

# The 2022 Annual Perinatal HIV Hotline Roundtable

## Breast/chestfeeding with HIV: Parent Perspectives and Evolving Practice

May 24, 2022 | virtual session

### Background

The National Perinatal HIV Hotline ([www.nccc.ucsf.edu](http://www.nccc.ucsf.edu)) hosts annual roundtables to promote dialogue around challenging topics and build community among providers. Discussion notes are distributed via the ReproIDHIV listserv and [posted on our website](#). For more information or to be added to the listserv, please contact Marliese Warren, [marliese.warren@ucsf.edu](mailto:marliese.warren@ucsf.edu).

For the 2022 Annual Roundtable, the Hotline partnered with The Well Project ([thewellproject.org](http://thewellproject.org)) to present an interactive webinar on May 24, 2022. The roundtable is intended for healthcare providers. This year's event also welcomed all those interested in the intersection of maternal/infant health and infant feeding for birthing parents living with HIV.

### Attendees

How roundtable participants self-identify	No. (%)
Clinician	86 (49.7%)
Allied Health <sup>^</sup>	15 (8.7%)
Non-clinical professional*	49 (28.3%)
Person living with HIV (PLWH)	12 (6.9%)
Other+	11 (6.4%)
<b>TOTAL</b>	<b>173</b>

<sup>^</sup>Allied health providers include social workers, doulas, and lactation consultants.

\*Non-clinical professionals are those who self-identified as public health professionals and researchers.

+Other includes legal services, students, and community advocates.

### Introduction

Infant feeding decision-making for parents living with HIV in the US and their healthcare providers can be confusing for a variety of reasons. As of the date of this event, US guidelines recommend against breast/chestfeeding with HIV, but state that “individuals with HIV who choose to breastfeed should be supported” to do so. This webinar provided a didactic overview of the existing research on perinatal transmission of HIV during breast/chestfeeding, followed by dynamic conversations between parents living with HIV and clinicians and attorneys about their experiences navigating the infant feeding landscape. This portion of the event was recorded and can be accessed [here](#) or on our website at [here](#). Finally, the attendees split up into 13 small groups to enable more intimate discussions. This summary provides a synopsis of the main discussion points of the breakout sessions.

Objectives of the webinar included:

1. Understanding the history and landscape of research and guidelines (e.g., World Health Organization (WHO) vs US/resource-abundant areas) around breast/chestfeeding and HIV.
2. Illuminating the intersection of maternal and infant health and breast/chestfeeding for birthing parents living with HIV.
3. Providing information to support informed decision making around infant feeding.
4. Understanding implications for infant providers.

*A note on language: We acknowledge that not all people who get pregnant and give birth identify as women and not all people who identify as women can or will get pregnant and give birth. We made an effort to use gender-inclusive and person-first language throughout the event and this document.*

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## Major themes

We are at an inflection point in the infant feeding discussion for parents living with HIV and providers serving those parents and their infants. Infant feeding is a complex and nuanced issue and viewpoints are wide-ranging. There are many people who strongly advocate for people with HIV to have access to information and support around breast/chestfeeding decision-making, while others think providers should continue to recommend against breast/chestfeeding. Many folks are in between, unsure, or would like more information.

There is a lack of systematic data on breast/chestfeeding while living with HIV in the United States and other high-resource settings. This is often cited as a barrier to creating guidelines and support for breast/chestfeeding.

There is not a push for parents to start breast/chestfeeding, but rather a desire to open the conversation to options and that a parent who wants to breast/chestfeed can be safely supported in that decision, if they choose.

Panelists and participants highlighted the importance of the care teams that support both the birthing parent and the infant and the need to have every member of both care teams supporting the parent's infant feeding decision.

Many providers highlighted the importance of the US DHHS Guidelines in their clinical decision-making and expressed concern that if they are not following the guidelines, there will be some backlash, or their funding will be impacted.

Many participants desired more information, such as:

- More data.



- Protocols for both parent and infant.
- How to begin and continue the conversation about infant feeding.
- Guidelines and resources on how to support a parent who wants to breast/chestfeed.

Providers and parents emphasized the harm that occurs when Child Protective Services (CPS) becomes involved as a result of a parent's expressed desire to breast/chestfeed their infant. Legal, medical, and community experts agree that engaging Child Protective Services or similar agencies is an inappropriate response to the infant feeding choices of an individual with HIV.

### **Additional discussion points:**

#### **Clinical education**

- There is a need for more detailed information on how to provide care to breast/chestfed HIV-exposed infants, e.g., pros and cons of continuing prophylaxis for babies beyond 6 weeks of life.
- There is a need for guidance (e.g., protocols, scripts, and care team roles) for providers to learn from and point to for education.
- Many participants offered a reminder: providers are not here to make the decision for the patient but to provide the people we are serving with guidance in making that decision.

#### **Research/data**

- There were many requests for more published case data from the US.
- Participants wanted a clear review of existing data to clarify the risk of HIV transmission while breast/chestfeeding. See Dr. Levison's slides on our [website](#) or watch the recording of the webinar [here](#).
- There was a desire to see the UK registry: This is a pregnancy database for all pregnant women with HIV. The clinician fills it out (similar to the Antiretroviral Pregnancy Registry): <https://www.ucl.ac.uk/integrated-screening-outcomes-surveillance/>
- Participants expressed encouragement to UK researchers to publish/make public their findings regarding people with HIV who choose to breast/chestfeed.

#### **Best practices**

- An overarching theme is the importance of having the entire care team on board with whatever decision the parent makes.
  - There is a pressing need to involve folks from various disciplines to ensure continuity of care and medical care coordination for parents and infants.
  - We need to widen the definition of the care team (e.g., in-hospital nurses, doulas, lactation consultants, and social workers), not just provider teams on the parent's and infant's side.
  - Given that providers are just one piece of the team, how do we support them in advocating for their patients with other providers, legal services, and other members of the care team? How can we teach providers to be better advocates for their patients?
- Include CPS in discussions at the hospital system level so they are aware of appropriate and inappropriate involvement in care decisions.



- Address the power imbalance between providers and patients to allow a safe, non-judgmental space for patients to make an informed decision.
- Inform providers and patients of the latest research findings.

#### **What do providers need?**

- More supportive language in published guidelines.
- Protocols and tools to support conversations (with parents and between clinicians), share information with parents, and successfully support parents who choose breast/chestfeeding.
- Easy access to the latest research findings, data, and stories.
- A list of breast/chestfeeding-friendly, HIV-knowledgeable obstetrician/gynecologists, pediatricians, and other providers such as lactation experts.

#### **What do parents need?**

- Access to research and data, as well as personal support; ideal for clinicians to provide these things.
- Some Black, Indigenous, and person of color (BIPOC) parents prefer BIPOC providers.
- Safe spaces for birthing parents/families to come together to talk about options. Peer-led support groups are helpful.
- Data and stories of parents who have breast/chestfed their infants and clinicians who have provided support.
- A list of breastfeeding-friendly, HIV-knowledgeable pediatricians.
- Infant feeding support in light of formula shortages. Human milk banks may not be financially accessible for all parents.
- Knowledge of why and when a provider or institution might refer them to CPS.

#### **Barriers/challenges**

- The guidelines are unlikely to change significantly or quickly without vocal advocacy from community members.
- Flaws in infrastructure - e.g., supply chain issues (ARVs, testing supplies, formula); lack of clarity on what insurance will reimburse (several clinicians have experienced insurance denials for repeat testing of infant) - have an impact on care provision and limit options.
- Lack of US data.
- Clinical time is limited and shared decision making/explaining what we know and what we don't know takes a lot of time.
- Guidelines clearly state breast/chestfeeding is not recommended.
- The risk of HIV transmission with breast/chestfeeding is too high for some clinicians to feel comfortable recommending or supporting it.
- Unwanted disclosure when an infant is on ARVs or requires increased testing during breast/chestfeeding.
- Even when the guidelines are updated, not all clinicians are aware of the updates. Patients can sometimes be more informed than providers.
- Practice differs across medical disciplines/specialties (neonatology, gynecology, pediatricians, etc.).

- The challenges of getting the whole team on board, and recognition that the care team evolves through the pregnancy and up to/after delivery. For example, even if the entire antenatal/prenatal care team has been in communication and is supportive, unanticipated and distressing interactions involving other health care workers can occur during acute care hospitalizations including delivery.
- Personal bias impacts counseling. Regardless of the data, medical paternalism persists and providers often harbor stigma toward people living with HIV.
- Clinicians often have assumptions about who is likely to remain adherent to care postpartum and will have varying levels of comfort with each individual's infant feeding choice – how can they provide equitable and unbiased counseling that allows for bodily autonomy and patient-driven decision making.

### **Suggested strategies**

- Loop in CPS, CDC, and other agencies so they can update guidelines and practice.
- Update published guidelines with better language to be clear about what shared decision making means. Infant feeding decisions should be made by the mother or birthing parent.
- Put a specific line in the guidelines that CPS referral is not recommended or helpful because the NCCC regularly receives calls to the perinatal HIV hotline about CPS referrals.
- Clarify to clinicians that the DHHS perinatal guidelines are just that, guidelines, and that they are intended to be used to inform clinical decision-making, not as an irrevocable law.
- Empower and prepare people of pregnancy potential to advocate for themselves.

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Discussion notes are distributed via the ReproID HIV listserv, the NCCC website, and The Well Project's website and social media channels. The ReproID HIV Listserv is a dynamic forum for clinicians and other healthcare professionals who specialize in reproductive infectious diseases. Participants use the forum to discuss clinical cases, share clinical approaches and protocols, network with colleagues, and arrange patient referrals. For more information, or to join the listserv, please contact [marliese.warren@ucsf.edu](mailto:marliese.warren@ucsf.edu).

As always, we are stronger together and there are many people who contribute to the success of our annual Perinatal HIV Roundtable. We want to offer our deep and everlasting gratitude to:



Our panelists and presenters: Allison Agwu, Gregg Alleyne, Ciarra “Ci Ci” Covin, Alyssa Crawford, Catherine Hanssens, Antoinette Jones, and Judy Levison

Our moderators: Olivia Ford and Lealah Pollock

Our facilitators: Allison Agwu, Gregg Alleyne, Chris Bositis, Ellen Chadwick, Carolyn Chu, Deborah Cohan, Ci Ci Covin, Alyssa Crawford, Olivia Ford, Catherine Hanssens, Antoinette Jones, Judy Levison, Krista Martel, Lealah Pollock, Ted Ruel, and Marliese Warren.

Our notetakers: Alejandra Duque, Grissel Granados, Barbara Jungwirth, Cindy Mackey, April Nakayoshi, Heather O’Connor, Connie Rose Shearer, Deb Storm, Hoa Su, Hasiya Yusuf

Our National Perinatal HIV Hotline Woman and Child Health team: Deborah Cohan, Pooja Mittal, Christine Pecci, Peter Havens, Ted Ruel, Lisa Rahangdale, Judy Levison, and Lealah Pollock (Director)

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2022 roundtable planning committee: Krista Martel, Olivia Ford, Ciarra “Ci Ci” Covin, Lealah Pollock and Marliese Warren

The entire ReproID HIV Listserv and greater perinatal and pediatric HIV communities