

A photograph of a woman with curly hair breastfeeding a baby. A red HIV awareness ribbon is pinned to her shoulder. The image is dimmed to serve as a background for the text.

Updated HIV Infant Feeding Guidelines: Implementation and Lessons Learned

Care Partnership

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A Note on Language

In our program, we have only had the opportunity to support cisgender women who have chosen to breastfeed. We want to acknowledge that there are multiple terms to describe infant feeding from the chest. For purposes of this presentation, we will be using breastfeeding and chestfeeding interchangeably. However, we want to acknowledge that our program will absolutely and without any hesitation support any individuals who would like to feed their infant from their body.



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Milk
Bank

UCSD Mother, Child and Adolescent Program (MCAP) Mission

- Through research, clinical care and education, to constantly improve the care and treatment of women, children and youth living with and affected by HIV and prevent new HIV transmissions
- Our mission is accomplished through a multidisciplinary team approach that provides high quality, comprehensive, culturally sensitive, accessible medical care, health promotion, HIV prevention and family centered social services in San Diego County



Populations Served



2023 MCAP Demographics

362 infants, children, youth and women

226 in our Women's program

75 in our Adolescent program

44 in our Pediatric program

30 in our Obstetric program

30 Exposed infants

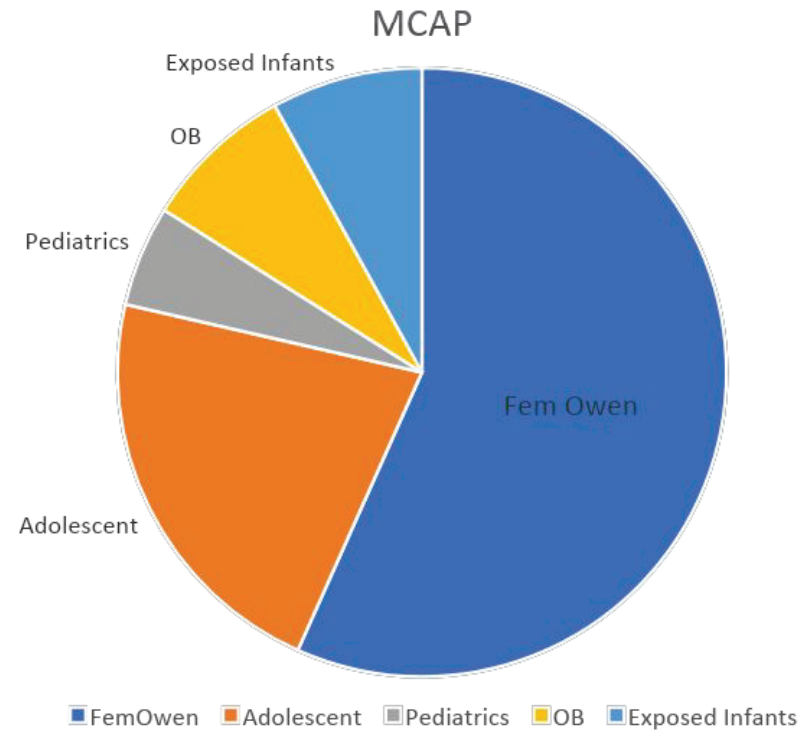
13 Breastfeeding Dyads

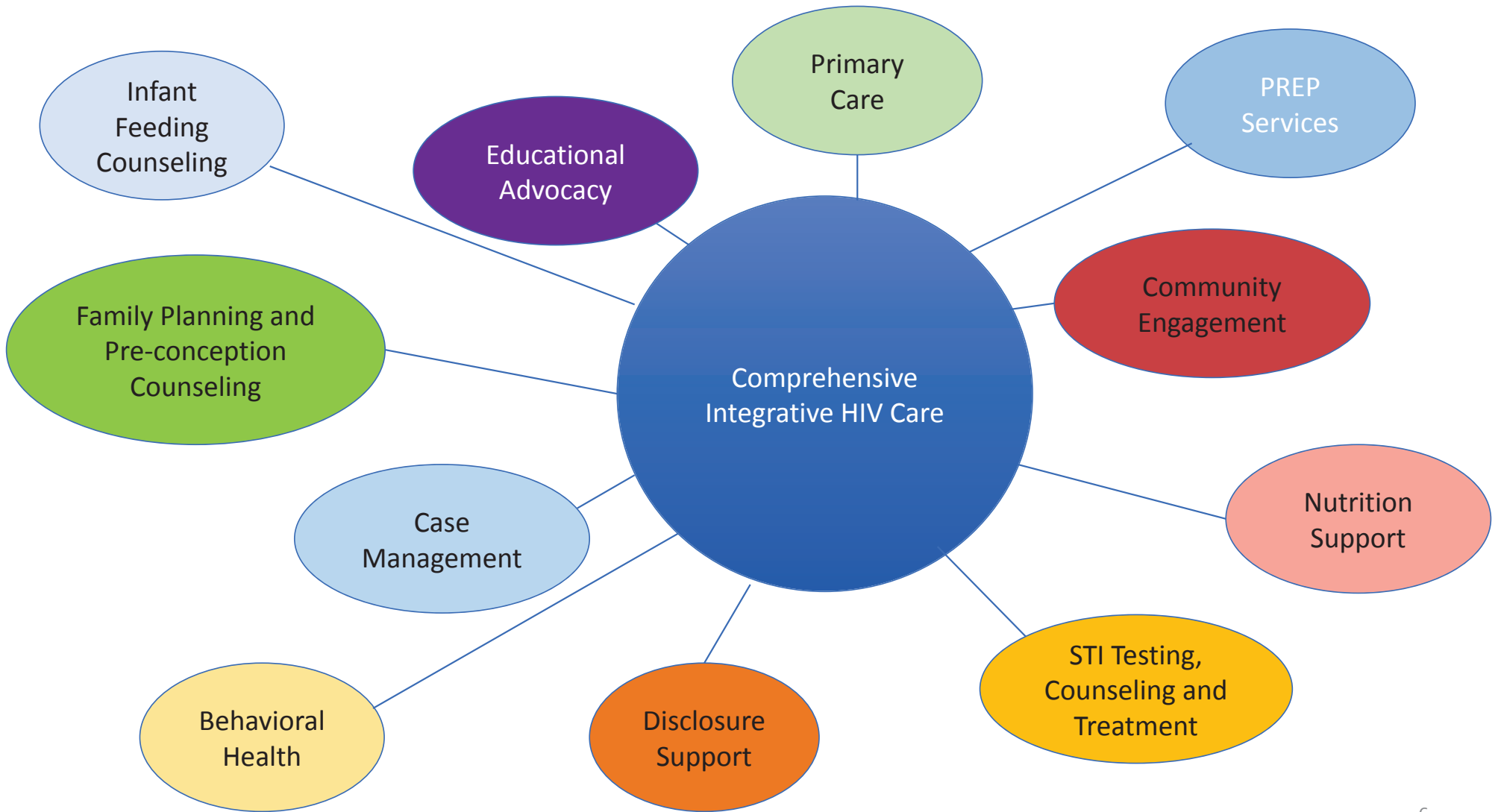
72% Cisgender Female

27% Cisgender Male

1% Gender

Diverse/Transgender/Non-Binary





Multidisciplinary Team Approach

- Client
- Partners, family and support system
- Medical providers (physicians, nurse practitioners, nurses)
- Social workers and case managers
- Therapists
- Psychiatrist
- Substance use counselor



Labor and Delivery/Neonatal HIV Consultation Services for San Diego & Imperial County

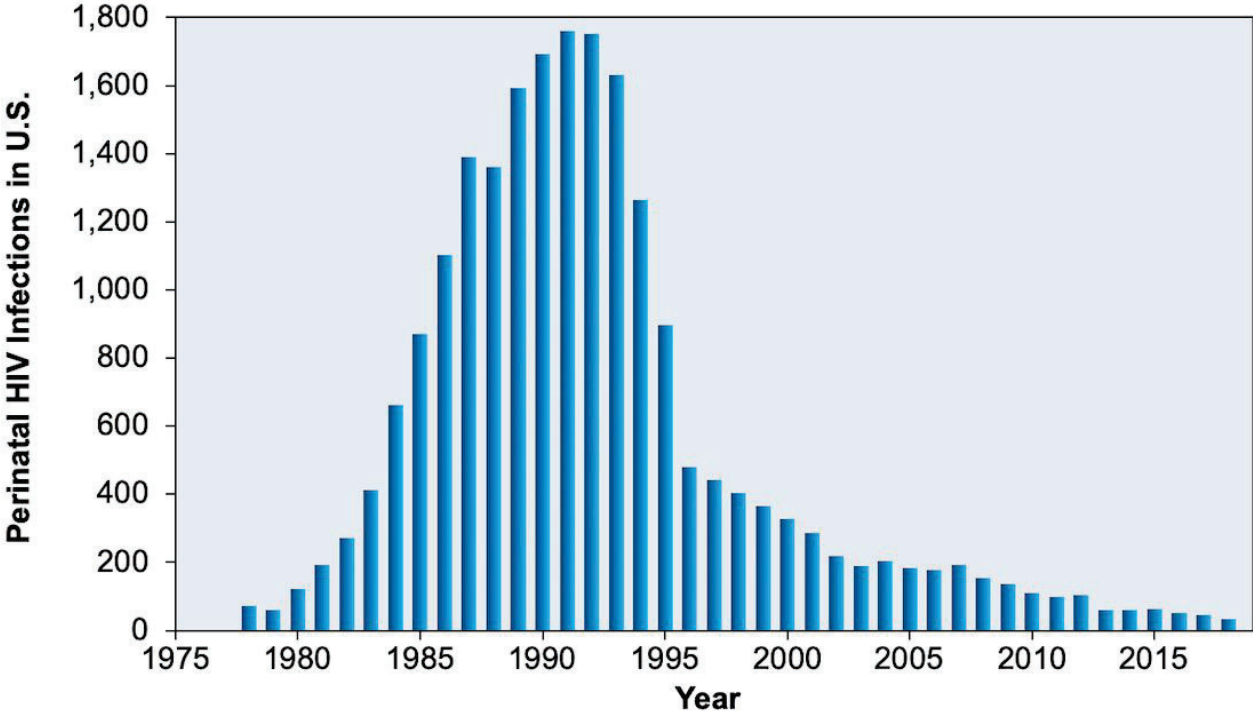
MCAP NP available 24/7 to receive pages/calls from area clinics and hospitals

Provides management advice and support to medical staff for the following cases:

- Preliminary positive HIV result: Management and Guidelines
- Known HIV positive women with detectable or undetectable Viral Loads at Delivery
- Management of Newborns
- Bilingual follow-up support to families after discharge (including lab follow up, medication management, and enrollment in services, if needed)



US Perinatal Infections



Spach, D, Kalapila, A.
<https://www.hiv.uw.edu/go/key-populations/pediatric-infants-children-hiv/core-concept/all>

Perinatal HIV Transmission: 2010 - 2019

TABLE 1

Estimated Numbers of Hospital-Based Live-Birth Deliveries Among Women With an HIV Diagnosis and Reported Numbers of US-Born Infants With a Diagnosis of Perinatally Acquired HIV by Year of Birth, 2010–2019

	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
Live births ^a	4557	3721	3725	3815	3890	3899	4005	4195	3635	3540
Diagnoses of perinatally acquired HIV ^b	74	62	70	47	48	51	49	45	36	32

a National Inpatient Sample, Healthcare Cost and Utilization Project.

b National HIV Surveillance System.

Margaret A. Lampe, Steven R. Nesheim, Keydra L. Oladapo, Alexander C. Ewing, Jeffrey Wiener, Athena P. Kourtis; Achieving Elimination of Perinatal HIV in the United States. *Pediatrics* May 2023; 151 (5): e2022059604. 10.1542/peds.2022-059604

Perinatal HIV Transmission

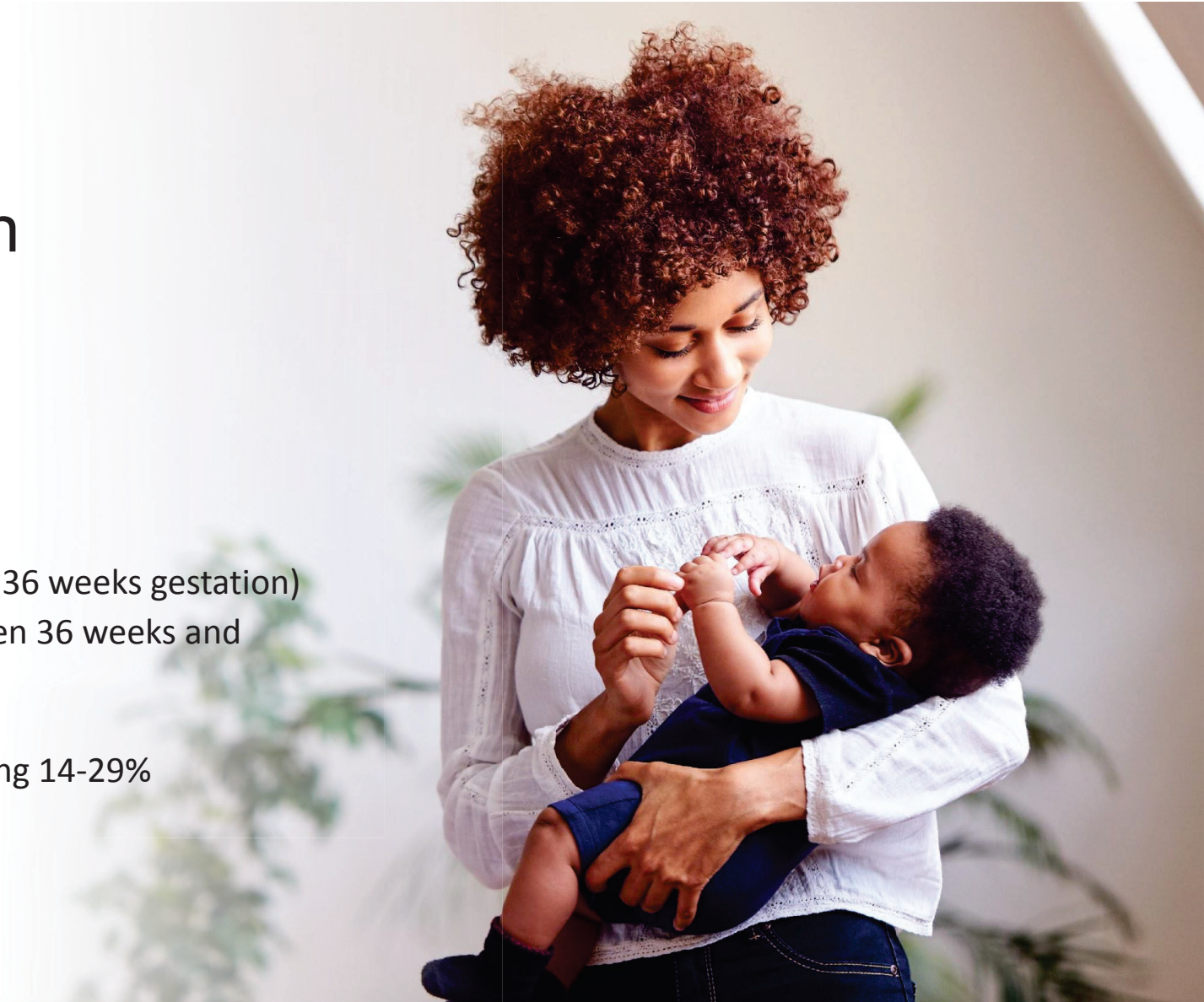
- **Transmission Rates**

- Without treatment 25%
- With treatment <1%

- **Timing**

- Intrauterine 20% (before 36 weeks gestation)
- Intrauterine 50% (between 36 weeks and delivery)
- Intrapartum 30%
- Post-Partum/Breastfeeding 14-29%

Source:
<https://www.hiv.uw.edu/go/prevention/preventing-perinatal-transmission/core-concept/all#citations>



U=U

Undetectable = Untransmittable

Does U=U apply to breastfeeding?

What do the studies tell us?

- 2017 Meta Analysis of 6 studies in low-income settings by Stephanie Bispo and her colleagues:
 - Estimated transmission 1.08% at 6 mos
 - Higher transmission rates if moms started ARVs later in pregnancy
 - Higher transmission (3%) if breastfeeding was continued past 6 mos (HOWEVER, many of those moms stopped ARV at 6 mos and continued breastfeeding)
- PROMISE Trial in South Africa compared moms on ART with infants on NVP (until 18 mos or cessation of BF)
 - 0.3% at 6 mos and 0.7% at 12 mos in maternal ART arm
 - Moms were maintained on ART for this study and there was no difference in the group with moms on ART vs infants on NVP ((this study did not have moms and babies on ART at the same time)
- HIV Prevention Trials Network 046: NVP to breastfed infants for 6 months
 - No difference between NVP and placebo if moms were stable on ART.

Issues with the Data available

- Studies include moms who started ART at any time in pregnancy
- In some studies, transmission occurred after mom stopped taking ARVs
- None of these studies have both mom and baby on meds



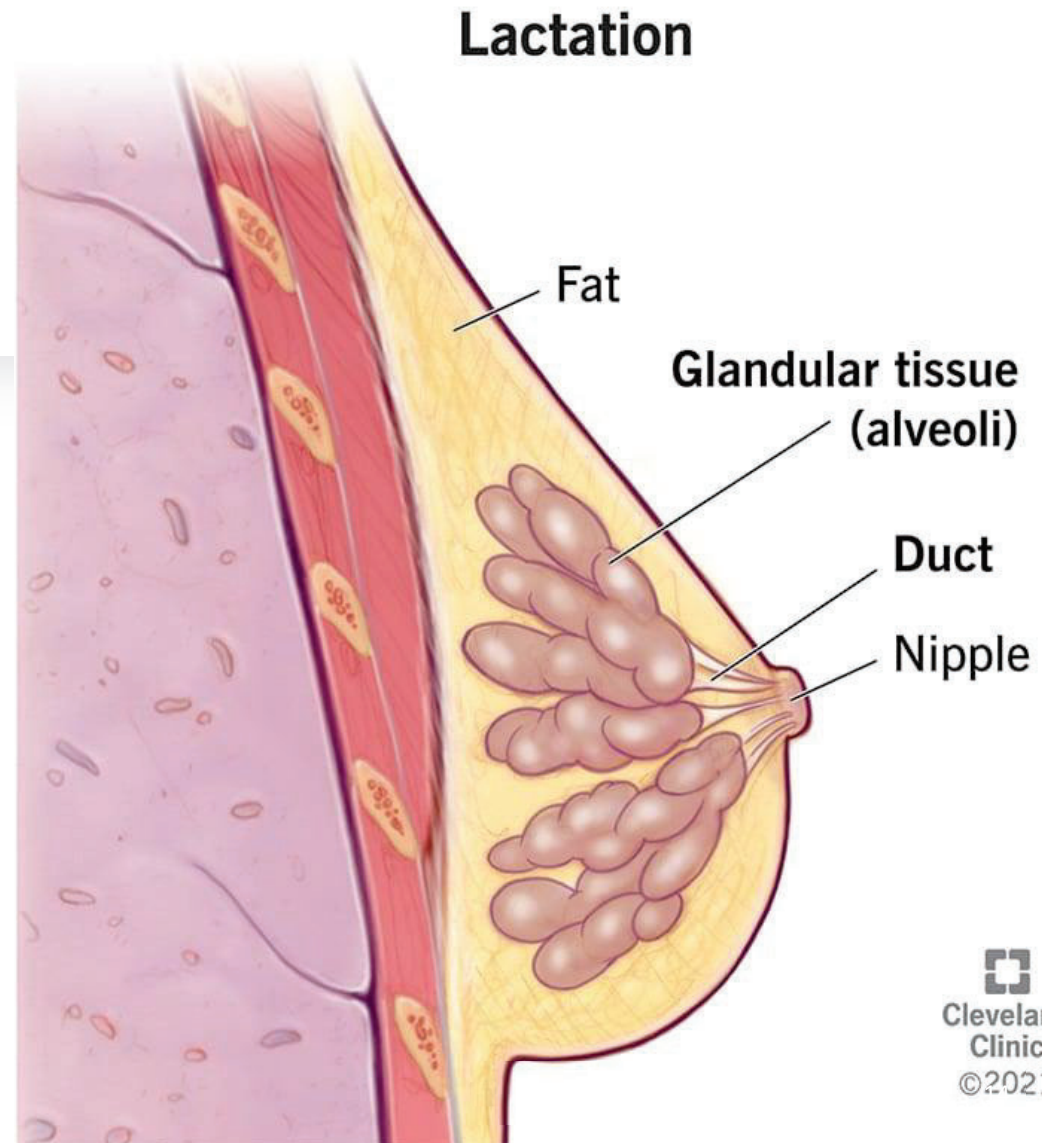
Breastmilk vs Plasma Viral Loads

- Malawian Breastfeeding, Antiretrovirals and Nutrition (BAN) study and the Vertical Transmission Study in KwaZulu Natal
- Both studies had cases of moms with undetectable VL in plasma, but detectable HIV RNA in breastmilk

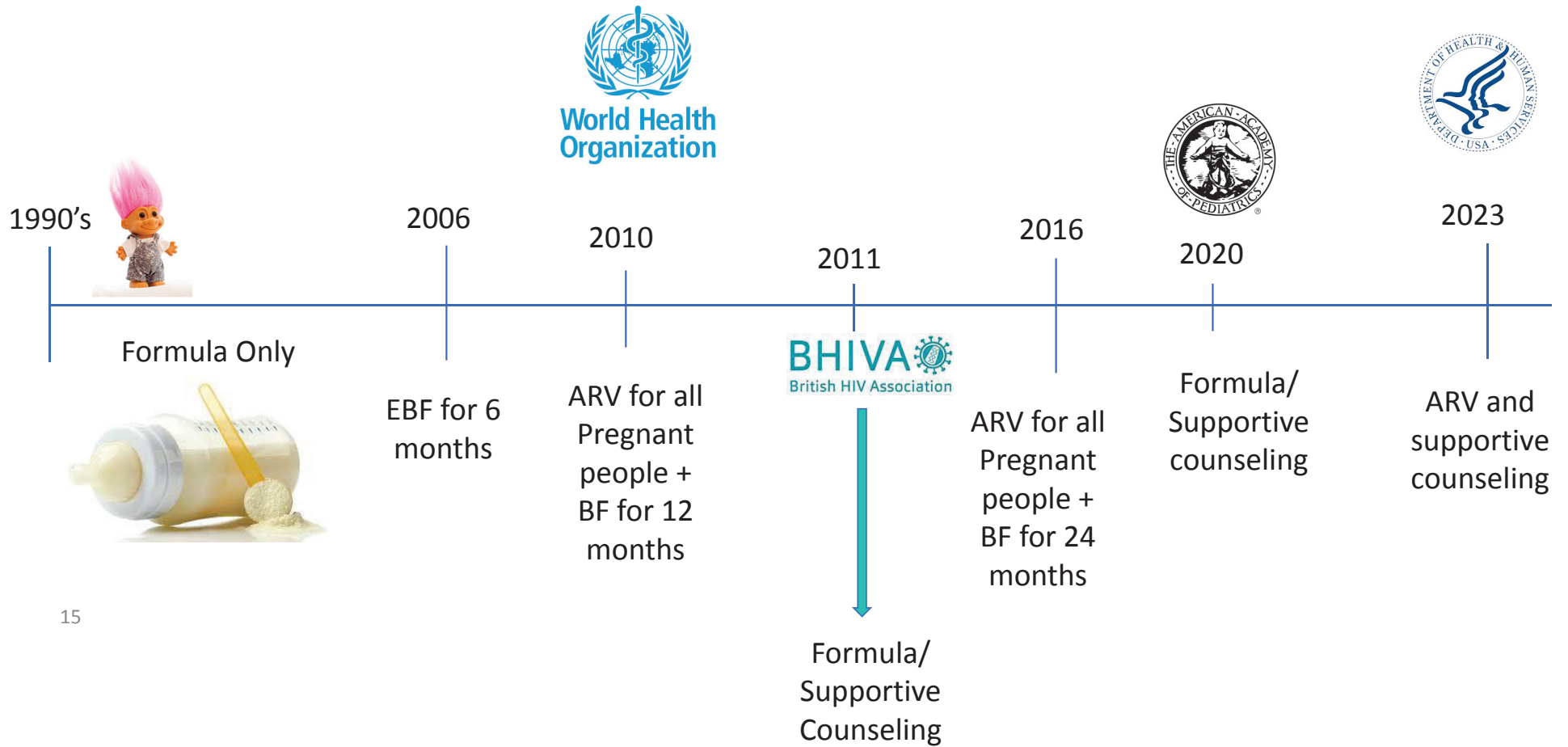
Virus present in the cells and outside of the cells?

Virus in other parts of the breastmilk or the breast?

Mastitis? Other infections?



International Breastfeeding Guidance



US Perinatal HIV Guidelines Update 2023:

Recommendations for the Use of Antiviral Drugs During Pregnancy and Interventions to Reduce Perinatal HIV Transmission in the United States

- Infant Feeding for Individuals With HIV in the United States

Panel on Treatment of HIV During Pregnancy and Prevention of Perinatal Transmission. Recommendations for Use of Antiretroviral Drugs in Transmission in the United States. Available at <https://clinicalinfo.hiv.gov/en/guidelines/perinatal/whats-new>

US HIV clinical guidelines: <https://clinicalinfo.hiv.gov/en/guidelines>



US Perinatal HIV Guidelines Update 2023

Revised Infant Feeding Counseling Guidance: Key Points

Breastfeeding transmission risk is <1% but not zero for those who achieve and maintain viral suppression during pregnancy and postpartum during breastfeeding

Replacement feeding (formula/donor milk) eliminates the risk of HIV transmission to the infant

- Replacement feeding (formula/donor milk) is recommended for those not on ART and/or do not have suppressed viral load during pregnancy/delivery
- Women on ART with a sustained undetectable viral load who choose to breastfeed should be supported in this decision
- Women who do not meet the guideline criteria will be supported in their choice and we will work together to decrease the risk of transmission as much as possible

US Perinatal HIV Guidelines (2023) Revised Infant Feeding Counseling Guidance

Perinatal Guidelines from Jan 2023- support expanded infant feeding choices

- Maternal antiretroviral therapy (ART) reduces but does not eliminate the risk of HIV transmission via breast milk;
- Women choose how to feed their infants based on multiple factors: cultural, societal, beliefs, etc.
- Criteria for low-risk breastfeeding:
 - Undetectable VL throughout pregnancy
 - >37 weeks
 - No concerns with gut integrity
- No mixed feeding
- Women need support/tools to manage infections, nipple problems



Patient Story

34-year-old woman from Africa, pregnant with her 3rd child. She was diagnosed with HIV in 2009 and has been on medications since that time. Her virus has been undetectable for many years. With her 2 older children, she was told that she should not breastfeed and she recalls feeling ashamed and judged by her family and community. She feels that culturally, if you don't breastfeed your baby, everyone will assume you have HIV. She also has always desired to breastfeed and wonders if she would have a different bonding experience with her baby.

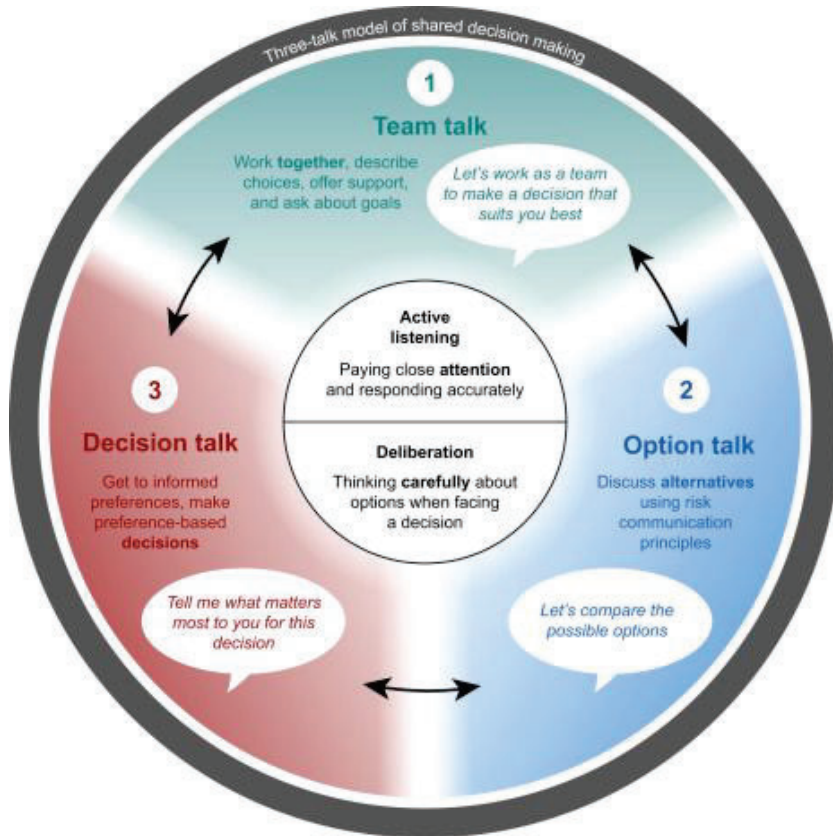
Patient Motivators to Breast/Chestfeed

- **Stigma**- wanting to feel like a “normal” parent, care/feed their child without judgement
- **Disclosure**- concerned about having to share or how to hide their HIV status from partner or family/friends
- **Access to resources/means**- lack of knowledge on how to navigate or obtain resources (formula, transportation)
- **Emotional Attachment**- normalizing their experience living with HIV and bonding
- **Messaging**- conflicting messaging regarding “breast is best”

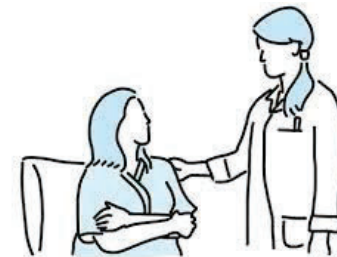


Patient/ Provider Relationship

Shared-Decision Making



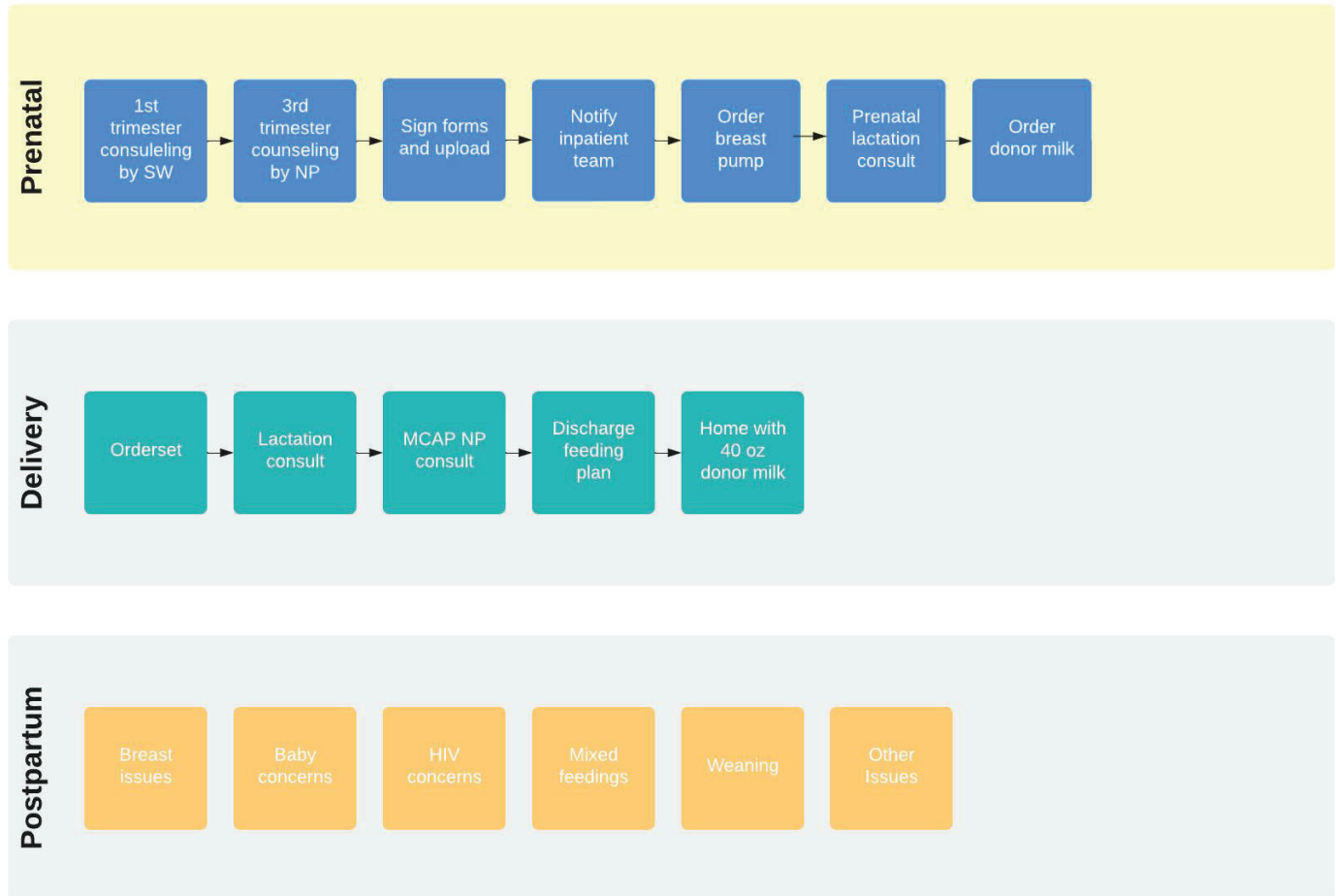
- Trust- Creating meaningful connection between patients and their providers
- Better adherence to treatment plan
- Greater treatment engagement
- Setting realistic expectations for treatment and recovery
- Increased Patient Satisfaction- patients' choices are more consistent with their informed values



Patient Story

The patient was counseled on her feeding options as well as the benefits and risks of breastfeeding. She decided to move forward with breastfeeding.

Patient Centered Initiative



Breast/ Chestfeeding: Patient Centered Initiative

Update

Update the UCSD Mother-Child HIV Protocols to include new guidance

Create

Create Internal Protocols

- Lab monitoring for mom and baby, management of VL surges, breast infections and problems, low milk supply, etc

Seek

Seek Partnerships

- UC Health Milk Bank
- Lactation Support (Pre-delivery, Inpatient, PP)

Spread

Spread the word

- Meetings with NICU, PP, Community Providers, OB, SW, Lactation teams
- Presentations at local, state and national conferences

MCAP counseling letter with specific recommendations

MCAP Counseling on Infant Feeding for People Living with HIV

- MCAP recognizes that each patient deserves adequate counseling and support, taking into account the evidence, motivation, health and cultural factors to formulate the best decision for their family.
- Breast/chestfeeding provides certain benefits to the patient and infant that are not possible with formula feeding.
- Your motivation for breastfeeding has been discussed.
- If you are considered "low risk" for breast/chestfeeding by the 2023 Perinatal HIV Guidelines, the risk of transmission of HIV to your infant is believed to be <1% (but not zero) if you maintain viral suppression throughout breastfeeding.
- **If you do not meet criteria to be considered "Low Risk" for breast/chestfeeding by the 2023 Perinatal HIV Guidelines, there may be significant risk of HIV transmission via breastmilk to your infant and we would recommend that you use formula or donor milk for infant feeding.**
- If your baby were to become infected with HIV as a result of breastfeeding, they will need lifelong HIV care and medications.

To reduce potential harm to your baby from breastfeeding, you understand and agree to the following:

Unexpected complications:

- Sometimes unexpected things happen. For example, your baby could be born too early or they could have a medical complication. If something like this occurs, the MCAP team may advise that breastfeeding is not safe for your baby.

Taking your own HIV medicines faithfully:

- It is extremely important for you to stay on your HIV treatment regimen, and to not miss doses of these medications while you are nursing to keep HIV viral counts as low as possible.

Breast/Chestfeeding Guidance:

- We recommend that you exclusively breastfeed your baby and not offer other foods or formula for the first 6 months, because mixed feeding has been associated with more risk of babies getting HIV infection from breast milk. This means your baby should not be given substitute or supplemental formula, water, juice, or other foods, and you must nurse your baby or offer pumped stored breast milk for each feeding. In the case that supplemental milk is needed, MCAP and the San Diego Breast Milk Bank can provide you with a short term supply for Donor milk free of charge.
- You have been given information about proper nursing technique and who to call for questions or problems.
- You must notify your care provider right away if you develop redness or tenderness in your breast or run a fever, because these may be signs of an infection in breast, which can increase the risk of your baby getting HIV infection from nursing.
- Your MCAP care provider can help determine if it is safe to continue nursing and will give you instructions on whether it is best to "pump and dump" breast milk for a period of time.
- If your baby develops thrush, we may recommend that your baby stops breastfeeding until it is resolved. The baby will need to receive medication to treat the thrush and should not have breast milk.
- Weaning your baby at 6 months of age is recommended, with weaning to be done gradually over 1 month.

Prenatal and Postpartum Lactation Consult

- Breast exam
- Anticipatory guidance
- Pump education, flange fitting
- Nipple care
- Develop relationships



Partnership
with UC Health
Milk Bank: take
home donor
milk packs



A close-up photograph of a newborn baby's hand, wearing a blue hospital identification band. The band has a white circular sticker with a handwritten number '2' and several small holes for ventilation. The baby's hand is resting on a white, textured surface, possibly a blanket or bedsheet. The background is softly blurred, showing more of the baby's hand and the white fabric.

Hospital Implementation: Create a Multidisciplinary Team

- Pediatric and Adult ID Specialists
- MCAP Nurse practitioner and Social Worker
- NICU and Newborn providers
- Breastfeeding Medicine Specialists
- Lactation
- Nursing
- Nutrition Services
- Nursing Leadership

Patient Story

Patient presented to UC San Diego Health, Jacobs Medical Center at 40 weeks, 1 day and delivered a healthy male via NSVD. Baby was placed S2S and latched to breast immediately.

Couplet was seen by the LC daily and was discharged home exclusively breast feeding with 40 oz of donor milk and a breast pump.

Plan for monthly viral load testing for mom and baby.

Patient Centered Initiative



Get everyone on the same page

Breastfeeding for Women Living with HIV: LOW RISK INFANT ONLY

- Low risk for perinatal HIV transmission per Perinatal HIV guidelines
- ≥ 37 weeks gestational age
- No conditions that might compromise gut integrity
- No other contraindications as determined by MCAP Team

Baby MUST meet low risk criteria!

Background: In January 2023, the Perinatal HIV guidelines were updated to reflect a model of evidence-based, patient-centered counseling to support shared decision-making about infant feeding for women living with HIV:

- Achieving and maintaining viral suppression through antiretroviral therapy (ART) during pregnancy and postpartum decreases breastfeeding transition risk less than 1%, but not zero.
- Individuals with HIV who are on ART with a sustained undetectable viral load and choose to breastfeed should be supported in this decision.
- Engaging Child Protective Services is **not** an appropriate response to the infant feeding choice of an individual with HIV.

Counseling: Families will receive extensive counseling from the Maternal Child Adolescent HIV program providers prior to delivery. They will assess their individual situation and offer recommendations on a case-specific basis. Families will receive education, handouts, and will sign "MCAP Counseling on Infant Feeding for People Living with HIV" if they choose to breastfeed- this form will be scanned into the mother's EMR.



In the Hospital:

1. Baby can be placed skin-to-skin after delivery, wipe visible blood from baby. Bath can be delayed until after the first feed.
2. Mother should receive early and ongoing lactation support during hospitalization to ensure an adequate milk supply. Early pumping is recommended if concerns regarding milk production.
3. NO MIXED FEEDINGS! Formula can cause increased gut permeability and should not be given if mother is breastfeeding. If supplementation is needed, please give donor milk after consent. NO FORMULA.
4. All mothers should have a breast pump at home or be discharged home with a pump.
5. UC Health Milk Bank will provide a small amount of donor milk to family in case supplementation is needed at home. This should be arranged prior to delivery.
6. The MCAP staff will be in contact with family on a regular basis and will be available for any questions.

References:

[Infant Feeding for Individuals with HIV in the US](#)
[CDC: Breastfeeding and Special Circumstances](#)
[NIH: Preventing Perinatal Transmission of HIV](#)

5/5/2023

MCAP Contact Information:

- Cell: 619-577-0949
- Pager: 619-290-3118

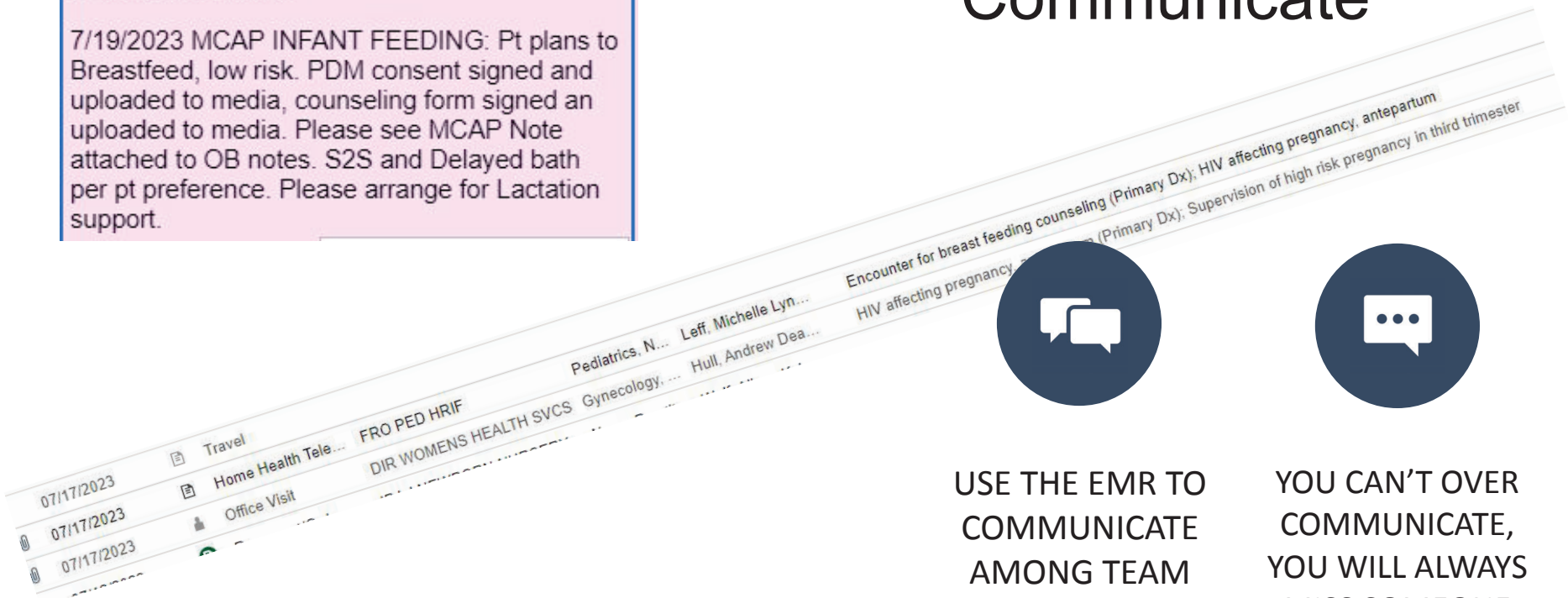
Pregnancy Sticky Note



Pap 8/21 Pap PP
Pt has not had COVID vaccine
LDASA at 12 weeks

7/19/2023 MCAP INFANT FEEDING: Pt plans to Breastfeed, low risk. PDM consent signed and uploaded to media, counseling form signed and uploaded to media. Please see MCAP Note attached to OB notes. S2S and Delayed bath per pt preference. Please arrange for Lactation support.

Communicate, Communicate, Communicate



USE THE EMR TO
COMMUNICATE
AMONG TEAM
MEMBERS



YOU CAN'T OVER
COMMUNICATE,
YOU WILL ALWAYS
MISS SOMEONE

1. MCAP NP notified of admission and birth
2. Standardized Epic Order Set (update in progress)
 - Specific feeding order
 - Skin to skin/bath after delivery
 - Medications
 - Labs
 - Lactation consult

Admission to L&D

IP PED Additional Orders for Infants with HIV+ Mother [333086]

Patient Care		Priority:	Frequency:	Comments:	Specify:	Phase of Care:	Process Instructions:	Priority:	Frequency:	Comments:	Specify:	Defaults	Available Buttons
<input checked="" type="checkbox"/>	Research Nurse Pager Number [NUR338]											Routine ONE TIME For 1 Occurrences Research RN pager number: Pager 5458 or 3118. Page Research RN Upon Patient Arrival	[Ongoing] [1 Time]
<input checked="" type="checkbox"/>	Send HIV-1 RNA Quant, Blood [NUR338]											Routine ONE TIME For 1 Occurrences Lab draw can be delayed to be drawn with other routine or research labs. The lab does NOT have to be drawn prior to starting zidovudine (AZT). Do NOT discharge infant prior to obtaining this lab. Send HIV-1 RNA Quant, Blood (1 mL lavender EDTA tube)	[Ongoing] [1 Time]



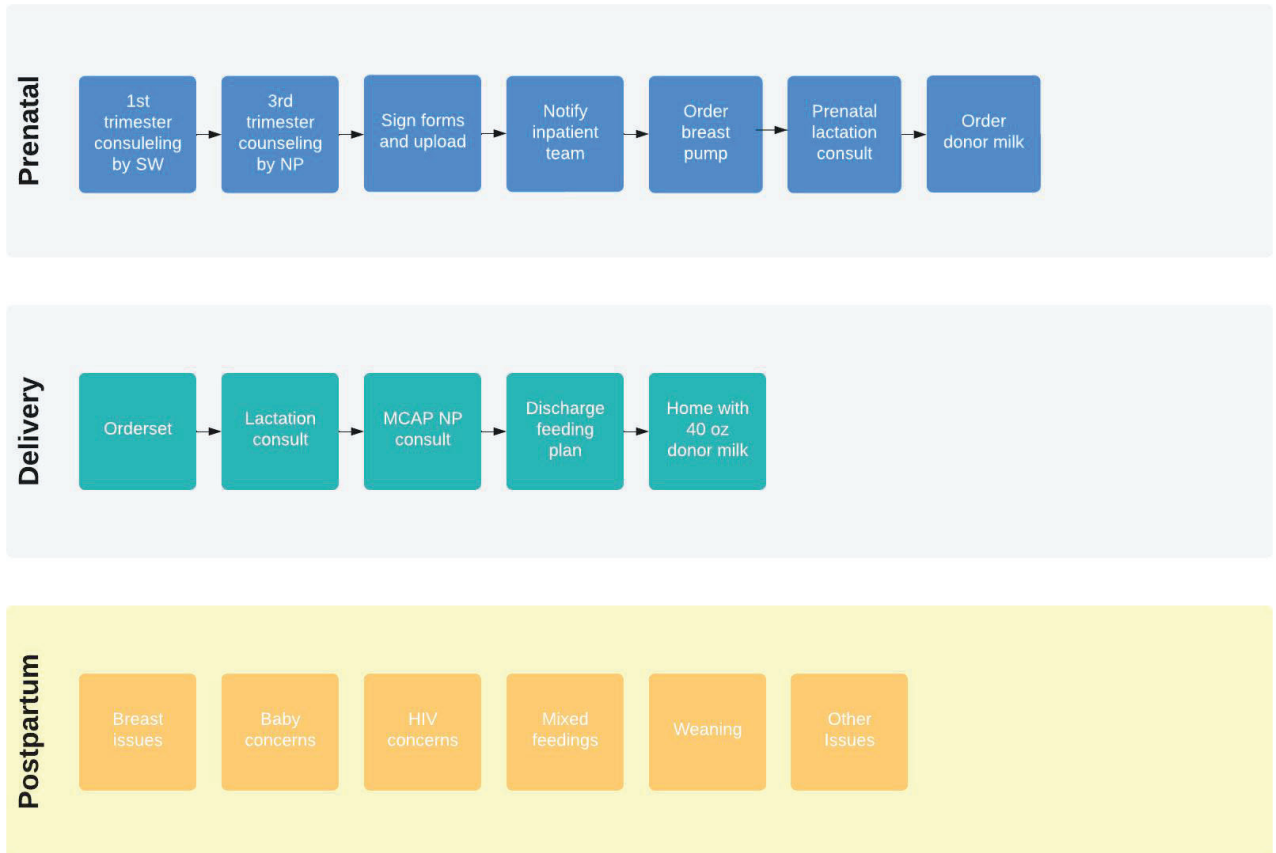
Lactation support in the hospital

- Early lactation consult
- Initiate pumping if any concerns of production issues
- Daily lactation assessment
- Donor milk if supplementation is needed
- Written discharge feeding plan
- Assure pump available and flanges fit
- Take home donor milk pack

Patient Story

Patient had several visits with outpatient lactation consultant. At appx 1 month of age, patient developed redness and heat on her right breast. She was referred to the ED and they were not clear if she had mastitis. They advised her to continue breastfeeding and monitor symptoms because this universal protocol for mastitis.

Patient Centered Initiative



Identified Gaps and Lessons Learned: more communication and outpatient support

Importance of communication among team and providers

Community support and warm handoff

Postpartum Lactation support

Medical management of suspected breast infections

Low milk supply

Identified Gaps and Lessons Learned: surprises along the way

Non-disclosure cases

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graph TD; A[Non-disclosure cases] --> B[Viral surge]; B --> C[Ethical concerns]; C --> D[Bottle refusal/refusal to wean]
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Viral surge

Ethical concerns

Bottle refusal/refusal to wean

Identified Gaps and Lessons Learned: lack of funding

- Outpatient lactation support
 - Insurance coverage
- Funding to support initiative
- Grant applications
- Donor milk coverage



Patient Centered Initiative Outcomes

13 Breastfeeding Dyads = happy parents, healthy babies!

- 1 prior to guideline change
- 12 since change in guidelines
- 50% of our current OB patients plan to breastfeed



Patient Story



Solutions: HIV Chestfeeding Working Group

- Research
- Social Work
- Lactation Medicine Specialist
- Community IBCLC
- Family Medicine
- Pediatric ID
- HIV NP and RN
- Milk Bank Executive Director





Solutions: Working on Protocols

- Mastitis
- Thrush
- Cracked nipples



Next Steps



- Crosstrain: breastfeeding training of HIV providers and HIV training of lactation providers
- Provider and community education/sensitivity training
- How to implement at other health systems?
- Research to support practice

Questions?



Citations

- Bispo S, Chikhungu L, Rollins N, Siegfried N, Newell ML. Postnatal HIV transmission in breastfed infants of HIV-infected women on ART: a systematic review and meta-analysis. *J Int AIDS Soc.* 2017 Feb 22;20(1):21251. doi: 10.7448/IAS.20.1.21251. PMID: 28362072; PMCID: PMC5467610.
- Lai A, Young ES, Kohrman H, Chateau G, Cohan D, Pollock L, Hahn M, Namusaazi B, Toini OT, Levison J, Ruel T. Tilting the Scale: Current Provider Perspectives and Practices on Breastfeeding with HIV in the United States. *AIDS Patient Care STDS.* 2023 Feb;37(2):84-94. doi: 10.1089/apc.2022.0178. PMID: 36787411; PMCID: PMC9963479.
- Levison J, Pollock L. Pediatric Care of Human Immunodeficiency Virus-Exposed Breastfeeding Infants. *J Pediatric Infect Dis Soc.* 2019 Sep 25;8(4):369-370. doi: 10.1093/jpids/piz031. PMID: 31107950.
- Levison J, Weber S, Cohan D. Breastfeeding and HIV-infected women in the United States: harm reduction counseling strategies. *Clin Infect Dis.* 2014 Jul 15;59(2):304-9. doi: 10.1093/cid/ciu272. Epub 2014 Apr 24. PMID: 2477 1330.

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- McKinney, J, Gayatri Mirani, Judy Levison, Providers Have a Responsibility to Discuss Options for Infant Feeding With Pregnant People With Human Immunodeficiency Virus in High-Income Countries, *Clinical Infectious Diseases*, Volume 76, Issue 3, 1 February 2023, Pages 535–539, <https://doi.org/10.1093/cid/ciac761>
- Waitt C, Low N, Van de Perre P, Lyons F, Loutfy M, Aebi-Popp K. Does U=U for breastfeeding mothers and infants? Breastfeeding by mothers on effective treatment for HIV infection in high-income settings. *Lancet HIV*. 2018 Sep;5(9):e531-e536. doi: 10.1016/S2352-3018(18)30098-5. Epub 2018 Jun 27. PMID: 29960731.