

Pediatric AIDS Chicago Prevention Initiative

Annual Report – 2008

MISSION The mission of the Pediatric AIDS Chicago Prevention Initiative is to eliminate deaths from pediatric AIDS and to reduce transmission of the virus from mothers to their children in the state of Illinois.

The **Pediatric AIDS Chicago Prevention Initiative (PACPI)** is a collaborative enterprise of public and private partners representing HIV prevention and treatment statewide. In 2008, PACPI's Safety Net of Prevention (Enhanced Case Management, Perinatal Rapid Testing Initiative and the Illinois 24/7 Perinatal HIV Hotline) was recognized by the CDC as a model program. The Illinois Department of Public Health also recognized that achievement by increasing the number of perinatal enhanced case managers supported by PACPI – one position added to focus efforts on Lake County and the northern suburbs and a second position was added to focus efforts on Kane, DuPage and Will counties. Illinois also saw improvements in the high proportion of pregnant women who know their HIV status at the time of delivery. In addition, the number of HIV-infected newborns continues to decline.

Pregnant women know their HIV status

More moms are presenting to the hospital with a documented HIV status – which means that more women are being tested prenatally (over 94%). The success in Illinois is due in large part to the efforts of labor and delivery staff at every hospital in the state who are committed to helping prevent perinatal transmission in their own communities. In addition to the testing at hospitals, 99.99% of moms and babies going home from the hospital know their status. The number of babies

discharged without a known maternal HIV status also dropped in 2008 to less than 25 of the approximately 168,000 births! Also in 2008, the number of women identified at the time of delivery (11) was outpaced by the number of women identified before delivery as outpatients (15). Those women have a better chance at prevention due to their early identification as HIV-positive.

HIV-positive moms are having HIV-negative babies

All but one PACPI case managed moms who delivered in 2008 have HIV negative babies! Our one client with a positive baby was not referred for case management until after the infant was born. However, that infant is responding well to treatment and growing beautifully. PACPI targets the hardest-to-reach, hardest-to-link women with multiple issues that often contribute to a case of transmission. Through the hard work of our dedicated team, we have successfully linked all women case managed in 2008 to prenatal care, care for their HIV disease and helped to address many of the other social, financial, medical and basic needs. The PACPI case managers really go the extra mile – occasionally picking up the women in their cars and personally escorting them to their visits to ensure linkage.

Enhanced case management evaluation funded by CDC is complete!

PACPI was awarded a \$242,000 contract (one of two sites nationally) to evaluate our Perinatal HIV Enhanced Case Management Program in 2007. The evaluation includes case management outcome data, costs, qualitative client interview data, and an evaluation of our prenatal classes. The Sinai Urban Health Institute has been working with PACPI since 2007 to help collect and evaluate this data. A report on the finding will be available in 2009.

PACPI served a total of 105 women in 2008 with over 10,000 encounters. Almost half of those encounters are provided in person either in the home, in the clinic or at a location that is comfortable to the client. The other half of the encounters are by telephone to maintain frequent contact with the client. Part of PACPI's success is to provide intensive contact with the client, in order to ensure her needs are met, medical, prenatal and pediatric appointments are kept and that the mom is adhering to her medication regimen.

The majority of PACPI clients are women of color (72% African-American, 14% mixed race). Six percent are Non-Hispanic white women and another six percent of the women did not identify a race. Ninety percent (90%) of clients had at least one dependent with an average of 1.8 children.

The greatest challenge that the PACPI case managers face is working with newly diagnosed pregnant women who are afraid to disclose their status to anyone. HIV

in pregnancy can be so isolating that it becomes very hard to ask for and receive assistance. Medications and appointment adherence become an extra challenge because of their fear of disclosure. The PACPI case managers approach all their clients with an attitude of no judgment and work from the strengths of each client to create a service plan that will maximize her strengths while linking her to the care she needs to have her baby born free from HIV.

24/7 Perinatal HIV Hotline continues to serve a need

In 2008, the Hotline experienced a continued increase in call volume as compared to previous years. Calls to the Hotline increased by 63% as compared to 2007, 100% as compared to 2006 and 186% compared to 2005 (160 calls in 2008, 98 calls in 2007, 80 calls in 2006 and 56 calls in 2005). The Hotline received reports of 54 pregnant and positive women in 2008, either through calls identifying them directly to the Hotline or through retrospective reporting of preliminary positives. During 2008, a major focus was the continued development of the Hotline website. A beta site was finished and tested by Hotline staff as well as representative users (labor and delivery nurses, clients, family practice and obstetric physicians, etc.).

PACPI Housing Project

In our efforts to expand delivery of care, PACPI embarked on a new partnership with the AIDS Foundation of Chicago, Housing Opportunities for Women, Interfaith House and Christian Community Health Center in April 2008. The Pediatric AIDS Chicago Prevention Initiative Housing Partnership (PACPI-HP) targets homeless or unstably housed pregnant women and links them with permanent supportive housing units for them and their families. Special emphasis was placed on women who also needed support to take medications during pregnancy, using a housing-based model of hospital-based therapy. As of December 2008, all ten of the housing units allocated to the pilot program have been filled with PACPI clients experiencing a desperate need of permanent supportive housing. The PACPI-HP participants are provided furnished apartments, *Welcome Packs* for mother and baby, and the opportunity to participate in directly observed therapy (DOT) to ensure compliance with medication regimens for mom, baby or both.

Directly Observed Therapy

Through a grant from the Illinois Department of Public Health and the AIDS Foundation of Chicago, PACPI received funding to provide directly observed medication therapy (DOT) for pregnant HIV-positive clients in their homes. Prior to this grant, clients that needed additional medication adherence support had been admitted into the hospital for observation of doses. The funding provides a lower cost alternative. DOT has also been available for new moms who need assistance

with providing medication to their newborns. In 2008, five clients were provided with DOT assistance. The goal of DOT is to reduce viral load in the pregnant woman by the time of delivery to help maximize prevention of transmission to the newborn.

Prenatal Classes for HIV-positive pregnant women

PACPI held five sessions of its prenatal class for HIV-positive pregnant women in 2008. Four classes were offered in English and one in Spanish. The classes are 12 hours long – spread out over three weeks and include sessions on HIV 101, all three trimesters of pregnancy, the importance of medication adherence in pregnancy and for newborns, birth planning, delivery decisions, reproductive health care, and nutrition. The classes, kept small so women can engage in dialogue, help participants become actively involved in their care and the care of their newborns. A total of 39 women participated in the classes in 2008.

New Moms Making Positive Changes

The unique connection established between the women at the prenatal class is just a start for helping to address the isolation that many HIV-positive women feel, especially new moms. This is why PACPI joined forces with the Children's Place Association and the Illinois Department of Children and Family Services to start a new support group for new HIV-positive moms. In 2008, 9 women participated in the group covering topics such as parenting, medication adherence, emotional burden of HIV-infection, family support, return to work, confidentiality and disclosure.

Perinatal Case Management Training Course

To ensure that all HIV-positive pregnant women in Illinois receive a statewide standard of care through comprehensive case management, PACPI launched the Perinatal HIV Case Management Training Program in 2008. By the end of 2008, 32 case managers from around the Chicagoland area have been certified through the Perinatal HIV Enhanced Case Management Training Program. Startup funding to develop the training came from a grant through the US Centers for Disease Control and Prevention. PACPI anticipates that the case managers who complete our training program will feel better equipped to handle the unique challenges of HIV-positive women.

Our Plans for 2009

PACPI plans to continue our successful ongoing projects with the Hotline, enhanced case management, housing, DOT, prenatal classes, support group for new moms, and to support the continued efforts for making the rapid testing program in Illinois birthing and non-birthing hospitals successful. In addition to these efforts, there are a few initiatives specific to next year.

Evaluation of Enhanced Case Management Program

The Enhanced Case Management program evaluation finished data collection in September 2008. The evaluation team is in the process of preparation of final report and use the information to improve our program as well as to share the findings with the community. There are also plans to present the data nationally with CDC along with the other agency receiving funding to do this evaluation.

Hotline Website live!

A joint project with the Hotline and the PRTII project, the Hotline website includes materials for hospitals, providers and clients on HIV in pregnancy, rapid testing and services available by calling the hotline. The 24/7 Perinatal HIV Hotline, www.hivpregnancyhotline.org went live in March 2009.

New PACPI Website live!

PACPI launched a new website in April 2009 www.pregnantandpositive.org Stay connected with PACPI through becoming a member of our PACPI Facebook group and follow us on Twitter www.Twitter.com/PACPI.

Client-focused interviews

Through an intern provided by the Adler School of Professional Psychology, PACPI is compiling interviews of case managed clients in 2009 about their experiences receiving services with us. The clients have the opportunity to share their story in the hopes that it will encourage other women to access services and care.

Spanish language support group

Through a close collaboration with the Children's Place Association, PACPI will begin offering Spanish language support groups for expectant HIV-positive couples and couples with new babies. Some of our clients have requested this extra support in Spanish to help with the variety of issues faced by living the US as a non-native English speaker and being HIV-positive and pregnant.

PACPI in the Headlines

The Safety Net of Prevention — Illinois was recognized in April 2008 as a “model program” for perinatal HIV prevention nationwide, thanks to the efforts of Pediatric AIDS Chicago Prevention Initiative, along with the 24/7 Perinatal HIV Hotline and the Perinatal Rapid Testing Implementation Initiative. The Illinois Governor issued a press release commending the hard work of PACPI, the hotline and Illinois hospitals.

Illinois Department of Public Health Expands Perinatal Enhanced Case Management — The Illinois Department of Public Health awarded PACPI \$413,159 to support perinatal enhanced case management in July 2009. The funding included the addition of two new positions to focus on the collar counties to the north, west and south of Cook, reflecting an increase of clients in Lake, Kane, DuPage and Will counties.

PACPI’s Strategic Partnership — PACPI is pleased to announce our recognition by the Lodestar Foundation as a quarter-finalist in 2008 The Collaboration Prize competition. The Collaboration Prize recognizes collaborations among two or more nonprofit organizations that each would otherwise provide the same or similar programs or services and compete for clients, financial resources and staff. PACPI and the AIDS Foundation of Chicago were recognized for their co-location, in our efforts to mutually collaborate on policy and case management initiatives benefitting HIV-affected families.

PACPI Thanks Partners

PACPI thanks the following organizations that have generously supported our work with collaborative efforts to better serve HIV-affected women and their families.

Illinois Department of Public Health (IDPH)
Perinatal Rapid Testing Implementation in Illinois (PRTII)
24/7 Perinatal HIV Hotline
US Centers for Disease Control and Prevention (CDC)
Children's Memorial Hospital
AIDS Foundation of Chicago (AFC)
Mt. Sinai Hospital
Northwestern Memorial Hospital
John Stroger Hospital
University of Chicago Hospital
University of Illinois Hospital
Sinai Urban Health Institute (SUHI)
Department of Children and Family Services (DCFS)
Children's Place Association
Midwest AIDS Training and Education Center (MATEC)
Pediatric AIDS Chicago
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Polk Bros Foundation
The Private Bank
Hektoen Institute
Illinois Chapter of the American Academy of Pediatrics

DONORS

Private

AIDS Foundation of Chicago (AFC)
Pediatric AIDS Chicago
DIFFA/Chicago
Illinois Chapter of the American Academy of Pediatrics

Corporate

Dr. Scholl Foundation
Polk Bros Foundation
Abbott Fund
The Private Bank
Hektoen Institute

Government

Illinois Department of Public Health (IDPH)
US Centers for Disease Control and Prevention (CDC)

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AIDS Foundation of Chicago (AFC)
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Perinatal Rapid Testing Implementation in Illinois (PRTII)
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Northwestern Memorial Hospital
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Midwest AIDS Training and Education Center (MATEC)
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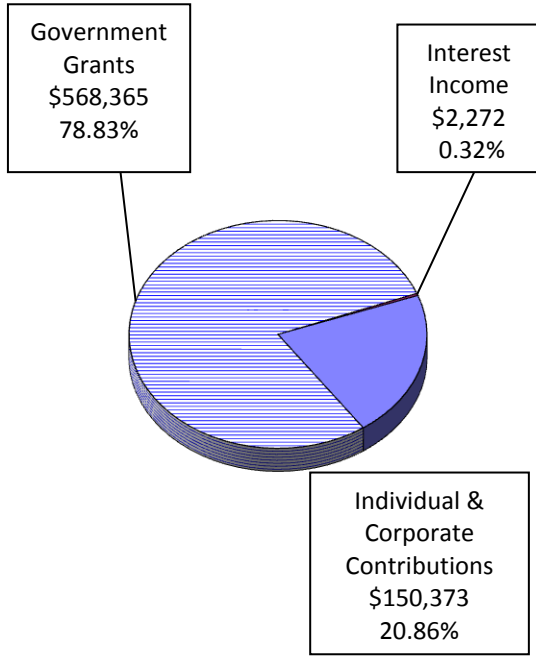
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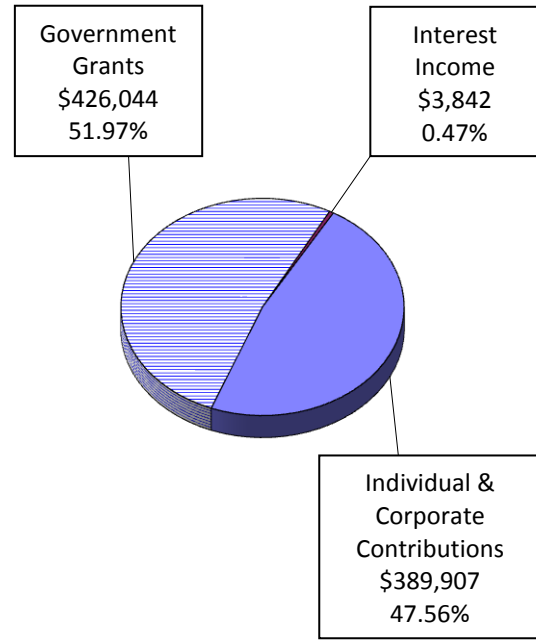
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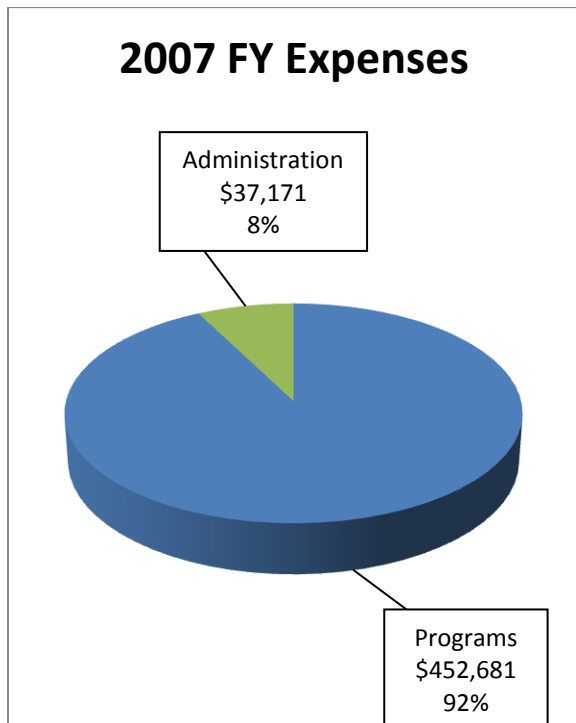
2007 FY REVENUE



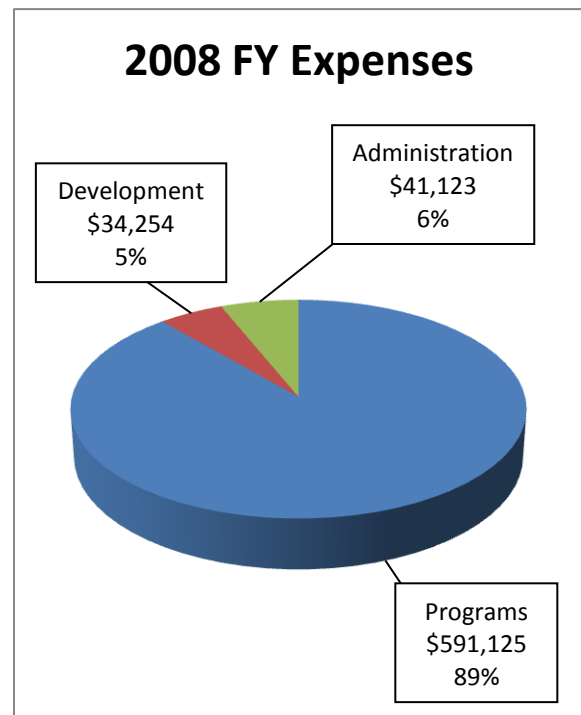
2008 FY REVENUE



2007 FY Expenses



2008 FY Expenses



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