

PACP | PEDIATRIC AIDS CHICAGO  
PREVENTION INITIATIVE



2013 ANNUAL REPORT

## A Message from our Leadership

Dear Friends and Supporters,

When PACPI programs began, we thought we would work as hard as we could to eliminate deaths from pediatric AIDS and reduce transmission of HIV, and that PACPI's programs would only last a few years until the funding ran out. Happily I can report that thanks to the excellent work by the board and staff, including the brilliant stewardship by Executive Director Anne Statton, PACPI has grown and thrived. There is now a system in Illinois, a Safety Net of Prevention, to prevent mother-to-child transmission of HIV. It is due to PACPI's efforts and through the contributions of many of you reading this now.

A year ago, PACPI underwent a major change at the board level. Our first and, up to that point, our only board chair, Dr. Pat Garcia, stepped down as part of the natural evolution of our organization and I moved into the chair role. Pat's leadership was second to none. Her leadership is one reason why PACPI has thrived since its creation 13 years ago, and, thankfully, she remains an active board member.

Our board also grew by the addition of two new members in 2013: Gina Metelica and Dr. William Grobman. They have brought additional expertise to the board with Bill having a national presence as a leader in the field of maternal fetal medicine and with Gina's business acumen and HIV knowledge in the pharmaceutical industry.

We participated in a unique program sponsored by the Donors Forum and underwritten by the Healthcare Foundation of Northern Lake County called A Double Boost. A Double Boost helped us increase our knowledge about the roles, responsibilities, and best practices of a nonprofit board of directors, customize our plans for strengthening the board, deepen the working relationship between the board and executive leadership, and further engage our board in PACPI's programs. Although it may sound dull, this opportunity for engagement and education has strengthened PACPI so we can look forward to a sustainable future.

As the delivery of healthcare is changing due to the Affordable Care Act, we too, need to change. We created board task forces to adapt to this changing landscape and have recently kicked off a strategic planning process that will wrap up in 2014. We also invite you to share your thoughts with us as we could not plan for another 13 years without your help.

The next few years will be exciting ones. Our work continues. Thank you for your ongoing support!

***Daniel Johnson, MD***

Chair, PACPI Board of Directors

## Meet Tamara.

Tamara is a young black woman who grew up on the West Side of Chicago. She is twenty-four years old and just had her first child, a happy little boy named Angel.



Tamara was happy about the pregnancy when she first found out because she wanted to have a child with her boyfriend. Then they started arguing a lot and she stopped taking his calls or texts, she wanted a break. Later that week, she attended her first prenatal appointment and found out she is HIV-positive.

Tamara was scared and felt alone. But her obstetrician assured her she would be in good hands because they are familiar with PACPI and they referred her to our Perinatal Enhanced Case Management program. The same day, one of our case managers called Tamara to say hello and arrange their first meeting.

### So what do PACPI Perinatal Enhanced Case Managers actually do?

The perinatal enhanced case management program helps women access comprehensive health services to achieve the best outcomes for her and her child. In 2013 our five case managers linked 109 HIV-positive and pregnant women to care. Thirty percent of our clients learn their HIV status *after* becoming pregnant so PACPI case managers meet them at a time of great concern.

But for some women it is not just a concern, it is a crisis. Many do not know they can have a healthy baby if they seek appropriate care. HIV/AIDS is not the only battle our clients are fighting.

- If a woman is homeless, our case manager works to find safe housing.
- If a woman has a substance addiction, we work with local agencies to help manage her health and her baby's health.
- If a new mother cannot afford a safe place for baby to sleep or to purchase food, diapers, or clothes, we will make sure she gets the proper items she needs for her family.

PACPI case managers show each client that they can be "OK". This year, case managers were able to link 94% of our clients to proper prenatal care and 95% of clients to proper HIV care before delivery to lower their viral loads to undetectable levels, which is important for a safe delivery.

PACPI case managers provide unique one-on-one support that creates trust and stewards the connection to vital healthcare for both mother and baby. Case managers communicate with each client on at least a weekly basis through home visits, phone calls, texts, and accompaniment on medical or social service appointments.



The PACPI prenatal class covers various topics to help clients make sense of HIV and pregnancy.

Prenatal class participants receive a full diaper bag with infant necessities like diapers, wipes, bottles, onesies, & bibs.



Tamara’s case manager accompanied her on her first appointment with an HIV care provider and referred her to the PACPI prenatal class a few weeks later. Tamara and her boyfriend reconciled and he attended the three-day prenatal class with her. It only took one session for him to open up and be the most outgoing class participant.

### What is different about the PACPI prenatal class?

PACPI began our own prenatal class so that HIV-positive women can meet together to learn about pregnancy and parenthood from the perspective of an HIV-positive individual. The PACPI prenatal class is unique because it is free and open to any woman regardless of her health care provider.

Our class provides high-quality reproductive, maternal, and child health, as well as HIV education to HIV-positive women regardless of their economic circumstances. Classes are taught by experienced medical and nutrition specialists in a small classroom setting, with an approach that promotes peer-based learning and health gains that are demonstrated to decrease the risk of transmission from mothers to their newborns.

Participants are encouraged to bring a support person such as a partner, mother, aunt, or friend who knows their HIV status and will be with them through the pregnancy. After completion of the class, participants receive a car seat to take the baby home in after delivery, as well as a diaper bag filled with vital newborn essentials.

Tamara's case manager talked her through the steps she would need to take to be healthy and deliver a healthy baby, including: taking her antiretroviral medications on time each day; attending all of her obstetric and HIV care appointments; finding a pediatric care provider; and sticking to her birth plan to deliver at her chosen perinatal HIV care center.

### Helping HIV-positive Women Plan for a Healthy Delivery

With the help of their case manager and their care team, each PACPI client creates a birth plan so she and her care providers will be prepared when labor begins. One key aspect of the birth plan is listing the hospital where the woman plans to deliver her child.

In Illinois, there are six perinatal centers whose labor and delivery departments are especially equipped to care for pregnant women with HIV. Even if a client is referred late in pregnancy and has received little care, administering antiretrovirals during labor and to the infant after birth can reduce transmission risk by 10%. Staff and resources are in place at these hospitals to help an HIV-positive woman deliver safely and with treatment for her newborn. These centers are:

Ann and Robert H. Lurie Children's Hospital of Chicago, Mt. Sinai Hospital,  
Northwestern Medicine, Ruth M. Rothstein CORE Center, Rush University Medical Center,  
University of Chicago Medicine, University of Illinois Medical Center

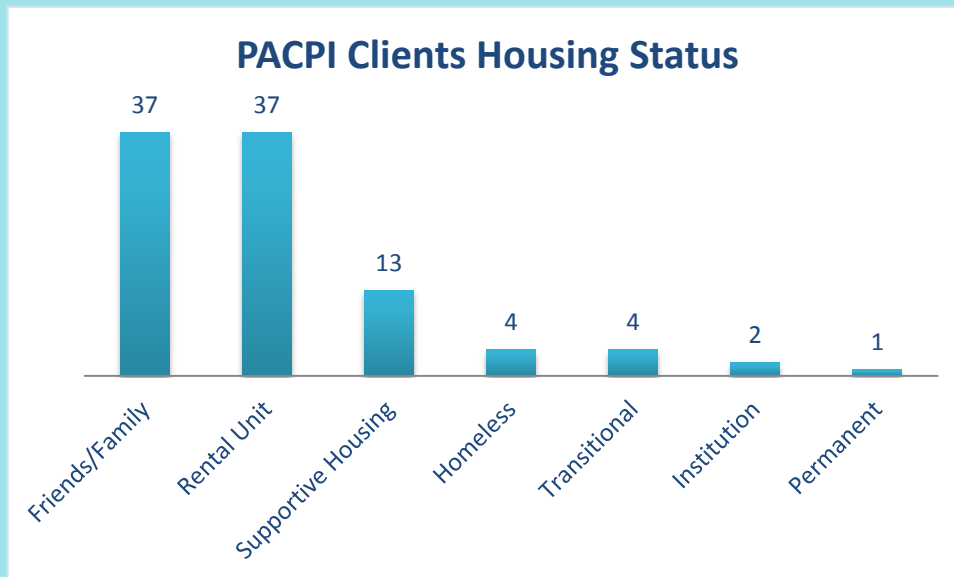
When HIV-positive women do not deliver at their planned hospital, there is a risk that they will not receive the timely HIV medications they need before and during delivery. Another reality is that the woman may be conflicted about disclosing her status to a doctor and medical team with whom she is unfamiliar, especially when labor is progressing.

**Delivering at the planned hospital is important to any expectant mother who has made a birth plan.  
For a woman with HIV, it could be the factor that prevents her child from being born with HIV.**

In 2013, **91%** of PACPI's clients delivered at their planned hospitals, **94%** of babies born to PACPI clients received antiretroviral medication at birth, and **96%** of newborns born to PACPI clients received antiretroviral prophylaxis for the next four to six weeks, as prescribed.

Pregnancy is a strong motivator to get healthy. Tamara had reduced her viral load to an undetectable level by taking her antiretroviral medications at the correct time each day and she attended all of her medical appointments for the duration of her pregnancy. Her delivery was without complications and Angel was born healthy and has not tested HIV-positive.

However, once Angel was born, Tamara didn't want to continue to go to her own medical appointments. She was tired and overwhelmed enough waking up several times each night, not to mention giving her newborn his antiretroviral medications. It took extra encouragement and creativity by her case manager to attend all the obstetric, pediatric, and HIV care appointments but Tamara was responsive and attended most appointments thanks to their good relationship.



Throughout most of her pregnancy, Tamara had been living with her aunt and other cousins but she knew it would not be a stable home for a newborn. Before Angel was born, she asked her case manager for help with finding a place to live and was able to apply for a one bedroom apartment in a building that welcomed other women at similar places in their lives.

### What does housing really mean to PACPI moms?

Housing means the living situation each person is in, or what kind of temporary or permanent residential location they are staying in. For PACPI clients, or PACPI moms as we often say, we allocate a housing status using the same categories used by the Illinois Department of Public Health. People who have always had a home to live in don't often think about it, but all of our clients are low-income and finding stable housing can be difficult on your own.

Thirty-seven percent of our clients have a rental unit which demonstrates a level of autonomy and self-sufficiency. Another 37% of our clients are living with family or friends. This housing status sounds good but the reality of living in someone else's home can be difficult, especially later in pregnancy or after the baby is born. Both mom and newborn need to be in a healthy and stable home which means away from smoking or other harmful activities as well as with a certainty that they won't be kicked out at a moment's notice.

In 2013, eleven women were either homeless, in transitional housing like a halfway house, or in an institution for treatment of addiction or mental health. These are also unstable living conditions. Institutional housing and transitional housing is safe but temporary. Homelessness is unsafe and unhealthy and PACPI case managers do everything possible to move clients off the street and to a safe place for the good of mother and baby.

Tamara showed great improvement after she adjusted to being a new mom and exited the program when Angel was six months old. PACPI followed up with Tamara three months later to ask about her health progress and offer support through encouragement and any additional referral we could make.

### Follow-Up Pilot Project

Retention in care frequently drops among our case managed clients after they exit the program, usually around six months postpartum. We know there are numerous reasons why women do not stay connected to care, especially for their own health, but we wanted to hear straight from the clients themselves and encourage them to continue healthy habits they practiced in our program.

The follow-up pilot project began in 2013 as a way to assess connection to care after leaving the program by following up with exited clients at three-month intervals. This program was possible thanks to interns from the Adler School of Professional Psychology and continued into 2014.

Former PACPI clients like Tamara who are reachable and willing to speak with us on the phone are asked non-invasive questions and are eligible to receive a gift card which is drawn each month. This pilot project has allowed us to begin evaluating the long-term impact of our program as we consider new strategic directions in 2014.

When Angel turned one year old, PACPI sent a birthday card with a small treat for Tamara. The birthday card project began in 2013, thanks to the Women's Connections Committee of the Metropolitan Club of Chicago. A group of club members gathered to create handmade cards to send to PACPI moms on their birthdays. Participants also donated gift cards for us to include in the cards as a special surprise for moms and as an encouragement from PACPI.



## Meet Sara.

Sara is thirty-two and came to the United States as a refugee when she was four months pregnant. Sara and her husband moved close to a relative but they live in a suburban neighborhood and Sara cannot drive.

Sara did not seek out medical care because she is not confident in her English language skills and she is still intimidated by the public transportation system. When she went into labor, her husband took her to the closest hospital. Because Sara was not seeking prenatal care, she did not have an HIV status on file and emergency room staff did a rapid test which revealed that Sara is HIV-positive.



## Rapid Testing in Illinois Hospitals

The rapid HIV antibody test is a screening test requiring only a small blood sample to detect antibodies to HIV, which can be collected and processed within a short interval of time (under 60 minutes). Rapid HIV tests allow for preliminary diagnosis and treatment of HIV in labor for women who have no documented HIV status at time of delivery. It is important for a pregnant woman who does not know her status to accept a rapid HIV test because it is possible to pass HIV to the baby during pregnancy, during childbirth, or through breastfeeding.

The rapid testing program began in 2004 to assist hospitals in implementing rapid HIV testing in labor and delivery units, as stipulated by the Illinois Perinatal HIV Prevention Act. Currently, every birthing and non-birthing hospital in the state submits a monthly report detailing deliveries, HIV-exposed births, and rapid HIV testing of delivering women and infants born without a documented maternal HIV status. PACPI collects these reports from approximately 172 hospitals each month.

Rapid testing data allows us to work with our partners and with statewide hospitals to identify gaps in the system and measure our efficiency as a state to be sure every woman and baby pair have a known status before being discharged from the hospital.

In 2013, PACPI collected data on 150,818 delivering women in Illinois. A total of 99.99% of mother-baby pairs had an HIV status documented at discharge. A woman can opt out of the test but she cannot opt out for her baby if her HIV status is unknown. In this case, the baby is rapid tested for the mother's antibodies, with a confirmatory test, if needed. 6,367 women who did not present with a documented status (4.2%) accepted a rapid test on delivery where three of those women were later found to be confirmed HIV-positive through confirmatory testing. 31 women were either missed for testing or declined testing and of those, one infant had a rapid positive test which was later confirmed positive.



The attending physician called PACPI's 24/7 Illinois Perinatal HIV Hotline for guidance, and was connected to a Maternal Fetal Medicine fellow to ensure a safe delivery for mother and child. The Hotline offered to arrange for a PACPI case manager to meet the mother at the hospital and provide ongoing support and services to manage with her newborn and HIV diagnosis.

These immediate services will help Sara care for her HIV-exposed newborn, cope with her HIV diagnosis, and decrease the chances of her newborn becoming HIV positive through education and encouragement about bottle-feeding and medication adherence.

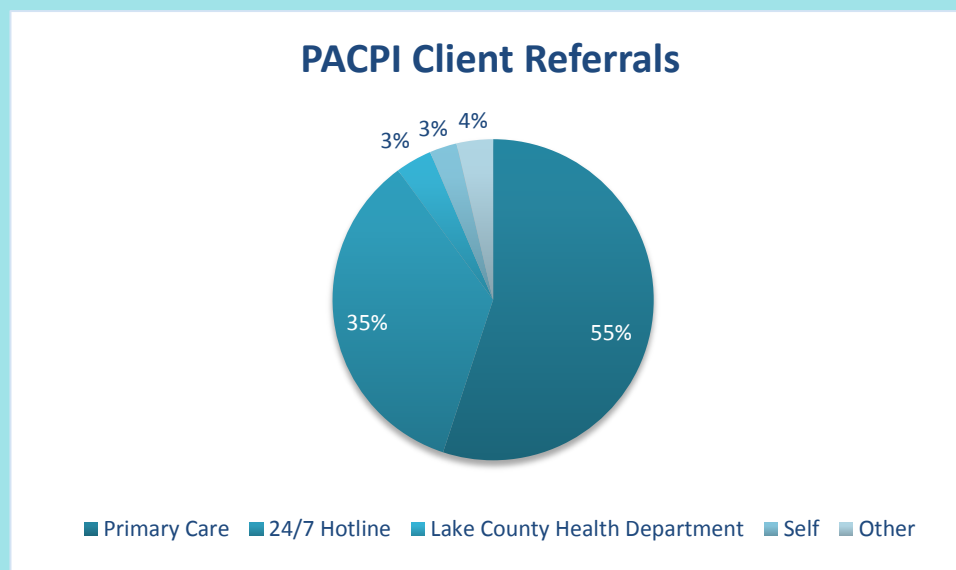
### 24/7 Illinois Perinatal HIV Hotline

The 24/7 Illinois Perinatal HIV Hotline was established in 2003 to provide access to immediate medical and social service consultation for the care of pregnant HIV-positive women around the clock. The Hotline provides real-time HIV medical consultation for perinatal care providers and social service providers for immediate linkage of newly diagnosed pregnant women to HIV and obstetric care. Hotline staff actively collaborate with PACPI staff to provide follow-up of rapid HIV testing in labor and delivery units and perinatal HIV enhanced case management services.

Calls to the Hotline in 2013 (189 calls) were consistent with calls in 2012 (190 calls), but this year relevant calls accounted for a growing proportion of all calls – 90% as compared with 71% in 2012. Relevant call inquiries include: rapid test reports, consults, referrals to medical care and case management, and perinatal HIV specific questions as opposed to general HIV information requests.

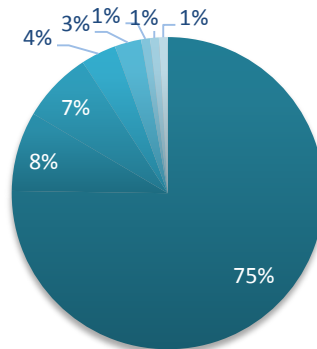
**35%** of client referrals to PACPI were from the Hotline in 2013 (see figure below).

The Hotline is housed at Prentice Women's Hospital of Northwestern Memorial Hospital and is funded by the Illinois Department of Public Health.



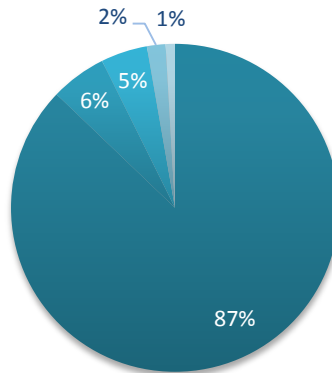
More demographic information on PACPI clients served in 2013:

### PACPI Clients by County



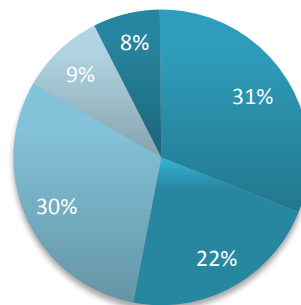
- Chicago
- Lake County
- Cook County Suburbs
- Will County
- Dupage County
- Kane County
- Kendall County
- McHenry County

### PACPI Clients Race/Ethnicity



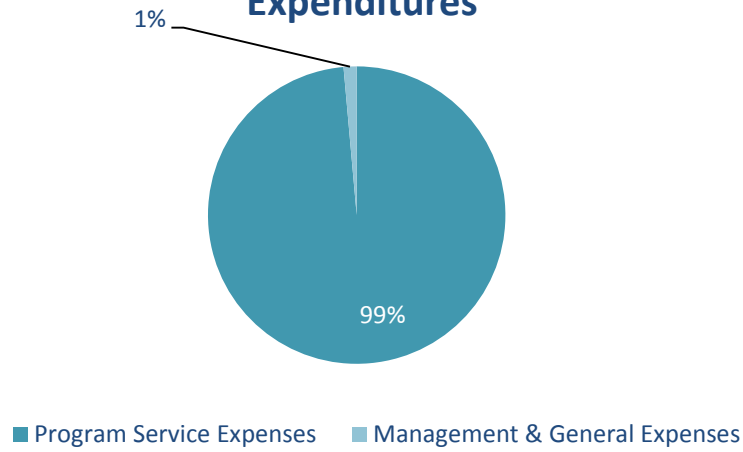
- Black
- White
- Hispanic
- Mixed
- Asian

### PACPI Clients Age

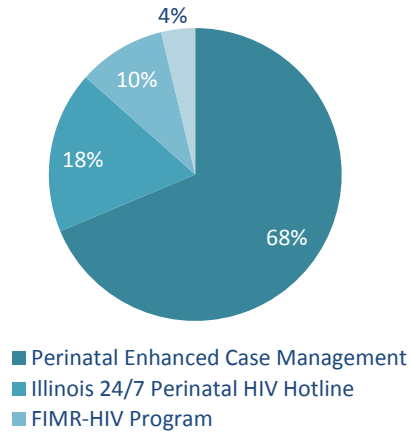


- 13-19
- 20-24
- 25-29
- 30-39
- 40-49

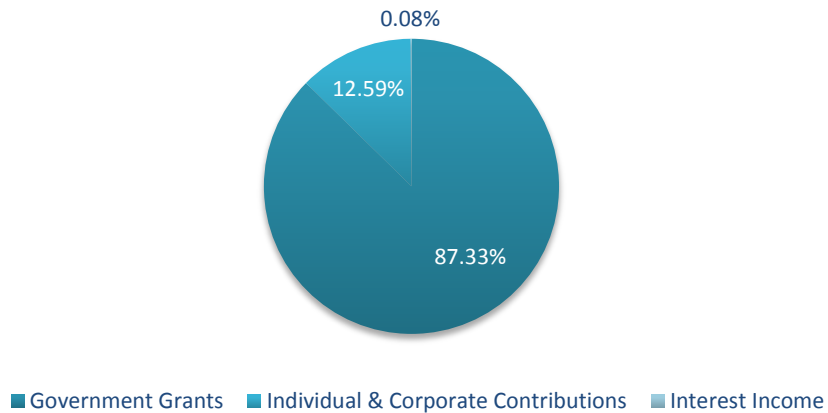
### Expenditures



### Expenditures by Program



### Revenue by Funding Source





## Thank you for your support this year!

PACPI gratefully acknowledges our many donors, whose contributions are critical to sustaining PACPI's successful perinatal HIV prevention and care programs. We acknowledge the following donors for their gifts made between January 1, 2013 and December 31, 2013.

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Healthcare Foundation of Northern Lake County

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And sign up for our e-newsletter by visiting [www.pregnantandpositive.org](http://www.pregnantandpositive.org).



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200 West Jackson Boulevard, Suite 2100  
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