I changed my three questions often, based on what aspect of my son's health I needed to understand, I often used this method to help start the conversation with his care team. Questions to understand your preemie baby's health status may include: What's my baby's main problem? What action do we need to take? Why is it important to do this?





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- **Celebrate your cultural heritage in the NICU:**

Many preemie families with a longer length of stay, celebrate one or more holidays in the NICU. We celebrated our son's first Valentine's Day in the NICU and received a beautiful gift bag with a handwritten card, a heart shaped pillow, handmade knit hat, and a children's book. We absolutely loved this special gift, and we cherish it to this day, five years later. In the United States, there are two major holidays observed in February, Valentine's Day and Black History Month. Black History Month was not acknowledged and celebrated in our NICU. In hindsight, our family could have created a teachable moment for the NICU staff by requesting a program, resource, or service for families that celebrated both holidays. If you find an opportunity to educate your NICU staff about your specific cultural observations, traditions, and holidays, I encourage you to create your own teachable moment. Most importantly, you have the right to request specific programming such as support groups, books, brochures, videos, websites, photos and imagery around the NICU, that reflect your culture and language needs. I also encourage you to use these special holidays, traditions, and practices to celebrate directly with your preemie baby. Ask family members and friends to visit, take photos or videos of their Draeger Isolettes decorated in what you're celebrating. The teachable moment with the NICU staff will allow them to support families similar to yours for years to come. This special memory will last a lifetime for your family!

- **Your non-clinical needs matter!** Returning back to work as a breastfeeding preemie mother, accessing medical insurance for your baby, roundtrip transportation to the NICU, eating healthy food, needing help paying for an expensive medication, needing a support group and counseling services, receiving easy to read brochures, videos, websites, etc. to understand your preemies health status are all non-clinical areas that your NICU's social worker can provide for you and your family. Eight short weeks into my son's NICU stay, I had to return to work. I cried two weeks straight leading up to the dreadful moment when I could not spend my entire day and night in the NICU by my son's bedside. I spoke with the hospital staff and learned that some parents were able to request a flexible schedule with their jobs so that they could still spend ample time in the NICU. This was a great non-clinical way that the NICU staff supported my transition back to work. Just as I transitioned back to work on an alternative schedule, my son was diagnosed with Retinopathy of Prematurity, which could have led to blindness. This was a scary diagnosis and I wanted to spend time with his new ophthalmologist. The NICU supported my request, and I was able to make all of my son's eye exams. Don't be afraid to let your social worker or trusted clinical care team member know what your non-clinical needs are. They will be a great resource to support your family, as your baby's caretakers.

For more information visit www.babyfirst.com

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