2018 NATIONAL RYAN WHITE CONFERENCE ON HIV CARE & TREATMENT

Perinatal HIV: A Wrap Around Model of Care

Cheri R Booth, RN, MSN, MPH, PHN &

Laura Hoyt, MD

Children's Hospitals and Clinics of MN

Disclosures

Presenters have no financial interest to disclose.

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Learning Objectives

At the conclusion of this activity, the participant will be able to:

1. Identify ways to improve care coordination between health systems
2. Recognize opportunities to partner with community organizations/health providers to address complex patient needs
3. Discuss the challenges that pregnant women living with HIV face and identify strategies to overcome barriers

National Picture of HIV

- Of the over 1.1 million people are living with HIV in the United States- approximately 25% are women
- 80% of women infected are childbearing age (15-44)
- *An estimated 1 in 5 of all people infected with HIV do not know their status.*
  - Many women learn their HIV status during prenatal testing

Perinatal HIV Transmission

Perinatal Transmission

Many men and women with HIV infection want to have children

Prevention of transmission to partners and babies is very possible, but requires a "team effort"

Coordinated care delivery/ team

- Patient (and partner)
- OB provider
- HIV provider
- Hospital
- Pediatric HIV specialist
- Well child care
- Social and support services / case management

Perinatal Transmission

Mom's status is what matters

- Amount of virus in mom's system
- Whether HIV infection is established or infection occurred during pregnancy or post-partum period (if breastfeeding)
- Whether or not HIV is well controlled, with undetectable VL

Mechanism of transmission

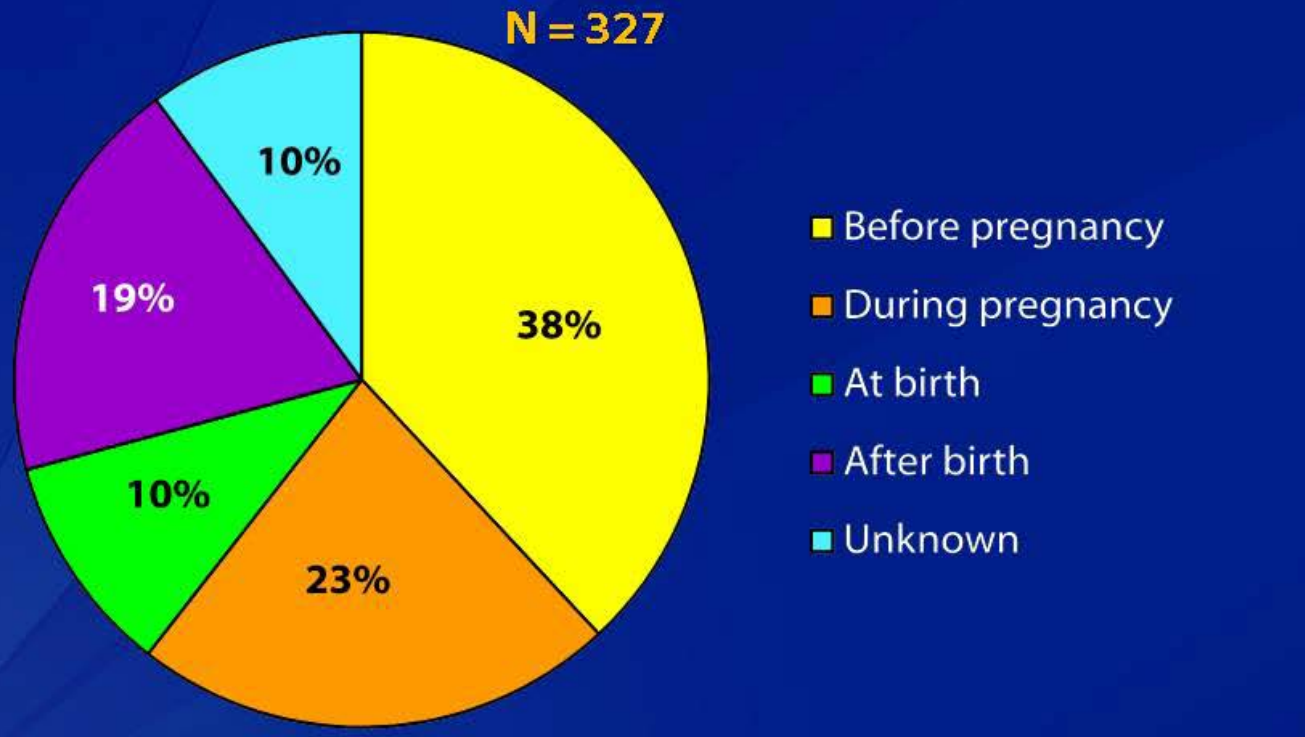
- Perinatally (in utero): 25%-40%
  - Typically with NEW infection
- Intrapartum (during labor and delivery): 60%-75%
- Additional risk associated with breastfeeding: 5-15%

Perinatal HIV Prophylaxis

- Without antiretroviral (ARV) drugs during pregnancy, mother-to-child transmission (MTCT) has ranged from 16% - 25% in North America and Europe
- In 1994 transmission rate was 21%
- February 1994, ACTG 076 Protocol (Zidovudine, ZDV, Retrovir, AZT)
  - Transmission:
    - 25% in placebo arm
    - 8% in AZT treatment arm, p=0.00006
- With the change in practice, transmission dropped to 11% in 1995
- MN: The rate of transmission has decreased from 15% between 1994 and 1996 to 1.6% in the past three years (2014-2017)

HIV testing in pregnancy

Time of Maternal HIV Testing among Infants with Perinatally Acquired HIV Infection Birth Years 2008–2011—United States



Note. Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis. All displayed data have been statistically adjusted to account for reporting delays, but not for incomplete reporting.

CDC

CDC (USPHS) recommendations for HIV testing of pregnant women

- Prenatal: routine, all, unless patient declines (opt out)
- Repeat screening in the 3rd trimester:
  - "Known to be at high risk for acquiring HIV"
  - High prevalence jurisdictions
  - Signs/symptoms of acute HIV disease ("mono," "influenza-like")
- Labor & delivery: routine rapid testing of all pts when HIV status is unknown
- Postnatal: rapid testing of all infants if mother's status is unknown
- Discordant couples

MMWR September 22, 2006/Vol. 55/No. RR-14

Additional HIV Testing goals: Partner testing

- Adult HIV care providers
  - Conversations about the role of fatherhood: value individual and cultural expectations about parenthood. Make this conversation about intention or desire to become parent part of routine care.
  - Ensure men with HIV understand particular high risk to female partners and infants if she is infected during pregnancy or while breastfeeding.
- OB – Encourage conversations about male-partner testing during pregnancy/ pregnancy planning.

Factors which influence risk of MTC transmission

- Little or no prenatal care
- HIV infection undiagnosed/ No HIV-specific care
- Acute maternal HIV infection during pregnancy or breastfeeding
- Other infections : chorion, amniotic membranes, reproductive tract
- Use of drugs/smoking during pregnancy
- Invasive procedures, such as amniocentesis or CVS, fetal scalp monitoring, use of forceps
- Artificial rupture or prolonged rupture of membranes
- Breastfeeding

Discussion about U=U in context of pregnancy and breastfeeding

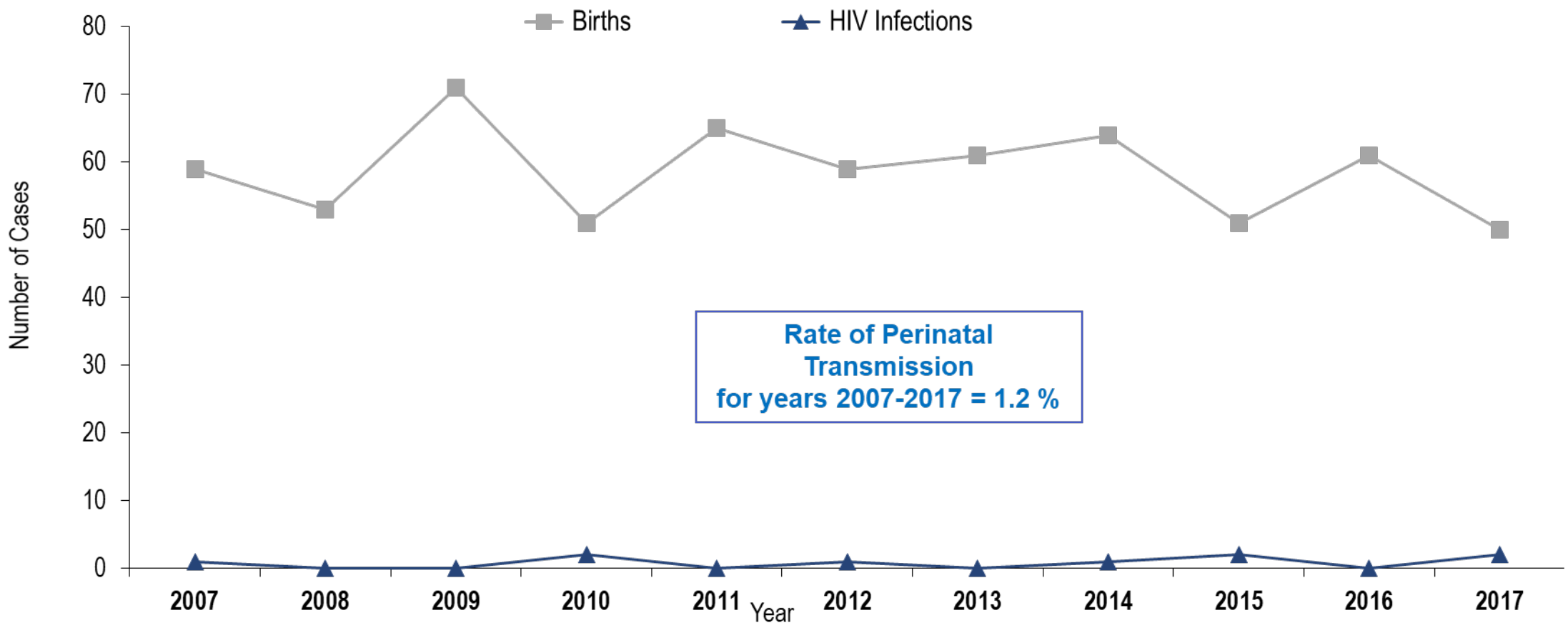
MN Specific Information

- Non centralized care, both for OB and HIV care. Hundreds of care sites across many systems
- No unified medical records system
- State mandated reporting of an HIV+ screening in a pregnant woman to the state department of health.

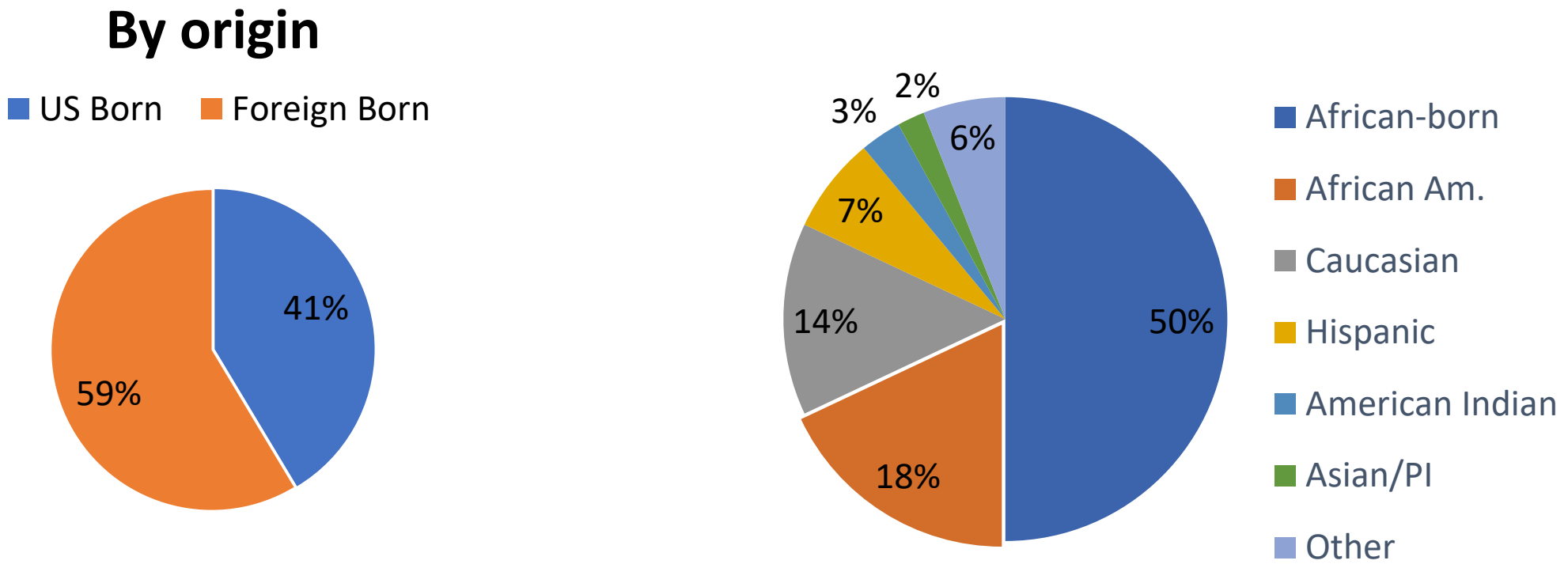
"Minnesota law, specifically Minnesota Rules Chapter 4605.7044, requires the reporting of pregnancy in a person chronically infected with HIV, including AIDS, to the Minnesota Department of Health within one working day of knowledge of the pregnancy." Via the online reporting form

- Purpose of the mandate- To facilitate a care coordination model that can address the gaps.
- Annually, 65,000 births; only about 70 are to HIV pos women, therefore our expectation is not that every provide know the recommendations, but that they know we are a resource of centralized expertise.

MN: Births to HIV-Infected Women and Number of Perinatally Acquired HIV Infections* by Year of Birth, 2007 - 2017



Perinatal Client Profile: MN 2007-2017



Goals for HIV positive pregnancy

1. Linguistically and culturally competent care
2. HIV positive identified through routine preventative care or early prenatal care in first trimester
3. Patient is established with ID care and appropriate supporting services (pharmacy, social work, and mental health)
4. Case report submitted by ID and OB to state health officials
5. Referral made to care coordination services. Health insurance active, or enrolled upon pregnancy diagnosis.
6. Education and ongoing coordination of care provided to patient. Monitoring of viral load and engagement in OB and ID care.

Goals cont'd

7. Delivery plan created, updated, and adapted to client needs submitted to delivery hospital by 32nd then 35th week of pregnancy.
8. Mom's privacy/ disclosure preferences outlined. - avoid accidental disclosure of mom's HIV status to family/ visitors
9. Infant care provider identified by 35th week and provided care plan for medication and care of/screening of HIV exposed newborn.
10. Coordination of mother's and infant's medication- verified and in- stock at delivery hospital and community pharmacy identified by patient. (IV AZT in stock if needed, liquid AZT for baby).
11. Pediatric care team often is not included in prep, coordination benefits infant care. Delivery plan includes instructions for baby's care- avoids testing and medication errors

Challenges : Client based

- Lack of health insurance
- Culture/ language barriers, difference in OB care expectations
- Stigma and lack of disclosure to community/family
- Social factors (poverty, homelessness, domestic violence, addiction)
- Lack of engagement with care coordination or case management services
- Maternity ‘deserts’: According to the American College of Obstetricians and Gynecologists (ACOG), in 2008 only 6.4% of obstetricians and gynecologists practiced in rural settings; and by 2010 almost half of all U.S. counties (most of which are rural) lacked an ob-gyn. Forty-five percent of rural counties no longer have hospitals with maternity wards.

Challenges: Provider based

- Inexperienced with perinatal HIV expertise- small % of births
  - Recommendation is to screen all women during pregnancy at beginning of prenatal care, and again during the 3rd trimester in setting of ongoing risk.
  - Reporting of all positive HIV screens to MDH
- Unaware of MN Perinatal and Pediatric HIV program.
  - Requires signed referral and release of information (ROI)
- Social/ systemic barriers to accessing and retaining in care – providers need education about these barriers in order to change practice accordingly
  - Ex: trauma informed care, flexibility of appointments, etc
- Facilitation of care coordination btw systems- active role in exchange
- Provider concern about losing patients
  - Educating that care remains with them, not 'taking patients'.
  - If not coordinated care often cause for last minute consultation with Phys Access MD (could be avoided)

Challenges: Systems based

- Maternity deserts- require a great deal more care coordination, fewer provider options to choose from
- ID care access- some areas have only one or two ID providers and reduced number of available appointments.
- Retention in care is difficult for those experiencing inconsistent housing, food insecurity, lack of transportation and child care.
- Insurance access is very complicated, especially for those new to the country or for whom English is not primary language.
- Stigma prevents many from accessing available support services that may alleviate some of the former concerns. This includes stigma around substance use.

Challenges- Systems based, MN specific

- Multiple systems of care across a large geographic area
- Usually at least two are involved but, sometimes for mother/baby care, four or more care systems are involved.
- Health information management systems have variable requirements/protocols
- Multiple ROIs must be completed (and kept updated) during pregnancy
  - Some systems require that their specific systems ROI be used

MN Perinatal & Pediatric HIV Program

Funded through Ryan White Parts A & D, MDH. Wrap- around services:

- Nursing care coordination for HIV+ pregnant women
  - During pregnancy, L&D, post-partum up to 6 mos
  - Coordination of care across providers, health systems
  - Development of delivery plan
  - Health education
  - Coordination of care/screening of HIV-exposed infant
- Preconception risk counseling and services
- Clinical and community education on HIV and pregnancy, families
- Family HIV medical case management
- Peer navigators
- Mental health support services
- HE/RR: Health Education and Risk Reduction

Children's Perinatal HIV program: Nursing Care Coordination

Nursing care coordination

- Intake and assessment
- Individual care plan
- Gather medical records and synthesize
- Make referrals to supportive services, care
- Ongoing education, support
- Customized delivery plan
- Care planning with delivery hospitals L & D unit as well as pharmacy
- Infant care plan submitted to pediatrician
- Monitoring infant screenings and medication
- Reporting to state health department

Perinatal HIV Care coordination, MN

- In MN there is care coordination for HIV positive pregnant women provided across the state by 2 coordinators. One for the Hennepin County Medical Center, and one for the rest of the state.
- Coordination is available to anyone who meets Ryan White criteria, however referrals are required.
- If, after 20th week of pregnancy, referral not made by OB or ID provider, care coordinator is notified by department of health staff and provided contact info for pt. At this time, the RN can contact pt and offer care coordination services. If declined, no further contact can be made.
- Delivery plan is created with available info from the state and submitted to the delivery hospital no later than 35th week or as soon as possible in cases after 35th week. Confirm with delivery hospital the medications are available/ ordered.

Nursing Care Coordination: Delivery plan

Maternal care:

- Mode of delivery
- Hospital planned for delivery
- Physicians: OB, Infectious Disease
- Current HIV medications & dosing
- Recent lab results: VL, CD4 count (T-cell)
- Standard maternal medications for delivery

Newborn care:

- Medications
- Recommended feeding
- Labs
- Follow-up

Children's Hospitals and Clinics of Minnesota

MN Perinatal HIV Program | Delivery Plan

Plan Date: ____ **Update:** ____

Confidentiality surrounding patient's diagnosis is very important. Please discuss HIV diagnosis/treatment with her alone and establish to whom, if anyone, she has disclosed her HIV status. ***Additional NOTE:***

Name: _____ **DOB:** _____ **Due Date:** _____

Planned Mode of Delivery: ☐ **Vaginal:** Spontaneous labor ☐ **Vaginal:** Induction date/time: ☐ **C-Section** date/time:

Hospital Planned for Delivery:

OB/GYN Physician: **Phone:** **Other:**

ID Physician: **Phone:** **Other:**

Current HIV Medications & Dosing:

Recent Lab Results

Date				
Viral Load				
CD4 count (T-cell)				

Standard Maternal Medications for Delivery:

- **If Viral Load <1000 copies/mL:** Oral HIV medications as prescribed. IV Zidovudine (AZT, ZDV) not required.
- **If Viral Load >1000 copies/mL:** Oral HIV medications as prescribed. IV Zidovudine (AZT, ZDV) recommended.

Patient and Provider Decision:

☐ Do **not** use IV Zidovudine (AZT, ZDV)

☐ **Use** IV Zidovudine (AZT, ZDV)
Zidovudine (AZT, ZDV) **2mg/kg IV loading dose over an hour, then 1 mg/kg/hr** continuous infusion until delivery. *(Goal: minimum of 3 hrs before delivery, no max time limit.)* **If on Combivir:** hold Combivir during IV AZT administration, give Lamivudine 150 mg bid.

Additional medications/orders:

Newborn Medications: **Zidovudine** (ZDV, AZT) syrup **4mg/kg po q 12 hrs beginning as soon as possible** and definitely by 6-12 hrs of age, continuing for a total of 6 weeks. *(Dose adjustments are warranted for premature infants **less than 35 weeks gestation**, or if any IV therapy is needed. Please contact pediatric ID consultation for adjusted orders if needed.)*

Additional medications/orders: **FORMULA FEEDING ONLY.**

NOTE: Please discharge pt with **at least 2 wks+** pediatric syrup; it is not easily available at community pharmacies. **Infant will need to complete full 6[£] weeks of Zidovudine.**

[£] Recommend any changes to length of ZDV treatment be determined by a pediatric infectious disease specialist, experienced in HIV, within the first weeks of life.

Community Pharmacy (if needed)**:**

Newborn Labs at Birth: CBC with diff and plts

Newborn Follow-up:
2 week HIV PCR screening **Pediatric ID clinic:** **Phone:**
Well Child Care **Clinic:** **Phone:**

NOTE: Please call the Perinatal Nurse Coordinator following delivery to help arrange for HIV screening apts.

For consultation: Please contact Dr. Laura Hoyt, Pediatric ID Consultant, Children's Hospitals & Clinics of MN
Physician Access Line: 612-343-2121 **Natl. Perinatal Hotline:** 1-888-448-8765

*****Please FAX mom's L&D records & newborn's nursery record to the Perinatal HIV Nurse Coordinator for follow-up, including mandatory state reporting, at 651-220-7233***

Nursing Care Coordination: After Delivery

- Essential to set up follow-up appointments for *mom* (HIV, OB) and *baby* (well child, HIV screening)
- HIV+ women can be more prone to "baby blues" (postpartum depression)
- Continued social support and case management
- Discuss family planning / reproductive health needs. Ensure mom has support and education on reproductive choices. Some OBs will address family planning needs, but not all. HIV providers generally do not.
- Consult with mom and HIV and OB provider on mom's postpartum appts and encourage/assist mom to prioritize those appts for her own health.
- Moms may need additional assistance to make/keep appts after delivery
  - "Mom brain"
  - Lack of sleep, stress of new infant

Children's Perinatal HIV program: Case Management

- Assess for eligibility to supportive programs and services (food, transportation, housing, SA counseling, medications assistance etc).
- Assist with enrolling clients in targeted services
- Assist with enrollment and retention of health insurance for patient and family
- Individualized case management plan- for the patient and family
- Mental health assessment and referral
- Ongoing assistance with appointments, transportation, etc
- Disclosure counseling, care advocacy, transition planning/ skill building

Children's Perinatal HIV Program: Peer Navigators

- Available for phone and in person sessions.
- Screened and hired by Children's
- Non- medical
- 4 peer navigators- specialized experiences to support pregnancy, youth, LGBTQ, and for families adopting HIV positive children

Coordination – Systems and providers

Recognize opportunities to partner with community organizations/health providers to address complex patient needs

- Work with L and D coordinators throughout the state
- Pharmacy- medications needed for delivery/ infant
- Monthly meetings with two larger ID practices
- Integral relationship with state health department
- Local and statewide trainings to bring awareness about perinatal HIV and referral options
- Individual clinic/provider education- identification of ‘champions’
- Physician Access Line for provider consultation
- Ability to travel- meet clients at home, clinics, treatment facilities, etc
- Referrals – Ex: Birth support doulas

Future goals and directions

- FIMR- Fetal and Infant Mortality Review: Assesses, reviews, and works to improve process and service systems. Example: IV AZT access
- Champions- Identification of OB, Peds, and Adult HIV providers who are well trained and versed in HIV perinatal and pediatric care provision
- Testing partners- Ongoing goal to improve adult HIV and OB provider's screening of partners during pregnancy or preconception period
- Administrative support- Dedicated admin to assist nurse, case manager, and peer navigators in order to expand capacity of the team to provide direct patient services.
- Reduce percentage of clients LTFU after infant screening period.
- Breastfeeding- Future development of individual risk reduction strategies and recommendations

Questions/Case studies

Complex patients: Case study 1

- 1st pregnancy
- Lupus- recent hospitalizations for ‘flares’
- Substance use- THC
- Inconsistent housing
- Has been unable to maintain consistent work
- Familial support- Partner and mother are aware of HIV status
- Care coordination and case management services provided

Complex Patients: Case study 2

- Outstate MN resident. Distance to care provider >1 hour
- Foreign born
- Married, Partner negative
- Recent HIV diagnosis <6 months
- Multiple prenatal care providers (out of state and out of country)
- Preterm delivery @ 32 weeks
- Alternative health beliefs/ practices
- No care coordination or case management services provided

Complex Patients: Case study 3

- US born
- Metro/ suburban metro resident
- Unexpected/ unplanned pregnancy
- OB and ID care provided by different systems. HIV viral suppression
- Partner and adult child of client unaware of client's HIV status
- Complicated cesarean delivery
- No care coordination or case management services provided

Clinical Resources

National Perinatal HIV Consultation and Referral Service

(24 hrs, 7 days/wk)

- **800- 448-8765**

MN Physician's Access Line for consultation

612-343-2121

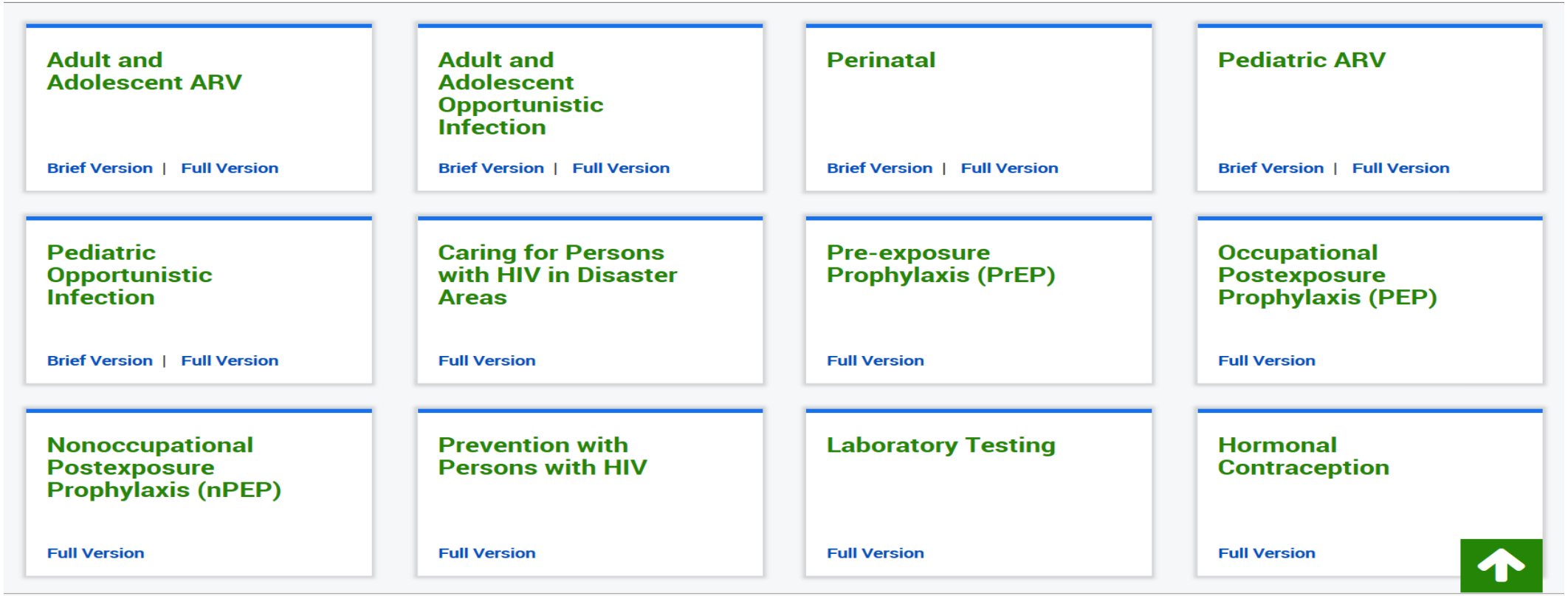
Minnesota Department of Health, HIV/AIDS Division, Perinatal HIV Transmission

- www.health.state.us/divs/idepc/diseases/hiv/hivperinatal.html

Resources

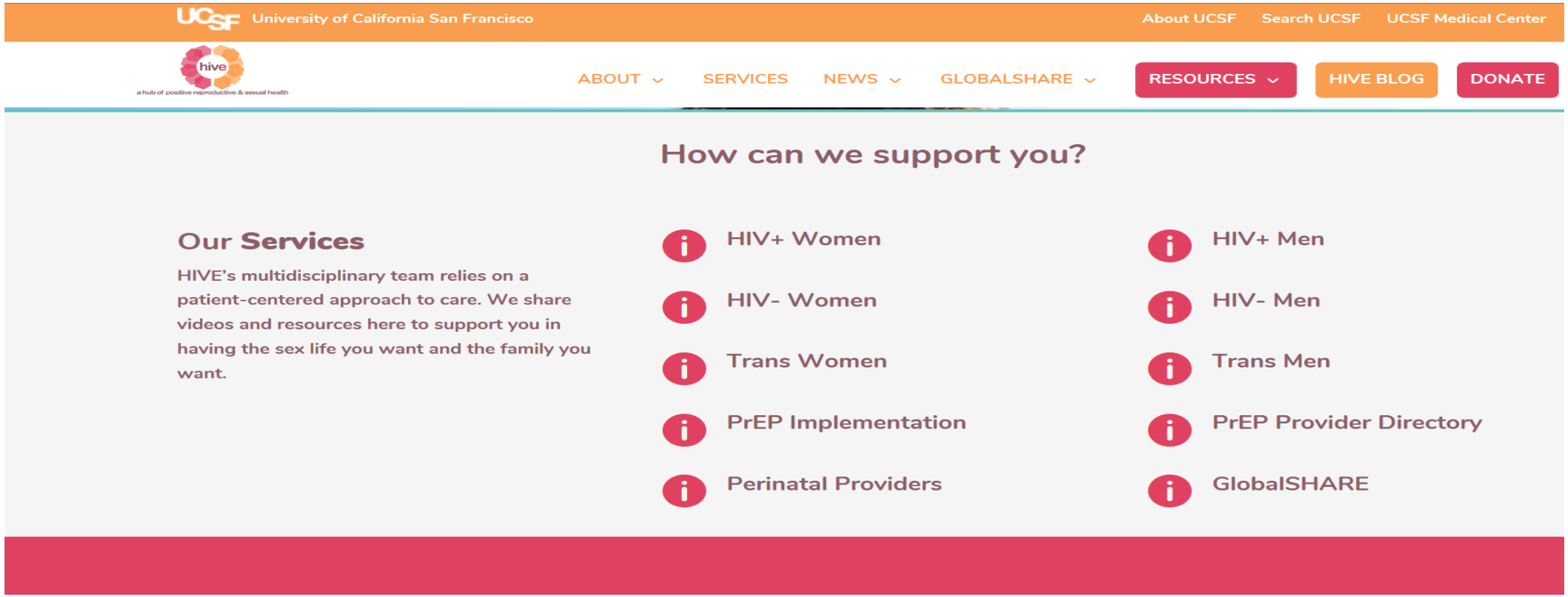
For guidelines about perinatal HIV

- https://aidsinfo.nih.gov/guidelines and select ‘perinatal’



Resources

The Hive: ‘Hub of positive reproductive and sexual health’. *Patient friendly*



Thank you for your time!

Please call or email with questions:

Cheri Booth, RN, MSN, MPH, PHN
Perinatal HIV Nurse Coordinator
(612) 387-2989
Cheri.Booth@childrensmn.org

Laura Hoyt, MD
Clinical Director
(612) 343-2121
laura.hoyt@childrensmn.org

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