



NICU Toolkit for Black Families



ACKNOWLEDGEMENTS

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PURPOSE

The purpose of this toolkit is to provide Black families with resources to better guide and support their NICU experiences.

This toolkit is based on the lived experiences of 85 Black families who participated in our NICU study and the current literature.

The quotes stated in this toolkit are directly from our NICU study participants. Some of the lived experiences shared may be triggering.

Table of Contents

Content	Pages
Themes	2
1. Hospital Stay	3
a. Helpful Tips.....	4
b. Communication.....	5
c. Questions to Ask Your Provider.....	6
d. Common NICU Terms.....	7-13
2. Emotional Health & Wellbeing.....	14-18
3. Lactation Support.....	19-22
4. Donor Human Milk.....	23-25
5. Racism & Bias.....	26-30
6. Policy & Advocacy.....	31-35
7. Community Resources.....	36-49
8. Words of Wisdom.....	50-51
References.....	52-55

Themes



1

Hospital Stay



2

Emotional Health



3

Lactation Support



4

Donor Human Milk



5

Racism & Bias



6

Advocacy & Policy



7

Community Resources



8

Words of Wisdom

1

Hospital Stay



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Hospital Stay



◆ Helpful Tips

- Ask how you can be involved in your baby's care.
 - Your role is very important!
 - You are an important member of the healthcare team.
 - Ask for a NICU Family Resource Guide.
 - Find out the NICU policies for visiting and staying overnight.
 - Ask if there is a Family Room or space where families can rest/relax.
 - Ask if there are any food, transportation, or housing vouchers available to support your stay in the NICU.
 - Ask when your baby's Care Team does Rounds, so you can participate in-person, by phone or video.
 - Find out about the NICU's pumping resources and policies related to bringing your milk from home.
 - If you experience any challenges during the hospital stay - ask to speak with the Patient Advocate or call the hospital's Patient Relations Office.
-

Hospital Stay

◆ Communication

- Staff may seem busy during this time; however, your questions are very important.
 - Staff are there to care for your baby and answer any questions you may have.
 - Remember there are no dumb questions.
 - Write down all your questions.
 - Questions can be asked at any time, you do not have to wait until Rounds.
 - Healthcare providers often have their own language.
 - If you do not understand something that has been explained - ask the provider or nurse to explain it in a different way - maybe with a picture or drawing an image.
 - Encourage your partner and other family members to also ask questions.
 - Schedule a meeting with the unit social worker, as soon as you can.
 - If you experience any challenges related to communication during the hospital stay - call the hospital's Patient Relations Office for additional assistance.
-



Hospital Stay



◆ Questions to Ask Your Provider(s)

- How long do you estimate my child will stay in the NICU?
- Who is the Primary Provider to update me on my infant's status?
 - This may change daily.
- Does my baby have a Primary Nurse?
- Who can I contact for the most up-to-date information about my baby, when I cannot participate in the Care Rounds?
- What time do Care Rounds take place?
 - Is it possible to participate by phone or video when I cannot be at the bedside?
- How can I participate in my baby's care?
- When will my infant be able to breastfeed/ chest feed/ take a bottle?
- What interventions are in place in the NICU that help keep my baby healthy?

Common NICU Terms

Common Terms Used



◆ Frequently Used in the NICU

- Rounds - This is when your baby's Care Team huddle around your baby's incubator or crib and discuss the plan of care. Rounds usually include everyone involved in your baby's care, for example: a neonatologist, nurse, respiratory therapist, social worker, case manager, and others.
 - Rounds typically occur in the morning; however make sure to confirm the timing with your baby's nurse.
 - This can be a good time to learn more about your baby's care plan.
 - If you cannot attend in person, ask if you can participate remotely.

For a more complete list, including descriptions of medical words and different NICU care team members, see pages 3-4 in this helpful NICU guide: <https://christianacare.org/documents/NICU%20Family%20Book.pdf>

Common Terms Used

◆ Mental Health



- **Perinatal Mood Disorder:** Perinatal refers to the period of time you become pregnant to a year after birth. Mood disorder is a term used to describe all types of depression and other mental health disorders.¹
- **Depression** is a common mood disorder that negatively affects how you feel, think, and act. Depression causes feelings of:¹
 - sadness
 - loss of interest in or energy for activities you once enjoyed
 - trouble sleeping or sleeping too much
 - even thoughts of death or suicide
- **Anxiety** is a disorder that causes excessive and persistent worry and fear about everyday situations. For example, you may avoid leaving your baby's bedside for fear that something may happen when you leave. Signs and symptoms can include:¹
 - feeling nervous
 - trouble sleeping
 - rapid heart rate and breathing
 - panicked or worn out
 - stomach problems
 - sweating

Common Terms Used

◆ Infant Feeding

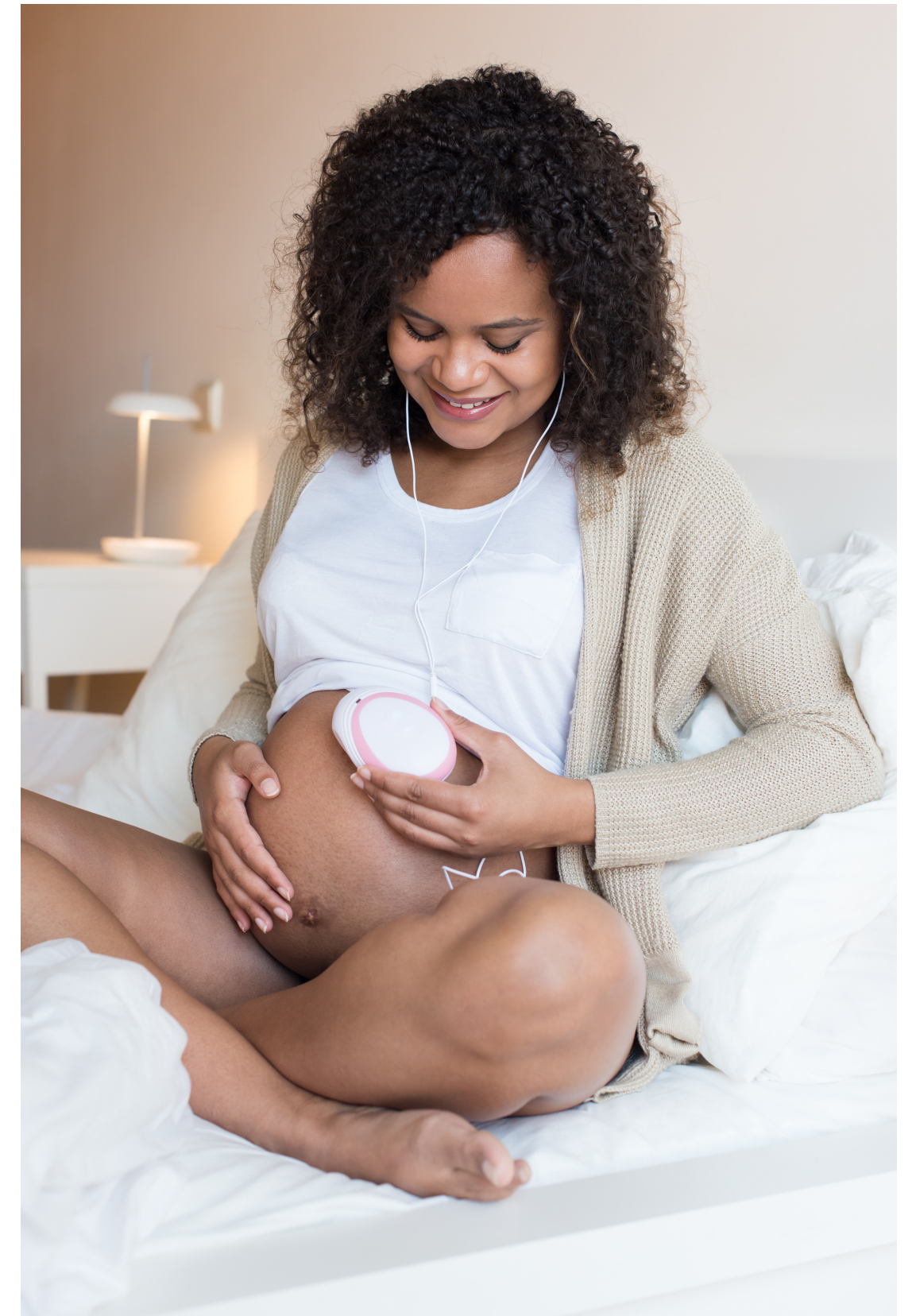


- MOM stands for Mother's Own Milk. Your milk is the ideal food for your baby and has the right balance of nutrients for your baby. Your milk changes based on the needs of your baby as they grow. The milk of parents who give birth early is different than milk made by a parent of a term infant. Studies have found more fat, protein, iron, and minerals in preterm milk than in term milk.²
 - DHM stands for Donor Human Milk. Donor milk is breast milk that is expressed by a mother or birthing parent and processed by a human milk bank. When MOM is unavailable or there is not enough, DHM should be used to feed baby if available.³⁻⁴
 - **Feeding Schedule:** Most NICUs will place babies on a feeding schedule every 2-4 hours. Preterm babies can have trouble latching, waking up for a feed, staying awake during a feed, or be unable to feed, so often times NICUs will have scheduled feedings until your baby is able to feed on their own and gain enough weight on their own schedule.⁵
-

Common Terms Used

◆ Caring for Yourself

- Intrapartum care is the care received during labor. Labor has 4 stages, where the last stage ends 2 hours after the birth of the placenta. It is important to talk with members of your Care Team and support persons to ensure your wishes surrounding your birth are known and heard.⁶
 - Postpartum care is the care received during the 12-16 weeks following birth. This is an important time period also known as the '4th trimester.' This time period is when your body is adjusting to changing hormones, learning how to feed and care for your baby. Making sure you are eating healthy foods, drinking lots water, addressing mental and reproductive health needs, and taking care of yourself are very important during this time period.⁶ Also, check out the [4th Trimester Project](#) for more information and resources.
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Common Terms Used

◆ Caring for Your Baby

- Feeding Cues are signs your baby will give to let you know when they are hungry and full. Signs your baby is full include baby “falling off” the breast, turning away from your breast, relaxes their body and opening their fists. Signs your baby is hungry include:⁷
 - fists moving to mouth
 - head turning to look for the breast
 - becoming more alert and active
 - sucking on hands
 - lip smacking
 - opening and closing mouth
 - Skin-to-skin also known as ‘kangaroo care’, refers to the practice of laying a baby directly on the birthing parent’s chest for at least an hour after birth or until after their first feed. Skin-to-skin can be done by any caregiver, this type of care is not limited to the birthing parent. Benefits include:⁸
 - improving baby's oxygen rates
 - shortening their hospital stay
 - calming or comforting baby
 - assisting with growth and temperature regulation
 - reducing baby and parent stress
 - increasing infant-parent bonding
 - can boost the parent's milk supply
-



Common Terms Used

◆ Lactation Profession



- Lactation Consultants provide a full range of human milk feeding (e.g. breastfeeding, chestfeeding, donor human milk, etc.) and infant feeding support. They provide care for families with complex problems. These professionals include:⁹
 - International Board Certified Lactation Consultants (IBCLC)
 - Advanced Lactation Consultants (ALC)
 - Advanced Nurse Lactation Consultants (ANLC)
- **Breastfeeding counselors** provide counseling to healthy, term infants and complete assessments on latch and positioning, pumping, and formula feeding. They also help support families in the hospital and community setting working alongside lactation consultants. These professionals include:⁹
 - Certified Lactation Counselors (CLC)
 - Certified Lactation Educators (CLE)
 - Breastfeeding Peer Counselors (BPC)

2

Emotional Health & Wellbeing



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Emotional Health & Wellbeing

◆ Did you know?

- Black mothers and birthing parents are more likely to develop a perinatal mood or anxiety disorder.¹⁰
 - Studies have shown that Black and Latina mothers have a 35-67% prevalence of postpartum depression, compared to only 10-15% in the general population.¹¹
 - Some people also experience anxiety during their pregnancy and/or after giving birth.¹²
 - 78% of the Black parents in our NICU study reported feeling sad or depressed, but only 36% were offered any mental health support.
-



"I felt that it was my fault that he was born early and in the NICU. I blamed myself for not having a faster delivery and for him not crying."

Emotional Health & Wellbeing

◆ What You Can Do

- Know that you are not alone and your feelings are valid.
 - Identify what mental health resources are available at the hospital or in your community.
 - Ask to speak with the unit social worker or a perinatal mental health provider.
 - Attend a NICU Parents Support Group.
 - Check to see if your insurance covers mental health services.
 - If you need emotional support or additional resources, call the Postpartum Support International HelpLine: 1-800-944-4773.
 - GLO Premies also has a 24/7 hotline for parents and families - call 1-855-907-4GLO or (855-907-4456).
 - If you are experiencing an emergency or crisis, the National Crisis Text Line is available: Text HOME to 741741.
-



Emotional Health & Wellbeing

◆ What You Can Do



- Taking care of yourself will be really important during this time.
 - Focusing on yourself may seem selfish at first; however if you are not well, you will not be able to care for your baby or family.
 - Create a self-care plan.
 - Identify activities that are calming or bring you peace.
 - Lean on your ongoing self-care strategies or faith community.
 - Remember to eat and drink plenty of water during your hospital visits.
 - When you can, take a break or nap with ear plugs.
 - Go for a walk around the unit.
 - Step outside the hospital for some fresh air.
 - When needed, reach out for help.
 - Ask what spiritual/cultural care is available (e.g., chaplain, community reps. etc.).
 - Request an Essential Self Care Kit from [Mighty Little Giants](#) and a NICU Essential Kit from [Project Sweet Peas](#).
 - Enroll in [GLO Premies 3 Step Program](#) for NICU families.
-

Emotional Health & Wellbeing

◆ Surviving an Infant(s) Loss



- Our deepest condolences on the loss of your little one(s).
 - We know this is an extremely difficult time for you and your family.
 - Below are a few tips that may be helpful during this time of bereavement.
 - Know that you are not alone.
 - Ask to speak with the unit social worker or a mental health provider.
 - Identify what bereavement resources are available for your family and baby at the hospital or in your community.
 - Examples: making footprints and handprints, saving a lock of hair, or taking photos, etc.
 - Download the NICU [Helping Hands' Resources for Bereaved Parents](#) and [First Candle's Surviving the Death of a Baby Resource Guide](#).
 - Attend a Bereaved Parents NICU Support Group.
 - Look into getting support from a bereavement doula or counselor.
 - Reach out to your faith community, if applicable.
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3

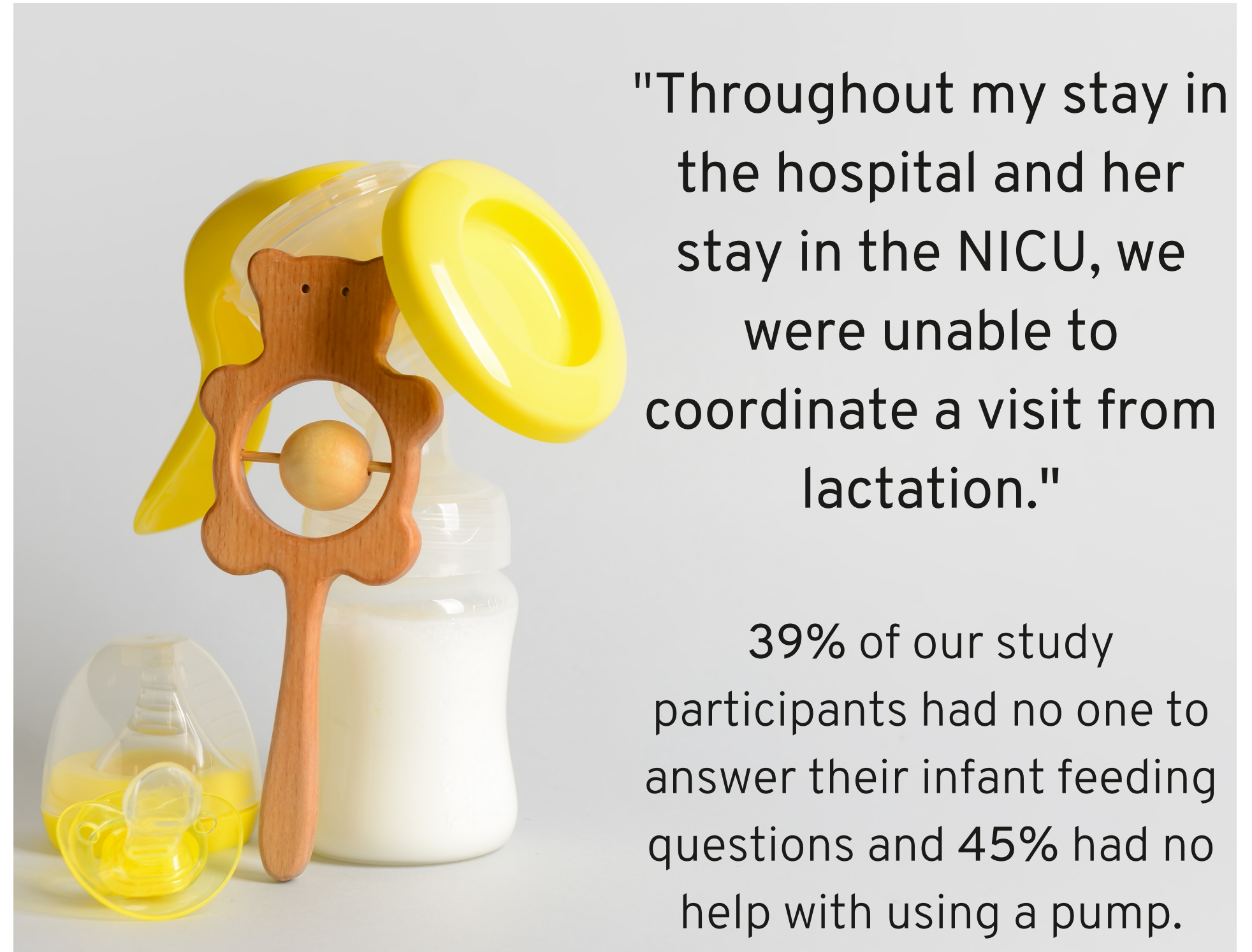
Lactation Support



Lactation Support

◆ Did you know?

- Human milk feeding provides significant health benefits to mothers, infants, and families throughout their entire life.¹³
- Most Black mothers and birthing people want to provide human milk to their infants.¹⁴⁻¹⁵
- However, due to barriers such as racism and bias, Black families have less access to maternity care practices that are supportive of human milk feeding.¹⁶⁻¹⁸



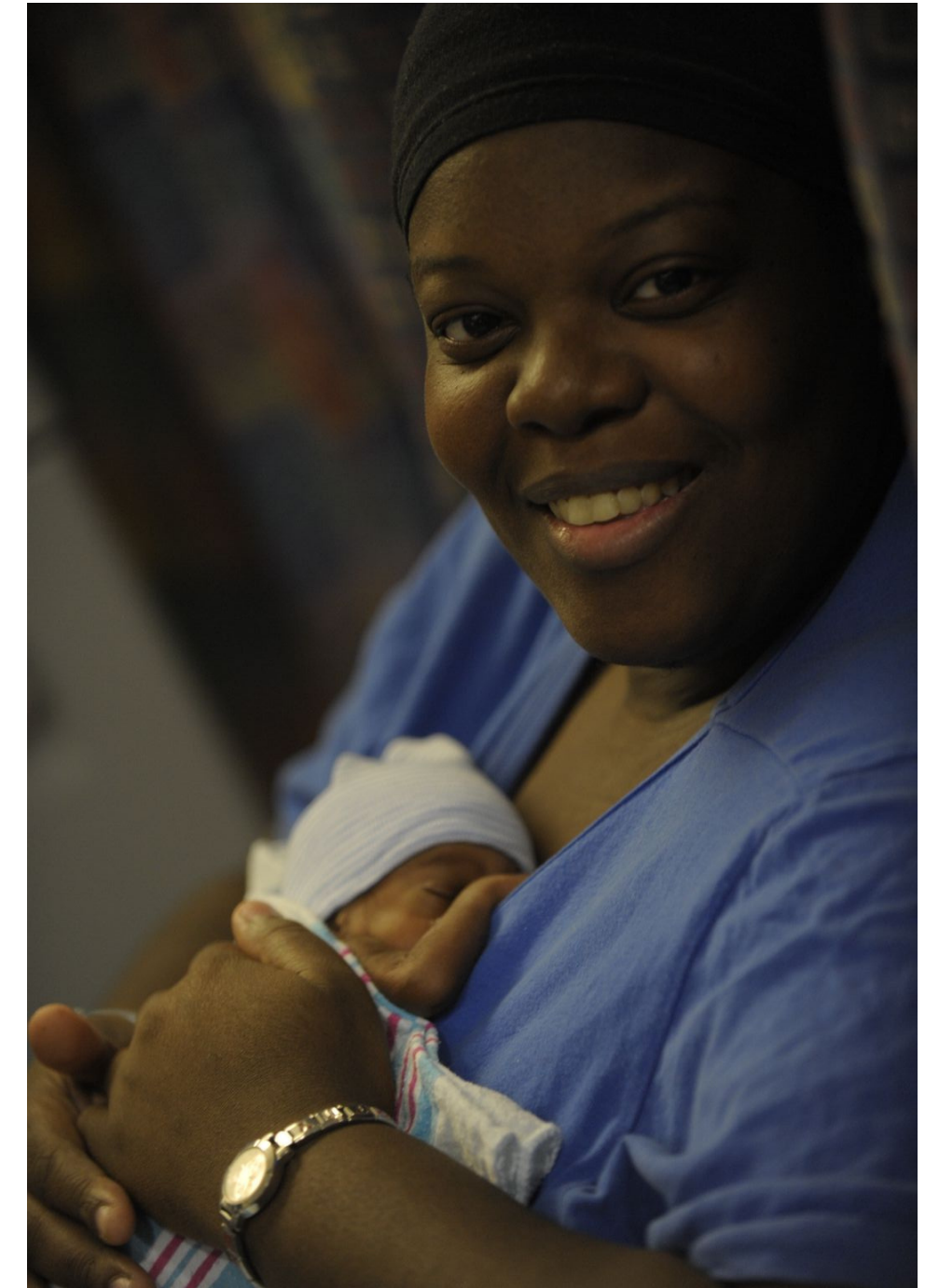
"Throughout my stay in the hospital and her stay in the NICU, we were unable to coordinate a visit from lactation."

39% of our study participants had no one to answer their infant feeding questions and 45% had no help with using a pump.

Lactation Support

◆ What You Can Do

- Sign up for the [WIC Program](#).¹⁹
 - Take a breastfeeding class and learn more about newborn cues and feeding readiness.
 - Ask to see a lactation consultant, breastfeeding educator, or breastfeeding peer counselor during your hospital stay.
 - Ask about contraceptive options that will not disrupt your milk production.
 - Ask how to get to a hospital-grade electric pump.
 - Learn how to set up and use your pump.
 - Ask about the supplies you may need to meet your lactation goals (i.e. pumping supplies, milk storage bags, ice packs, snacks, etc.).
 - If you will be pumping at work, discuss lactation accommodations with your employer.
 - If you encounter any obstacles with feeding, remember you are not to blame.
 - For ongoing support, find a lactation consultant or lactation support provider in your area or ask your Provider (e.g., Midwife, OB, Nurse Practitioner, etc.) and Pediatrician.
-



Infant Feeding Support

◆ What You Can Do

- Take an infant feeding class and learn about safe formula preparation, pace bottle feeding, slow paced nipples, and newborn cues and feeding readiness.
 - Ask to see a lactation consultant - they support all infant feeding practices, including formula feeding and supplementation.
 - If a lactation consultant is not available, ask to see a breastfeeding educator or breastfeeding peer counselor.
 - Ask what type of formula your infant is being fed.
 - Ask about the supplies you may need to meet your infant feeding goals.
 - If needed, find out if your baby's specialty formula is covered by insurance.
 - For ongoing support, find a lactation consultant or infant feeding support provider in your area.
 - If you encounter any obstacles with feeding, remember you are not to blame.
 - Sign up for the [WIC Program](#).¹⁹
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4

Donor Human Milk



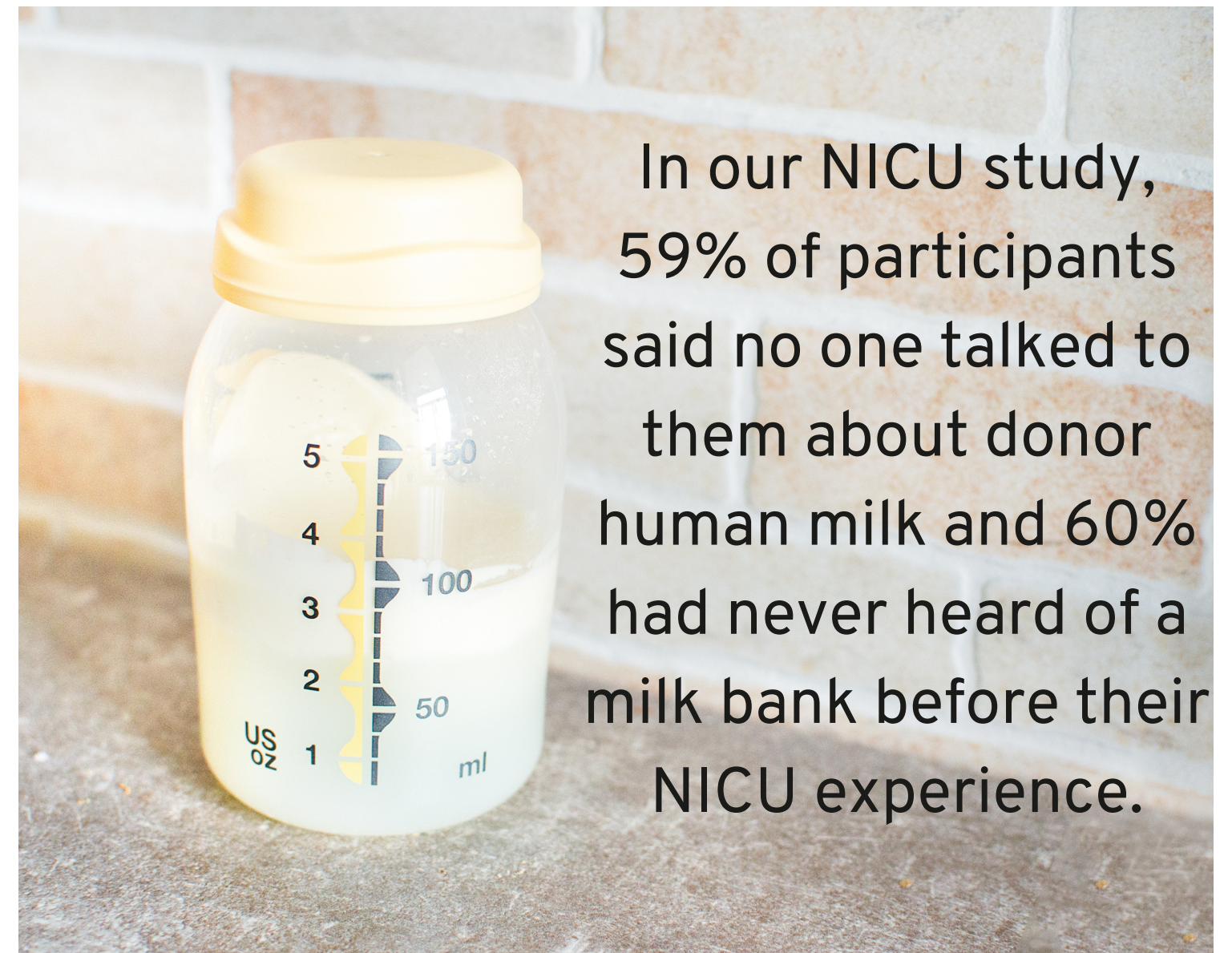
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Photo Source: United States Breastfeeding Coalition

Donor Human Milk

◆ Did you know?

- If your own milk is not available, donor human milk may be an option for feeding your baby.³⁻⁴
- Donor Human Milk is milk that is pumped or hand expressed by another mother or birthing parent that is donated to a local milk bank.²⁰⁻²¹
- Donor Human Milk is safe and pasteurized (heat-treated) to eliminate any bacteria or viruses that may be present.²⁰⁻²¹
- Milk donors are screened and tested for HIV, Hepatitis B, and syphilis.²⁰⁻²¹
- There are 31 nonprofit milk banks associated with the Human Milk Banking Association of North America (HMBANA).²²



In our NICU study, 59% of participants said no one talked to them about donor human milk and 60% had never heard of a milk bank before their NICU experience.

Donor Human Milk



◆ What You Can Do

- Learn about the benefits of donor human milk.
- Find out if donor human milk is available at your hospital and if your baby is eligible to receive it.
- If you have any questions or concerns about using donor human milk, make sure to ask the Care Team.
- Find out if your insurance covers donor human milk.
- Find a local milk bank.²²
- Learn about Community Milk Sharing at <https://www.Illi.org/breastfeeding-info/milk-donation/>
- Eats on Feets 4 Pillars of Safe Milk Sharing may be helpful:²³
 - Informed Choice
 - Donor Screening
 - Safe Handling
 - Home Pasteurization

5

Racism & Bias



Racism & Bias

◆ Did you know?

- Due to racism and bias, Black families experience the highest rates of maternal mortality and morbidity (e.g. death and injuries), infant death, NICU admissions, Child Protective Services (CPS) referrals, and postpartum depression.²⁴⁻²⁶
- 36% of our study participants reported experiencing racism or discrimination during their NICU stay. Participants also reported feeling judged, being questioned frequently by hospital staff.

"They constantly questioned if she was my baby because I was dark-skinned and she's very fair skinned."



Racism & Bias

Experiences with Racism



Unfortunately, racism exists, even in the NICU.

- Several researchers have noted differences in care and experiences of Black infants and families in the NICU.^{27,28}
 - Some families experience explicit (clear and direct) and implicit (not as clear or indirect) forms of racism and bias.²⁷⁻²⁹
 - Some families feel like they are constantly being watched or monitored.^{27,28}
 - Many families feel as though they are being treated differently than other families.²⁹
 - Many families feel like they have to advocate more or ask for resources several times before being helped.²⁹

"We seemed to be "monitored" and questioned more [about] our right to be there."

Racism & Bias

◆ What You Can Do

- Know that your life, lived experiences, voice and feelings matter.
 - You and your family deserve to be treated with respect.
 - Document any experiences with racism, as they occur.
 - Tell someone you trust (e.g. family member, friend, community member(s), provider, nurse, lactation consultant, breastfeeding peer counselor, etc.).
 - If you experience any challenges during the hospital stay - call the hospital's Patient Relations Office or ask for the Patient Advocate.
 - Complete the hospital patient satisfaction survey after discharge.
 - Review publicly available hospital reviews and ratings.
 - Share your experiences via the [iRTH App](#), a hospital review platform for Black and Brown families.
-



"I feel like my pain was overlooked multiple times, and my husband's questions were overlooked and unanswered."



"...closed mouths don't get fed. You've got to open your mouth and say something and almost demand it."

Advocating for Yourself

- Systemic racism and implicit bias projected by society and healthcare systems force Black families to constantly advocate for themselves.
- Many families in our NICU study reported that they needed to advocate for themselves and their family's health care needs.
 - Advocate for a primary nurse so they get to know you and your family's preferences.
 - Advocate for extended family visits.
 - Advocate for skin-to-skin as soon as possible, as long as possible, and as many times as you can during your NICU stay. See the Common Words section for more information on skin-to-skin.
 - If you find yourself needing to advocate for help, reach out to local community-based organizations and programs you trust for support.

6

Policy & Advocacy



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Photo Source: United States Breastfeeding Coalition

Policy & Advocacy

◆ Did you know?

- There are birth and lactation support professionals and advocates that meet monthly or quarterly in your community at the state and local levels to discuss policy and advocacy efforts. This group of local birth and human milk feeding professionals is known as a breastfeeding coalition.²⁸
 - Government officials often respond more positively to real-life stories than statistics. So sharing your experiences in-person, via email, or social media can really have an impact.
 - We recognize that everyone may not have the time and energy to engage with policy advocacy. If you have limited time, a great way to get involved with policy is registering to vote and using your voice.
 - Stay informed and call your local congressional representatives to push for policies that would benefit you and your family.
-



Policy & Advocacy

◆ Know Your Rights

- **Pregnancy Discrimination Act** - This act forbids discrimination based on pregnancy when it comes to any aspect of employment, including hiring, firing, pay, job assignments, promotions, layoff, training, fringe benefits, such as leave and health insurance, and any other term or condition of employment.



- **Affordable Care Act (ACA)** - This legislation increased access and affordability to health insurance and healthcare services for more people, especially low income families. However, only 39 states have expanded their Medicaid programs. Check out <https://www.healthcare.gov/> for more information.

ACA Health Benefits offered:

- Preventive health services
 - Coverage for pre-existing conditions
 - Dental coverage in the Marketplace
 - Birth control benefits
 - Breastfeeding benefits
 - Mental health & substance abuse coverage
-

Policy & Advocacy

◆ Know Your Rights

- The Federal Family Medical Leave Act (FMLA) - provides up to 12 weeks of unpaid, job-protected leave.
- Paid Family Leave (PFL) - Provides employees with protected paid leave to care for or bond with a new child, care for a really sick family member, or care for your family during active deployment. Unfortunately, there is no federally mandated paid family leave and only 11 states currently offer paid family leave.
 - Talk to your provider about breaking up your PFL so you have to bond with your baby after discharge
 - Ask your employer about the benefits you are entitled to and how you can stagger your benefits to support your family's needs.
- Federal Break Time for Nursing Mothers - This federal legislation mandates employers to provide break time and space (that is not a bathroom) for an employee to pump their milk for up to a year after giving birth.
- NICU Bill of Rights - The NICU Parents Network has created a NICU Baby's Bill of Rights to share with your baby's Care Team.
<https://nicuparentnetwork.org/bill-of-rights/>



Policy & Advocacy



◆ Programs You May Qualify For

- Children's Health Insurance Program (CHIP) - If you do not qualify for Medicaid, each state provides low-cost insurance for children through CHIP.
 - To learn more go to: <https://www.healthcare.gov/medicaid-chip/childrens-health-insurance-program/>
 - Supplemental Security Income (SSI) for Children - Your baby may qualify for Social Security Insurance (SSI) depending on your baby's birth weight and growth development.
 - To find out more go to: <https://mightylittlegiants.org/f/ssi-for-premature-babies>
 - To apply to the SSI Program go to: <https://www.ssa.gov/benefits/disability/apply-child.html>
 - Children with Special Health Care Needs (CSHCN) - Resources are available to support children with chronic physical, development, emotional, and behavioral conditions and their families.
 - To learn more go to: <https://childcare.gov/consumer-education/services-for-children-with-disabilities>
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7

Community Resources



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Community Resources

◆ Did you know?

- There are programs and organizations in your community geared toward supporting you and your family during this time.
- The Women, Infant, & Children (WIC) program provides lactation support, nutritional foods, recipes and cooking tips, health education, and referrals to other public health and social programs.¹⁹
- For lactation support, you can find lactation consultants or providers via the United States Lactation Consultant Association³¹ or the National Black Lactation Supporter Network.³²



Resources are constantly adapting to the needs of the community, including in your community. Research local lactation support organizations near you.

Community Resources



◆ NICU Support

- **Mighty Little Giants** - is a 501(c)(3) non-profit organization that advocates through providing support, education and encouragement for mothers and fathers experiencing pre-term deliveries resulting in long-term stays in the hospitals' NICU/NICCU. <https://mightylittlegiants.org/>
 - **GLO Preemies** - seeks to raise the voice of Black families in the NICU and post-NICU in terms of creating racial and health equity through policy advocacy, professional educational initiatives, family educational initiatives, and family support for African American families for continuous 18 years. <https://www.glopreemies.org/>
 - **Saul's Light** - is a New Orleans-based nonprofit that provides support and community to families with babies in the neonatal intensive care unit (NICU). <https://www.saulslight.org/>
 - **Project Sweet Peas** - is a 501(c)3 national non-profit organization coordinated by volunteers, who through personal experience have become passionate about providing support to families of premature or sick infants and to those who have been affected by pregnancy and infant loss. <https://www.projectsweetpeas.com/>
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Community Resources



◆ NICU Support

- March of Dimes - is a 501(c)(3) non-profit organization that supports lifesaving research; provides comfort and support to families in NICUs; and advocates for those who need their organization most, moms and babies. <https://www.marchofdimes.org/>
 - PreemieWorld - goal is to help guide families through the terrifying rollercoaster of their NICU journey, and beyond into recovery. <https://premieworld.com/>
 - Hand 2 Hold - provides personalized support before, during and after a NICU stay to help ensure all NICU families thrive. <https://handtohold.org/>
 - Miracle Babies - mission is dedicated to helping perinatal mothers and their families during their time of need by providing transportation, mental health assistance, and supportive services. <https://www.miraclebabies.org/>
 - National Perinatal Association - is an interdisciplinary organization bringing people together who are interested in perinatal care to share, to listen, and to learn from each other. <https://www.nationalperinatal.org/>
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Community Resources

◆ Emotional Health & Wellbeing



- Shades of Blue Project - is dedicated to helping women before, during and after child-birth with community resources, mental health advocacy, treatment and support. <https://www.shadesofblueproject.org/>
 - Sisters in Loss - is dedicated to replacing silence with storytelling around pregnancy and infant loss and infertility of Black women. <https://sistersinloss.com/>
 - Sista Afya Community Mental Wellness - is a social enterprise that provides low-cost mental wellness care that center the experiences of Black women. <https://www.sistaafya.com/>
 - Black Men Heal - an organization that provide access to mental health treatment, psycho-education, and community resources to men of color. <https://blackmenheal.org/>
 - The Loveland Foundation - is committed to bring opportunity and healing to communities of color, and especially to Black women and girls. <https://thelovelandfoundation.org/>
 - Postpartum Support International - goal is to promote awareness, prevention and treatment of mental health issues related to childbearing in every country worldwide. <https://www.postpartum.net/>
 - Open Path Collective - is an organization made up of mental health professionals that provide therapy at an affordable rate. <https://openpathcollective.org/>
 - CDPH Maternal Mental Fact Sheet - provides a handy 2-page overview. <https://tinyurl.com/2p87eak7>
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Community Resources



◆ Dealing with an Infant(s) Loss

- **NICU Helping Hands** - mission of NICU Helping Hands is to develop hospital- and community-based programs that provide education and support for families with babies while in the NICU, during their transition from hospital to home and in the event of an infant loss (Angel Gown Program). <https://nicuhelpinghands.org/>
 - **First Candle**- is committed to the elimination of SIDS and other sleep-related infant deaths through education, while providing support for grieving families who have suffered a loss. <https://firstcandle.org/>
 - **Support 4 NICU Families** - is an interdisciplinary workgroup that was brought together to develop interdisciplinary guidelines for psychosocial support services for parents whose infants are hospitalized in neonatal intensive care units (NICUs). <http://support4nicuparents.org/>
 - **Now I Lay Me Down to Sleep** - is an organization that captures remembrance photography to parents suffering the loss of an infant. This organization has photographers throughout the United States. <https://www.nowilaymedowntosleep.org/>
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Community Resources



◆ Lactation Support

- Reaching Our Sisters Everywhere (ROSE) - works to normalize breastfeeding by providing resources and networking opportunities for individuals and communities. <https://breastfeedingrose.org/>
 - Black Mothers Breastfeeding Association (BMBFA) - seeks to provide education, valuable resources and ongoing support to black families and public/private agencies that service these families. <https://blackmothersbreastfeeding.org/>
 - Chocolate Milk Cafe - provides a sacred space where families that are part of the African Diaspora can be supported and empowered to breastfeed and provide human milk to their children. <https://www.chocolatemilkcafe.com/>
 - Breastfriends Lactation Support Services - goal is to increase breastfeeding rates in the Black and Brown community with individual consultation, group education, and community lactation training. <https://www.breastfriendslactation.org/>
 - National Black Lactation Supporter Network - is a national list of Black lactation support providers. <https://tinyurl.com/mp9ts7fp>
 - Soul Food for Your Baby - is an organization that empowers Black Families to breastfeed with their mind, body & soul. <https://www.soulfood4yourbaby.org/>
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Community Resources

◆ Donor Human Milk

- Human Milk Banking Association of North America (HMBANA)
 - accredits more than 30 nonprofit milk banks in the United States and Canada. Member milk banks follow rigorous guidelines for donor milk safety and pasteurization.

<https://www.hmbana.org/>

- La Leche League International - mission is to help mothers worldwide to breastfeed through mother-to-mother support, encouragement, information, and education, and to promote a better understanding of breastfeeding as an important element in the healthy development of the baby and mother.

- Milk Donation and Sharing -

<https://www.llli.org/breastfeeding-info/milk-donation/>



Community Resources



◆ Community Milk Sharing

- Eats on Feets - is a worldwide network that facilitates Facebook pages for parents, caretakers, and professionals who have made the informed choice to share or support the sharing of human milk.

<https://www.eatsonfeets.org/safeMilkSharing>

- Human Milk 4 Human Babies- the mission of Human Milk 4 Human Babies Global Network is to promote the nourishment of babies and children around the world with human milk.

<https://www.facebook.com/hm4hb>

- Link to local community Human Milk 4 Human Babies pages -

tinyurl.com/hmt3xz2e

- Academy of Breastfeeding Medicine - Position Statement on Informal Breast Milk Sharing for the Term Healthy Infant -

<https://www.liebertpub.com/doi/10.1089/bfm.2017.29064.nks>

Community Resources

◆ Racism and Bias

- Black Mamas Matter Alliance (BMMA)- is a Black women-led cross-sectoral alliance that centers Black mamas and birthing people to advocate, drive research, build power, and shift culture for Black maternal health, rights, and justice. <https://blackmamasmatter.org/>
- Black Women Birthing Justice (BWBJ) - is a grass-roots collective of Black women and individuals across the African Diaspora who are committed to transforming birthing experiences for Black women and birthing people. <https://www.blackwomenbirthingjustice.com/>
- Birthing Cultural Rigor - is to improve the quality, safety, and value of health care experiences of Black women, girls, and gender expansive people. <https://www.birthingculturalrigor.com/>
- National Birth Equity Collaborative (NBECC) - creates transnational solutions that optimize Black maternal, infant, sexual, and reproductive wellbeing. <https://birthequity.org/>
- Irth App - is the Yelp for the Health Equity Movement: This is an app that shares experiences of bias in maternal care. <https://irthapp.com/>



Community Resources

◆ LGBTQIA Families



- The Knights and Orchids Society - mission is to build the power of transgender, lesbian, bisexual, and gay Black people across the south by providing a spectrum of health and wellness services. <https://tkosociety.com/>
 - LGBTQ Perinatal Wellness Center Resources - aims is to create innovative approaches to perinatal health equity through financially accessible, culturally competent care, and through LGBTQIA reproductive rights advocacy, and to promote the inestimable health value of safe community. <https://lgbtqperinatalwellnesscenter.org/resources>
 - Rainbow Families - mission is to support, educate and connect lesbian, gay, bisexual, transgender, and queer (LGBTQ+) families, parents and prospective parents by offering a wide variety of education programs, support groups, opportunities to connect and more. <https://rainbowfamilies.org/>
 - Return to Zero HOPE - is a national non-profit organization that provides holistic support, resources, and community for all people who have experienced unimaginable loss during the journey to parenthood. <https://rtzhope.org/lgbtq> and <https://rtzhope.org/bipoc>
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Community Resources



◆ Policy & Advocacy

- United States Breastfeeding Coalition - aims to drive collaborative efforts for policy and practices that create a landscape of breastfeeding support across the United States. <https://www.usbreastfeeding.org/>
 - MomsRising - a transformative on-the-ground and online multicultural organization of more than a million members and over a hundred aligned organizations working to increase family economic security, to end discrimination against women and mothers, and to build a nation where both businesses and families can thrive. <https://www.momsrising.org/>
 - Center for Reproductive Justice - is a global human rights organization of lawyers and advocates who ensure reproductive rights are protected in law as fundamental human rights for the dignity, equality, health, and well-being of every person. <https://reproductiverights.org/>
 - Center for WorkLife Law - is an advocacy and research organization at UC Hastings Law that seeks to advance racial, gender, and class equity. <https://worklifelaw.org/>
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Online Communities & Resources

Facebook

- Black Breastfeeding Mamas Circle Group
- Breastfeeding Support Group for Black Mothers
- Black Exclusively Pumping Mamas
- Black Moms Breastfeeding Uncensored
- Breastfeeding Support Group for Black Moms
- Birth and Breastfeeding in Color
- Midnight Milk Club
- Mahogany Milk Support Group

Instagram

- Voices for Birth Justice
- NICU Parent Network
- NICU Awareness
- Alliance 4 Black NICU Families
- Blactivist
- The NICU Dad
- Black Girls Breastfeeding Club



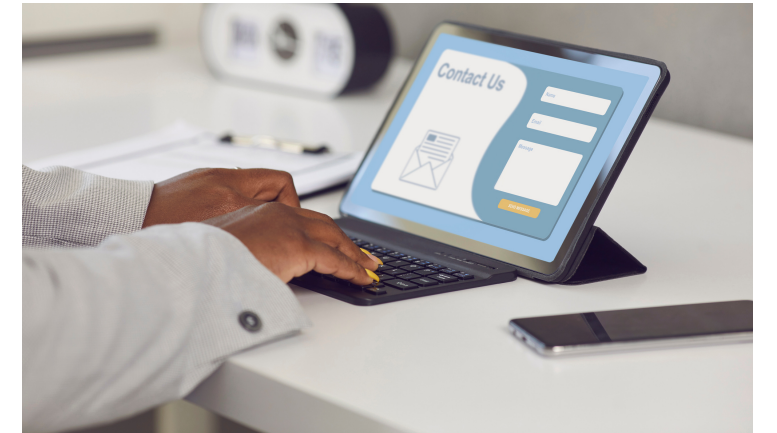
Online Communities & Resources

Websites

- California Perinatal Quality Care Collaborative (CPQCC)
 - Quality Improvement Tools - https://www.cpqcc.org/improvement/qi-tools?field_resource_category_tid=All
 - Recorded webinars on Health Literacy and Language - <https://www.cpqcc.org/IP2022>
 - Nutrition Toolkit (section 4 in particular) addresses Human Milk and Breastfeeding Support - <https://www.cpqcc.org/resources/nutritional-support-vlbw-infant>
 - Anti-racism/bias Exposure - <https://www.cpqcc.org/ip-2021-pre-palooza-page>
- Stanford Medicine Hand Expression - <https://med.stanford.edu/newborns/professional-education/breastfeeding/hand-expressing-milk.html>
- NICU Awareness - <https://www.nicuawareness.org/nicu-resources.html>
- NEC Society - <https://necsociety.org/>

Mobile Apps and TV

- March of Dimes - MyNICUBaby® App (download via Apple Store or Google Play)
- GLO Premies - Roku TV Station



In Closing....

Words of Wisdom

We know this time may be challenging. We hope these resources help support your NICU experience. Below are a few words of wisdom from our study participants:

"You know, that's what we have to do as a community, as a people, well, we got to show people that we're not playing around. And that we're not gonna allow the, you know, the health community to treat us like this anymore."

"...don't let anybody discourage you...
You know, even if you're, um, breastfeeding just a little bit. You know, a little bit is better than nothing."

"...while in the NICU, um, for me, there's something so beautiful that happens when you get people going through the same storm, you put them in the same room, if you're able to do a support group because that builds relationships with other NICU families and that shows that you're not by yourself in this."

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Notes



Best wishes on this journey!

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