Working to Prevent Perinatal HIV, Congenital Syphilis and Reducing Infant Mortality

24th Annual Illinois HIV/STD Conference
October 29, 2015
National Fetal and Infant Mortality Review
- Enhances the health and well-being of women, children and their families
- Identifies factors leading to an infant’s death

Fetal Infant Mortality Review–HIV
- Main goal is to eliminate perinatal transmission of HIV
- Identifies and addresses missed opportunities and local systems issues associated with Perinatal HIV exposure and transmission
How can we improve systems of care for pregnant women in order to maximize healthy birth outcomes?
Welcome to Prevent Perinatal HIV, Congenital Syphilis and Reducing Infant Mortality

AGENDA
October 29, 2015
9:30am – 12:00pm

9:30am - 9:40am Welcome and Introduction (Christi Jackson)

9:40am - 10:40am Background on Perinatal HIV, Congenital Syphilis and Infant Mortality in Illinois
- Perinatal HIV – 9:40am-10:00am (Anne Statton)
- Congenital Syphilis – 10:00am-10:15am (John Creviston)
- Infant Mortality – 10:15am-10:30am (Virginia Julion & Bernadette Taylor)

10:40am – 10:50am Update on Progress (Christi Jackson)

10:50am - 11:00am Break

11:00am - 11:15am Description of Goals for FY2016 (Eduardo Alvarado)
- Goal #1: Advocate for universal repeat 3rd trimester HIV testing and educate providers of the importance to adhere to the Illinois Prenatal Syphilis Screening Act that mandates 3rd trimester screening for syphilis.
- Goal #2: Educate medical providers and consumers about inter-conception health.
- Goal #3: Raise awareness and educate medical providers about the impact of trauma and mental health on the health of women of reproductive age.

11:15am - 11:50am Participant Feedback and Discussion (Eduardo Alvarado)

11:50am – 12:00pm Wrap Up and Opportunities for Involvement (Christi Jackson & Eduardo Alvarado)
Perinatal HIV

Working to Prevent Perinatal HIV, Congenital Syphilis and Reducing Infant Mortality

October 29, 2015
Springfield, IL
Preventing Perinatal HIV

1. Universal HIV Testing & Reproductive Health and Family Planning services and preconception care

2. Comprehensive real-time case-finding

3. Clinical and psychosocial services for pregnant, HIV-positive women

4. Case review and community action (FIMR-HIV)

5. Data Reporting

6. Research & Long-term monitoring
1. HIV Testing: Illinois Deliveries

HIV-Positive Women Delivering in Illinois

- 2010: 132
- 2011: 144
- 2012: 136
- 2013: 119
- 2014: 121
- 2015-partial: 66
## Illinois HIV Prevalence Among Females, 2014

<table>
<thead>
<tr>
<th>Race</th>
<th>Living, HIV (non-AIDS) cases</th>
<th>% of Total LWH</th>
<th>Living, AIDS cases</th>
<th>% of Total LWA</th>
<th>Living, HIV Disease cases</th>
<th>% of Total PLWHA</th>
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### Age

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<th>% of Total LWA</th>
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<td><strong>7710</strong></td>
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2. Case-finding: HIV at delivery and Triage

Positive rapid HIV tests

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<th>Triage</th>
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<tr>
<td>2015</td>
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3. Clinical care: Adherence predicts outcome

![Graph showing the correlation between percentage of pills taken and viral suppression.]

- **95-100% Pills Taken:** About 80% viral suppression.
- **90-95% Pills Taken:** About 60% viral suppression.
- **80-90% Pills Taken:** About 50% viral suppression.
- **70-80% Pills Taken:** About 20% viral suppression.
Safety Net of Prevention: Illinois

Key elements of the safety net include:

24/7 Illinois Perinatal HIV Hotline

Rapid HIV testing in labor and delivery units and maternal hospitals throughout the state

Enhanced perinatal HIV case management for the highest risk women and their infants.
Supports **Rapid HIV Testing** across all Illinois Maternity hospitals (collects monthly data, provides advice and support to staff)

Manages the **Perinatal Enhanced Case Management** Program (PECM). Intensive case management services offered to HIV-positive pregnant and recently delivered women. Assistance with pregnancy planning, during pregnancy, at labor and delivery and for six months after delivery for mom and baby.

Coordinates Rapid Testing and PECM with the **24/7 Perinatal HIV Hotline** to ensure linkage to care for all referred women, support to hospitals for reporting rapid positive reports and follow up for women and infants who were missed for testing.

Provides chart abstraction for the **Fetal Infant Mortality – HIV (FIMR-HIV)** Review process.
Perinatal Enhanced Case Management

- Designed for pregnant, HIV-positive women who need extra support during their pregnancies

- Coordinated services ensure:
  - *Women get the help and support they need to ensure a healthy pregnancy and birth*
  - *Postpartum care for both mother and her HIV-exposed infant*

- PACPI Serves women in Chicago and collar county area
- Heart of Illinois serves women in Peoria
- Project ARK serves women in the East St. Louis area
Statewide resource for medical and social service providers caring for pregnant HIV positive women

Provides up-to-date treatment recommendations for pregnant women and their HIV exposed infants

The official reporting mechanism for positive rapid HIV tests performed on mothers and infants and it initiates follow-up and support for hospital rapid test reports
4. Case Review: FIMR HIV

Review of cases of missed opportunities associated with perinatal HIV exposure and transmission

FIMR-HIV Case Review Team has reviewed a total of 90 HIV cases, which includes:
   - 6 cases of maternal perinatal acquisition
   - 12 cases of infant transmission
69/90 (77%) had a history of one or more of the following challenges or were impacted by the following social determinants of health during or after pregnancy:

- Substance abuse – 50 (72%)
- Mental illness – 34 (49%)
- [28 (82%) suffered from depression]
- Homelessness – 19 (28%)
- Incarceration – 16 (23%)
- Domestic violence – 17 (25%)
Cases of Documented Maternal HIV Seroconversion during pregnancy in IL

17 cases of maternal HIV seroconversion identified between Jan 2007-June 2015

7/17 (41%) infants HIV-infected
5. Research & Long-term Monitoring: CDC

Estimated Annual Incidence of Perinatal HIV Infection, 33 States, HARS, 2003-2007 (N=463)

Estimated annual incidence declined from 4.5 cases/100,000 live births (2003) to 3.0 cases/100,000 live births (2007).

Annual rate of diagnoses of perinatal HIV infection per 100,000 infants aged ≤1 year, by race/ethnicity — 34 states, 2004-2007

Lampe, MA., MMWR, 2010, Vol. 59 No. 4
6. Data Reporting: PHER

Pediatric HIV Exposure Reporting (PHER) in Chicago 2012 - 2014

- 300 HIV positive women delivered
- 227 women were known HIV positive
Initiation of prenatal care, by trimester (n=300)

- 1st Trimester: 202
- 2nd Trimester: 68
- 3rd Trimester: 22
- No prenatal care: 4
- Unknown: 4
Initiation of HAART (n=300)

Prior to preg 124
1st Trimester 60
2nd Trimester 75
3rd Trimester 25
No Treatment 12
Unknown 4

*NOTE:
- 5 women received no treatment because of lack of prenatal care
- 3 were known HIV negative during pregnancy (no third trimester test done) - diagnosed after pregnancy.
- 4 women were diagnosed at delivery
STIs in Pregnancy (n=116)

- Chlamydia: 24
- Genital Herpes: 28
- Hep B: 4
- Hep C: 5
- Gonorrhea: 5
- Syphilis: 13
- Trich: 37
Co-morbidities (n=73)

Mental Illness:

- 37 women suffered from depression
- 30 women suffered from other mental illnesses such as Bipolar Disorder, Anxiety Disorder, and Schizophrenia

Substance Abuse:

- 90/300 women used substances during pregnancy
Remaining Gaps

1. **Repeat 3rd trimester testing**
   Ongoing cases of perinatal transmission have been among women who contracted HIV during pregnancy, after an initial HIV test was negative, and were not retested/diagnosed prior to delivery.

2. **HIV-positive women fall out of care after pregnancy**
   Low rates of postpartum appointment attendance and return to HIV primary care postpartum. There is limited documentation of pregnancy planning, birth spacing and contraception use among HIV-positive women in Illinois.

3. **Mental health and trauma**
   Women experiencing mental health and trauma have challenges accessing care, adhering to care plans and medication, and the system is also challenged.

4. **Stigma**
   Disclosure of status is a barrier to services and HIV stigma can impact adherence. Near perfect adherence is essential for prevention of perinatal transmission.
Thank you!!

Thank you to Isiah Duckworth, Laurie Ayala and Christi Chandler-Jackson for their assistance with this presentation.

PACPI is supported by the Illinois Department of Public Health.
Congenital Syphilis

John Creviston
Syphilis Prevention Coordinator, IDPH
On Behalf of:
Irina Tabidze, MD MPH
Epidemiologist
Treponema Pallidum
Syphilis

• Syphilis is a chronic infection caused by the bacterium *Treponema pallidum*.

• The manifestations of this infection vary and may present quite differently in each individual.
Syphilis in Pregnancy

• Primary & secondary syphilis is usually devastating for the fetus

• About half (52%) of untreated latent infections result in adverse pregnancy outcomes

• Adverse outcomes include:
  • Fetal loss and stillbirth: 21%
  • Neonatal death: 9.3%
  • Prematurity or low birth weight: 5.8%
  • Congenital syphilis: 15%

Gomez et al. 2013
Syphilis in Newborns

- Most live-born neonates with Congenital Syphilis (CS) are asymptomatic at birth.

- Infection can manifest in the fetus, the newborn, or later in childhood.

- The infant may have symptoms at birth or be asymptomatic until 6-8 weeks of life (delayed form).

- Clinical manifestations after birth are divided into:
  - Early CS (<=2 years of age) and
  - Late CS ( >2 years of age)
Signs of Congenital Syphilis

• Symptoms include:
  – Snuffles
  – Hepatosplenomegaly
  – Syphilitic Skin Rash
  – Pseudo Paralysis
  – Jaundice/Hepatitis
  – Edema
Signs of Congenital Syphilis

- Signs of congenital Syphilis
Late Congenital Syphilis

- Hutchinson’s Triad
  - Interstitial keratitis
  - Deafness
  - Teeth abnormalities
Late Congenital Syphilis

• Symptoms Include:
  – Tooth abnormalities
    • Moon’s Molars or Mulberry Molars
  – Maldevelopment of the Maxilla
    • Bulldog Facies
  – Perioral Fissures (Rhagades)
Preventing Adverse Outcomes

• Mother To Child Transmission (MTCT) of syphilis is prevented by testing and treatment of pregnant women

• Serological testing should be done on the mother at the time of the first prenatal visit and again at during the third trimester as required by the Illinois Prenatal Syphilis Act (410 ILCS 320/)

• Timely and appropriate treatment is critical
  • At least 30 days prior to birth for effective treatment of the fetus
  • Benzathine penicillin

• Partner testing and treatment
Treatment in Pregnancy

• Early Syphilis: 2.4 million units Benzathine penicillin G (Bicillin-LA) IM in a single dose.

• Latent Syphilis: 2.4 million units Benzathine Penicillin G (Bicillin-LA) IM weekly for 3 weeks. Injections must be at seven day intervals.

• Penicillin Allergy
  – Consider penicillin skin testing and if true penicillin allergy mother must be desensitized and treated with Benzathine penicillin G in accordance with appropriate stage of infection.
Epidemiology

- More newborn infants are affected by CS than any other neonatal infections, including human immunodeficiency virus (HIV) infection.

- During 2013, 348 cases of CS were reported nationally.

Congenital Syphilis—Infants—Rates by Year of Birth and State, United States and Outlying Areas, 2013

NOTE: The total rate of congenital syphilis for infants by year of birth for the United States and outlying areas (Guam, Puerto Rico, and Virgin Islands) was 8.6 per 100,000 live births.
Congenital Syphilis—Reported Cases Among Infants by Year of Birth and Rates of Primary and Secondary Syphilis Among Women, United States, 2004—2013

*CS* cases (in thousands)

<table>
<thead>
<tr>
<th>Year</th>
<th>CS Cases</th>
<th>P&amp;S Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>2004</td>
<td>0.4</td>
<td>0.2</td>
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<tr>
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<td>2006</td>
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<td>2009</td>
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<td>2010</td>
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<tr>
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<tr>
<td>2013</td>
<td>0.4</td>
<td>0.2</td>
</tr>
</tbody>
</table>

*CS* = congenital syphilis; *P&S* = primary and secondary syphilis.

CDPH, STI Surveillance reports
Congenital Syphilis cases by Race, Chicago, 2008-2014

CDPH, STI Surveillance report
Congenital Syphilis cases by Age Groups, Chicago, 2008-2014

CDPH, STI Surveillance report
Prenatal Testing - CS cases, Illinois, 2014

- 27 cases
  - 15 (55%) No/Unknown prenatal care
  - 12 cases (45%) Prenatal care
    - 9 cases Tested >30 days of delivery
      - 4 (sero converted at delivery)
    - 3 cases Tested ≤30 days of delivery
      - 5 cases treated ≤ 30 days of delivery

CDPH, IDPH 2014 Unpublished data
Messages to Ensure Prevention

• Provider education

• Continuity of care from prenatal visit to delivery

• Adequate prenatal care and screening at 1\textsuperscript{st} and 3\textsuperscript{rd} trimester

• Timely reporting of positive serologic screening

• Timely and adequate treatment of mother $> 30$ days prior to delivery
Acknowledgments

• Chicago Department of Public Health
• Illinois Department of Public Health
• Centers for Disease Control and Prevention
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John Creviston
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217-782-2747
Infant Mortality: An Overview

Bernadette Taylor RNC, MSN, APN
Perinatal Network Administrator

University of Chicago Medicine
U.S. lags behind other wealthy nations on infant mortality

Infant mortality rates in selected OECD countries, 2010

Finland: 2.3
Japan: 2.3
Portugal: 2.5
Sweden: 2.5
Czech Republic: 2.7
Norway: 2.8
Korea: 3.2
Spain: 3.2
Denmark: 3.4
Germany: 3.4
Italy: 3.4
Belgium: 3.6
France: 3.6
Israel: 3.7
Greece: 3.8
Ireland: 3.8
Netherlands: 3.8
Switzerland: 3.8
Austria: 3.9
Australia: 4.1
United Kingdom: 4.2
Canada: 4.9
Poland: 5.0
Hungary: 5.3
New Zealand: 5.5
Slovakia: 5.7
United States: 6.1

Infant deaths per 1,000 live births

Source: CDC

Note: Canada data from 2009
Infant Mortality........the facts

Unfortunately, over 23,000 infants died in the United States in 2013 (CDC, 2013)

• Despite healthcare spending levels that are significantly higher than any other country in the world, a baby born in the U.S. is nearly three times as likely to die during her first year of life as one born in Finland or Japan.

• Higher infant mortality rates are primarily found in lower socio-economic classes in the U.S.

• Babies born to underprivileged mothers are more likely to die than babies of wealthier mothers.

• Babies born to underprivileged mothers in other rich and developed nations do not see the same dramatic rise in mortality rates that we do in the U.S.

Infant Mortality and Infant Mortality Rate

**Infant Mortality** - The death of a baby before his or her first birthday

**Infant Mortality Rate** - an estimate of the number of infant deaths for every 1,000 live births.

Source:
http://www.cdc.gov/reproductivehealth/maternalinfanthealth/infantmortality.htm
On September 29, 2014, a Washington Post reporter wrote......

“Our infant mortality rate is a national embarrassment”

• If Alabama were a country, its rate of 8.7 infant deaths per 1,000 would place it slightly behind Lebanon in the world rankings.

• Mississippi, with its 9.6 deaths per 1,000, would be somewhere between Botswana and Bahrain.

What about Illinois?
Illinois Infant Mortality Rate
2010-2014

Source: IDPH Maternal and Child Health Data Book, July 2015
Identified causes related to the inequity in the availability and access of quality healthcare between economic classes and minority groups

Most of these babies die as a result of the following:

- Birth defects
- Preterm birth (birth before 37 weeks gestation) and low birth weight
- Sudden Infant Death Syndrome (SIDS)
- Maternal complications of pregnancy
- Injuries (e.g., suffocation).

http://www.cdc.gov/reproductivehealth/maternalinfanthealth/infantmortality.htm
What’s Illinois doing about it?

Illinois is committed to improving birth outcomes and decreasing infant mortality.

• CDC provides support to Perinatal Quality Collaborative (PQC) initiatives in California, New York, Illinois (ILPQC), Massachusetts, North Carolina, and Ohio.

Networks of perinatal care providers and public health professionals are working together to implement the following best practices:

• Real-time reporting of perinatal clinical quality metrics (e.g., elective deliveries less than 39 weeks of gestation
• Administration of antenatal steroids [medication given before birth to speed up a baby’s lung development]) in an effort to prevent prematurity and improve outcomes for infants born too early and too small.
• CoIIN: Collaborative Innovation and Improvement Network Project: IDPH and Illinois is addressing infant mortality by focusing on Perinatal Regionalization, Social Determinants of Health, Preconception/Inter-Conception Care and Safe Sleep
• Right place, Right Time
Virginia Julion RNC, BSN, MPH
FIMR Coordinator
Fetal and Infant Mortality Review (FIMR)

- Identifies fetal deaths (infants born dead after the 20th week of gestation) and neonatal deaths (any live born infant regardless of gestational age and weight) who dies within the first 28 days of life
- Effective in identifying the social and economic factors impacting pregnancy outcomes in the City of Chicago (606 zip codes) through case reviews
FIMR Objectives

• Examine and identify the significant health, social, economic, cultural, safety and education system factors that are associated with fetal and infant mortality through review of individual cases
• Plan a series of intervention and policies that address these factors to improve the service systems and community resources
• Participate in the implementation of community based interventions and policies
• Assess the progress of the community based interventions
### Race

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<thead>
<tr>
<th>Year</th>
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Priority Areas Identified

• Interconceptual care that includes well woman, high risk care, chronic disease care
• Mental health services
• Cigarette, alcohol, and substance abuse services
• Cultural competency
• Systems (medical and social systems)
• Marketing
Preconception Health

- This is not a new concept
- American College of Obstetrics and Gynecology and American Academy of Pediatrics started the first guidelines for perinatal care in the 1980s
- March of Dimes Birth Defects Foundation statement in the 90s “Risk reduction should be emphasized and family planning counseling and services routinely available. Annual preconception or interconception visits should become the standard of care”
- Healthy People 2000 objective: Increase to 60% the proportion of providers who provide age appropriate preconception care and counseling
- Healthy People 2020 objective: Reduce the proportion of pregnancies conceived within 18 months of a previous birth
Preconception Health Care

- Part of overall health among women and men during their reproductive years
- Focuses on steps that women, men, and health professionals can take to reduce risk and promote healthy lifestyles
- One of the best ways against low birth weight and poor pregnancy outcomes
- Most effective when this service is provided as part of general preventive care or health maintenance
- Risks can be identified
- Maximizes maternal health
- Intervenes to achieve outcomes
- Ideal time to
  - Complete risk assessments
  - Provide education and health promotion
  - Provide medical and psychosocial interventions
Evidence Based Effectiveness

• Many preconception interventions reduce the risks of adverse pregnancy outcomes that include birth defects, fetal loss, low birthweight, and preterm delivery
• Interventions to reduce risk:
  • - managing medical conditions, including counseling on safest medication choices during pregnancy
  • - counseling women to avoid certain risks (such as alcohol use, smoking, prescription and over the counter medications, excessive vitamins, under/over nutrition, toxic substances
  • - counseling men on engaging in healthy behavior and avoiding certain risks
  • - likely higher rate of pregnancy intendedness for those who become pregnant
Remember Preconception Health

- Usually means nothing to the general public
- Not everyone (women, men, future grandmothers) understands the importance of the earliest weeks of pregnancy
- Women in most need of preconceptual health promotion are often those who are least likely to receive it
Interconceptual Interval

• The interval between one pregnancy outcome and the next regardless of pregnancy outcome

• An interpregnancy interval less than 18 months is often associated with adverse outcomes

• Adverse outcomes are more increased for interpregnancy intervals of 6 months or less
Interconceptual Period

• During this time provide additional intensive interventions to women who have had a previous pregnancy that ended in an adverse outcome (infant death, fetal loss, birth defects, low birth weight, preterm birth, significant maternal morbidity)

• Continue integration of preconception health into existing public health and related programs especially for women with previous adverse conditions

• Maximize public health surveillance and related research mechanisms to monitor preconception health
Interconceptual Care Should Include

• Appropriate family planning/education
• Quality well woman care
• Improving, stabilizing chronic/preexisting medical conditions
• Accessing appropriate level of care
• Education on what to expect during prenatal care visit
• Maintaining optimal health for next pregnancy
• Access to affordable/quality care
• Genetic counseling
• Mental health services*
How will this be done?

• Educate providers and consumers on what is proper pregnancy spacing and when should it be used (reproductive life plan)
• Include sex education/family planning in age appropriate school health curriculum
• Provide cultural sensitivity training for staff on all levels
• Encourage early health promotion
• Provide access to high quality medical care
Working to Prevent Perinatal HIV, Congenital Syphilis and Reducing Infant Mortality

24th Annual Illinois HIV/STD Conference
October 29, 2015
Perinatal HIV 3rd Trimester Testing

- In 2014, a “Dear Colleague” letter was sent to Obstetrician/Gynecologists, Family Medicine and mid-level practitioners, to strongly recommend 3rd trimester testing in clinical practice with pregnant women in Illinois.

- A follow-up survey revealed that only a few had actually implemented third trimester testing.

- IDPH and other key stakeholders continued to work on the Perinatal HIV third trimester testing legislation. The proposed language not only addressed the need for third trimester testing for all pregnant women in IL, but also included HIV testing of women identified as pregnant and being treated for other health conditions in an emergency care setting.
Perinatal HIV Case Management Trainings

- A 2-day training about the overall care of pregnant HIV+ women, preventing perinatal transmission, and effectively using existing resources available across social service systems

- Collaboration with IDPH, PACPI, MATEC, IDHS

- Locations: Chicago, Springfield: Upcoming – Mt. Vernon, IL
The FIMR–HIV methodology was applied to review cases of congenital syphilis.

Cases are identified by FIMR–HIV Case Review Team members from Chicago Department of Public Health, Cook County Department of Public Health and Illinois Department of Public Health

Data abstraction forms specific to congenital syphilis have been developed in order to collect the information needed to provide an in-depth look at the care a mother and her infant received.
FIMR–HIV Opportunities for Success

- Engaging Experts & Community Stakeholders
  - Internal: IDPH HIV, STD & OWHFS
  - External: Caregivers, Advocates & Clients

- Collaborative Action Plan Development

- Evidence–informed Policies & Programs

- Prevention, Public Health & the Life Course
  - Enhanced Screening, Data Collection & Surveillance
  - Improved Infrastructure for Perinatal, HIV & STI Care

- Change through Community Action
2016 Goals

- Advocate for universal repeat 3rd trimester HIV testing and educate providers of the importance to adhere to the Illinois Prenatal Syphilis Screening Act that mandates 3rd trimester screening for syphilis.

2) Educate medical providers and consumers about inter-conception health.

3) Raise awareness and educate medical providers about the impact of trauma and mental health on the health of women of reproductive age.
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- 24/7 Illinois Perinatal HIV Hotline
- Chicago Department of Public Health
- Cook County Department of Public Health
- Fetal Infant Mortality Review/HIV (FIMR/HIV) Team
- Illinois Department of Human Services
- Illinois Department of Public Health – Office of Women’s Health
- Midwest AIDS Training and Education Center
- National Fetal and Infant Mortality Review
- Pediatric AIDS Chicago Prevention Initiative (PACPI)
Thank You!!!

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