Perinatal HIV Prevention in Illinois

Illinois Department of Public Health

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Pediatric AIDS Chicago Prevention Initiative (PACPI)

Perinatal Rapid Testing Initiative for Illinois (PRTII2)

IL Perinatal HIV Advisory Board; IL FIMR/HIV Project

IL 24/7 Perinatal HIV Hotline; IL Perinatal Network
Background – Perinatal HIV Prevention in Illinois
1988 – Women & Children HIV Program/Cook County Hospital/Chicago (now a Ruth M. Rothstein CORE Center program, Cook County Health & Hospitals System);
Women & Children HIV Program 1990-ongoing

- HRSA/MCHB Pediatric AIDS Demonstration Project; later HRSA/Ryan White Title IV/Part D serving women, children, adolescents, families, including incarcerated and detained women and youth

- Statewide Regional Perinatal Network of Birthing/Non-Birthing Hospitals with referral protocol to better manage high risk pregnancies and improve birth outcomes

- Pediatric AIDS Clinical Trials (PACTG); Women Infants Transmission Study (WITS); Women’s Inter-Agency HIV Study (WIHS)

- 1995 – HRSA/HAB SPNS Grant led to the statewide practice of routine voluntary HIV screening of pregnant women with ACOG endorsement.
Comparable Developments

- 1989 and ongoing – Families’ & Children’s AIDS Network (FCAN) and Pediatric AIDS Foundation Chicago advocacy/charitable groups launched; service providers, child welfare advocates, volunteers and consumers participated; *(and still do!)*


- 2000 – Pediatric AIDS Chicago Prevention Initiative (PACPI) launched
### Illinois Statewide Perinatal Network

**Northern / Suburban**  
30 B / 8 NB hospitals

**Chicago**  
66 B / 10 NB hospitals

**Central**  
39 B / 20 NB hospitals

**Southern**  
17 B / 22 NB hospitals

<table>
<thead>
<tr>
<th>Network</th>
<th>Birthing hospitals</th>
<th>Non-birthing hospitals</th>
</tr>
</thead>
<tbody>
<tr>
<td>University of Chicago</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Stroger (Cook County) Hospital</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>Northwestern</td>
<td>13</td>
<td>5</td>
</tr>
<tr>
<td>University of Illinois</td>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td>Loyola</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Rush</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Suburban Combined*</td>
<td>(18)</td>
<td>(2)</td>
</tr>
<tr>
<td>Rockford</td>
<td>12</td>
<td>6</td>
</tr>
<tr>
<td>Peoria</td>
<td>27</td>
<td>7</td>
</tr>
<tr>
<td>Springfield</td>
<td>12</td>
<td>13</td>
</tr>
<tr>
<td>St. Louis</td>
<td>17</td>
<td>22</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>133</strong></td>
<td><strong>58</strong></td>
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</table>
IL Perinatal HIV Prevention Act - 2003

- All pregnant women in Illinois must be counseled and offered an HIV test as early in pregnancy as possible.

- HIV test results will be documented in prenatal, L&D and newborn pediatric chart.

- If there is no documented maternal HIV status on arrival to L&D, the patient will be offered a Rapid HIV test (opt-in).

- If maternal status not known at delivery, newborn will be given rapid HIV test unless mother declines (opt-out).
Illinois Timeline

- Evaluation plan developed
- Evaluation plan implemented
- Complete Monthly Data Collection
- CDC/IDPH On-line Data Entry

**IL Perinatal Prevention ACT passed**
- IDPH buy-in
- PRTII formed

**IDPH funding begins**
- Binder development
- Needs Assessment: Survey/Focus Groups
- Regional Trainings
- Pilot Projects

**Hospital Rapid Testing Implementation**
- Revised IL Perinatal Prevention ACT signed

- Aug 2003
- Nov 2003
- Jan 2004
- July 2004
- August 2004
- Sept 2004
- Sept 2005
- June 2006
Illinois Safety Net of Perinatal HIV Prevention

Programs

Perinatal Enhanced Case Management
Perinatal Rapid Testing Initiative in Illinois (PRTII)
24/7 Perinatal Hotline and Website
PACPI-HP (Housing Program for Homeless Pregnant Women)
Directly Observed Therapy; HIV-Specific Prenatal Classes
New Moms Making Positive Changes

24/7 Illinois Perinatal HIV Hotline
800-439-4079
hivpregnancyhotline.org

20 Years of Leadership
A LEGACY OF CARE
Enhanced Case Management

Foundation:
Baseline expectations for all Ryan White Case Management of pregnant HIV positive women

Training/Technical Assistance provided on essential elements of Enhanced perinatal case management which includes:

1. outreach and case finding – real time
2. chaperoned visits / transportation assistance
3. wrap-around services
4. Direct Observed Therapy (hospital-based / community-based)

HIV-specific Prenatal Classes
Specialized housing assistance
Counseling/cultural competency skills
**PACPI Experience FY 2010**

- 116 clients served by 5 case managers
- 4,172 instances of transportation assistance
- 1,332 face-to-face meetings
- 2,533 home visits
- Clients: 78% African American; 12% Latinas, 6% White, 4% Multiracial or unknown race; 10% Spanish-speaking only
- Age: 13-24, 33%; 25-34, 46%; 35 years or older, 21%
- 86% Medicaid; 10% Medicare; 4% Private Insurance
- 84% reside in Cook County; remainder: Lake, Kane, DuPage and Kendall Counties
Project ARK/Southern IL Experience  (FY 2010)

- St Clair County/East St Louis region has the 3rd highest HIV incidence/prevalence in IL, behind Chicago and Suburban Cook County; 63% male/37% female; 51% African American

- One case manager provides enhanced case management services for pregnant HIV positive women in Southern Illinois.

- Twelve HIV positive pregnant women identified and served by this agency in southern Illinois (primarily East St. Louis/St. Clair County).

- All twelve women received all three arms of the AZT protocol to reduce perinatal transmission of HIV from mother to infant.

- All twelve women delivered HIV negative infants.
CORE Center/Women & Children HIV Program

2000-2010

- 2001-2008 – No cases of perinatal HIV transmission among any pregnant HIV positive woman served by the program.

- 2009 - One confirmed case of perinatal HIV infection.

- Four (4) prenatally infected young adults in the program have delivered or fathered HIV negative children. Three females and one male.

- Challenges of perinatally infected youth: Age 15 seems to be major turning point for many. Issues of non-adherence with medication; sexual relations may/may not be protected; disclosure issues associated with having HIV/AIDS. One perinatally infected youth died in 2009; one is terminal as of this writing.

- Urgent next steps: Specific Mental Health/Life Skills counseling for prenatally exposed young adults; comprehensive health/sex education
24/7 Perinatal Hotline & Website

Illinois Perinatal HIV Hotline
1-800-439-4079

The Hotline Provides:
Real-time medical information - to treat HIV-positive and preliminary positive pregnant women and exposed newborns

Linkage to care for HIV-infected pregnant women - matching women with a dedicated case manager

A reporting mechanism for positive rapid HIV tests - as mandated by the Illinois Department of Public Health

www.hivpregnancyhotline.org
24/7 IL Perinatal Hotline Data Summary
(Calls made in Calendar Year 2009)

County of Provider Referral (N=220)

<table>
<thead>
<tr>
<th>County</th>
<th>Number of Calls</th>
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<tbody>
<tr>
<td>Chicago</td>
<td>79</td>
</tr>
<tr>
<td>Suburban Cook County</td>
<td>32</td>
</tr>
<tr>
<td>Collar</td>
<td>26</td>
</tr>
<tr>
<td>Rest of IL</td>
<td>33</td>
</tr>
<tr>
<td>Non-IL</td>
<td>16</td>
</tr>
<tr>
<td>Unknown</td>
<td>34</td>
</tr>
</tbody>
</table>
**Calls: Pregnant HIV+ Women**

*(80 calls)*

**Patient’s Race (N=80)**

<table>
<thead>
<tr>
<th>Race</th>
<th>Number of Women</th>
</tr>
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<tbody>
<tr>
<td>NH White</td>
<td>6</td>
</tr>
<tr>
<td>NH Black</td>
<td>37</td>
</tr>
<tr>
<td>Hispanic</td>
<td>11</td>
</tr>
<tr>
<td>African</td>
<td>5</td>
</tr>
<tr>
<td>Unknown</td>
<td>21</td>
</tr>
</tbody>
</table>

**Linkage to Medical Care for Known Positive or Preliminary Positive Women (N=80)**

- **Known Positive**
  - Linked by Hotline to prenatal care: 12
  - Linked by Hotline to postpartum HIV care: 4
  - Linked - not by Hotline: 2
  - Refused linkage: 2
  - Not linked - no consent (retro report/lost to care): 4
  - Already linked to care: 23

- **Positive Rapid Test-true positive**: 7
- **Positive Rapid Test-false positive**: 1
- **Positive Rapid Test-indeterminate**: 1

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**Logo and Text**

20 Years of Leadership

A Legacy of Care
PRTII<sub>2</sub> Experience FY 2010

- Provides training and technical assistance with Labor & Delivery unit staff members (all shifts), at hospitals across Illinois.

- Training includes education/promotion of 24/7 perinatal hotline; enhanced case management services; HIV case reporting/enhanced perinatal surveillance and 3<sup>rd</sup> trimester HIV testing with pregnant women.

- Collects L&D rapid HIV testing data, following up on preliminary positive test results for confirmation.

- Conducts essential chart abstractions for the FIMR/HIV Project.
Illinois
Jan – Dec 2009
(as of 03/11/2010)

Delivered Women
160,050

Presented with Documentation
151,493 (94.7%)

Presented without Documentation
8,557 (5.3%)

Missed for RT*
32 (0.4%)

Declined RT
61 (0.7%)

Rapid Tested
8,464 (98.9%)

Positive
157

Missed for RT
32 (0.4%)

Refused RT
9 (10.3%)

Rapid Tested
58 (66.7%)

Rapid Tested
8,443

False Positive
4

True Positive
17

Negative
157

Positive
157

Fetal Demise
23

Newborns without Documentation
87**

** Includes 1 Safe Haven, 5 home deliveries, 7 transports, 1 birth at a correctional facility and 1 set of twins.

Maternal RT Post Partum
10 (11.5%)

Missed for RT
10 (11.5%)

Refused RT
9 (10.3%)

Rapid Tested
58 (66.7%)

Positive
1

Negative
57

Neglected documentation: 8,557 (5.3%)

HIV Documentation at Discharge: 99.97%

An additional 20 women had a positive rapid test as outpatients, 17 true positives.

* Rapid Testing = RT
Illinois HIV Care Connect Regions

www.hivcareconnect.com
Perinatal HIV Cases in Illinois
2008 – 1; 2009 – 4; 2010 (through 6/30) – 2

(48 cases from 2005 through June 30, 2010)
74% Black;
25% White
1% Others

52% Chicago;
13% Suburban Cook County;
10% Collar Counties;
25% Downstate
Illinois FIMR/HIV Project 2009-present

- Launched October 2009; only Statewide Project funded (CDC/ACOG/CityMatCH)

- Title V MCH Director & IDPH ID Medical Director serve as Co-chairs; 25 member Case Review Team (includes Chicago/Suburban/Downstate professional and consumer members)

- 25 cases (chart abstractions/maternal interviews) to be reviewed

- 8 cases reviewed thus far

- Community Action planning underway
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