

PACP | PEDIATRIC AIDS CHICAGO
PREVENTION INITIATIVE



2009 Annual Report

Message from PACPI's Leadership

Dear Friends of PACPI,

Healthy babies from healthy mothers. It's a simple concept but one that takes commitment and collaboration to achieve. This year, with the commitment of our enhanced case managers and the collaboration of many community partnerships, the Pediatric AIDS Chicago Prevention Initiative helped 116 HIV-positive women access care and treatment throughout the state of Illinois.

We are proud to report to you that all but one PACPI case managed client delivered HIV-negative and healthy babies in 2009.

In October 2010, PACPI will turn 10 years old! As we embark on this incredible milestone, we are evaluating the footprints we have made in the HIV/AIDS and maternal-child health communities. In March 2009, we started the process of Visioning for the Future – a strategic planning process to blueprint the organizational future of PACPI. We are engaging community members and our partners and hope to present you with a five year plan next year.

We offer the sincerest thanks to all our donors and partners whose support allows us to continue to advance our mission and strive to assure our patients that healthy babies can indeed come from healthy mothers.

Best Wishes,

Anne Statton
Executive Director

Dr. Patricia Garcia, MD, MPH
Board Chair, Board of Directors

Pediatric AIDS Chicago Prevention Initiative

Annual Report – 2009

The **Pediatric AIDS Chicago Prevention Initiative (PACPI)** is a collaborative enterprise of public and private partners representing HIV prevention and treatment statewide.

Client Story “Can’t thank her enough”

Overwhelmed with a six year old son, a three year old daughter, pregnant with a third child, and just breaking up with the father of her children, Jazz believed she had nowhere to turn. On top of all of that, Jazz just found out she was HIV positive and was not taking too well to her HIV meds. “I wanted to blame my nausea on the medications instead of on my pregnancy, so I just stopped taking them. Even though I knew deep down that I was having a baby and I was putting it in danger by not taking my medication, I just didn’t care. I couldn’t face it. I was barely surviving, and I just couldn’t face what I saw as another problem.”

“I was barely surviving, and I just couldn’t face what I saw as another problem.”

Hurt and confused, Jazz planned to leave everything she knew behind in Chicago and move with her two children to Minnesota so that no one would pass judgment on her for giving birth to a child she was sure would have HIV. Furthermore, Jazz became depressed with thoughts that she would be too sick to care for her children. However, when Jazz was referred to PACPI Enhanced Case Manager, Dolores Benton, she discovered her life could truly turn around. “I had no idea anything like PACPI existed,” Jazz says. Dolores completely evaluated Jazz’s situation and helped her secure an apartment so that Jazz could remain connected to her doctors and her family. Dolores lightened the load for Jazz with all of her struggles. With patience, kindness, and genuine caring, she helped Jazz to work through her painful issues, being an invaluable support in a time of great difficulty.

Through all her difficulties and achievements, Dolores has continued to be there for Jazz. “I was told after that after six months, I wouldn’t be hearing from Dolores any more. But she still remembers me and keeps calling! Sometimes I can be feeling really down, and it really helps to be able to talk with her about things like my job search and the difficulties I’m having with childcare. Just to know that someone else is looking out for me is really amazing. Seeing that Dolores cares about me, that this isn’t just a job. That’s what makes her so special.”

Like many women in her position, Jazz pushes through her struggles for the benefit of her children. Through the love she has for her children and the support she received through PACPI, Jazz is getting stronger every day. “Without Dolores, I would have been far away from here and without any of my children. I can’t thank her enough.”

Pregnant women know their HIV status

We are continuing to see that women are being tested prenatally, and only a small percentage (5.3%) are presenting for delivery without a known HIV status. This success of 94.7% of women being tested prior to labor and delivery is a testament to the understanding among providers that HIV testing is important. The success is due in large part to the efforts of labor and delivery staff at every hospital in Illinois who are committed to helping prevent perinatal transmission in their own communities. In addition to the testing at hospitals, 99.97% 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 2009 to less than 20 of the approximately 160,000 births! Also in 2009, the number of women identified at the time of delivery (17) was matched by the number of women identified before delivery as outpatients (17). 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 mom who delivered in 2009 had HIV negative babies! Our one client with a positive baby was not referred for care until delivery. 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 116 women case managed in 2009 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

PACPI served a total of 116 women in 2009 with 19,716 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. In addition, PACPI provided 3,711 one way CTA fare cards, 461 \$10 gas cards to 101 unduplicated clients as well as 1,289 one way taxi rides to 74 clients.

The majority of PACPI clients are women of color (78% African-American, 16% mixed race). Six percent are Non-Hispanic white women and one woman did not

identify a race. 82% of clients had at least one dependent child at intake with an average of 1.1 children.

Almost half of PACPI clients (49%) are between the ages of 25 and 34, with 29% between the ages of 13-24 and 19% aged 35-44. The majority (82%) of our clients list English as a primary language, 9.5% list Spanish as their primary language and the rest 8.5% list other languages as primary. Seventy-two percent of PACPI clients reside in the city of Chicago and the rest live in suburban Cook County, Lake, Kane, DuPage, Will, Kendall and Kankakee counties. A small number of our clients live in Northwest Indiana.

The greatest challenge that the PACPI case managers faced in 2009 was the growing number of women facing mild to serious mental illness. Combined with the existing challenges of fear of disclosure make HIV in pregnancy so isolating that it becomes very hard to ask for and receive assistance. Medications and appointment adherence become an extra challenge due to both mental illness (both diagnosed and undiagnosed) and 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 2009, the Hotline experienced a continued increase in call volume as compared to previous years. Calls increased by 34% as compared to 2008 and 120% as compared to 2007 (2009=215 calls, 2008=160 calls, 2007=98 calls). Much of the increase in call volume originated from outside of Chicago, particularly suburban Cook County and northern and downstate Illinois. Additionally, there was an increase this year in calls about mandatory newborn testing policy and HIV reporting requirements. The Hotline received reports of 73 pregnant and positive women in 2009 both through reports of positive rapid HIV tests and calls requiring assistance linking known positive patients to care. In March of 2009, the Hotline launched its comprehensive website for the state of Illinois accompanied by a marketing campaign announcing the website to providers throughout the state. The site can be found at www.hivpregnancyhotline.org.

PACPI Housing Project

PACPI's partnership with the AIDS Foundation of Chicago, Housing Opportunities for Women, Interfaith House and Christian Community Health Center continued to support homeless women with children. 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. As of December 2009, all ten of the clients housed in this pilot program remain stably housed! An additional two units are expected to be added to the existing ten units in late 2010.

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 and or their newborns in the home. In 2009, four mothers and one newborn were provided with DOT assistance. In addition, several women were hospitalized by their providers toward the end of their pregnancy as a last effort to reduce their viral load prior to delivery. In order to receive the service, clients must sign an agreement and have a PACPI case manager who works closely with the DOT worker to ensure that every dose is monitored and any issues are handled immediately.

Prenatal Classes for HIV-positive pregnant women

PACPI held four sessions of its prenatal class for HIV-positive pregnant women in English in 2009 which served a total 29 women. 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. In addition, two Spanish prenatal class sessions were held in 2009, serving a total of 10 women.

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. PACPI joined forces with the Children's Place Association to start a new support group for new HIV-positive moms. In 2009, 20 women participated in 41 group sessions covering topics such as parenting, medication adherence, emotional burden of HIV-infection, safe sex, dating, family support, return to work, infant care, confidentiality and disclosure. We also pioneered a Spanish-language support group at the request of our clients following a Spanish prenatal class. The support group had three sessions in 2009 serving ten women and their partners.

Visioning for the Future – Strategic Planning Projects

In March 2009, PACPI embarked on a strategic planning process to provide space for reflection, generative discussions, and an opportunity to chart our future in anticipation of PACPI's 10 year anniversary in 2010. PACPI conducted targeted interviews of over 30 key informants and conducted two focus groups with the community to determine areas for improvement, areas for expansion and ongoing needs for services currently provided.

PARTNERSHIP SHOWCASE

In 2009, PACPI strengthened our partnership with the Children's Place Association. Children's Place hosts the New Moms Making Positive Changes support group and worked with PACPI in 2009 to expand the group to include a couples support group in Spanish. Many of our Spanish-speaking clients had requested help with speaking to their partners and helping to work with them to support the baby. The support group is made up of first generation immigrants who are facing common challenges of lack of family support in this country, disclosure and legal issues. The support group is co-led by a Spanish-speaking HIV nurse from UIC and the clinical counselor from the Children's Place.

PACPI is turning 10!

October 2010 commemorates the 10th anniversary of PACPI. Founded in 2000 by community and healthcare leaders from around the Chicagoland area, PACPI has offered its services for ten years to HIV-infected pregnant women and HIV-positive women who become pregnant, especially those facing formidable challenges to maintaining connections to care and treatment.

This Year's Top Achievements

New Fundraising High for AIDS Run/Walk — 2009 was Team PACPI's most successful fundraising year for the annual AIDS Run/Walk Chicago. With nine team members, Team PACPI raised over \$5,500 to support services for HIV-positive women and their families.

MAC AIDS Fund Supports PACPI-HP — In 2009, PACPI established a new funder and partner in the PACPI Housing Program. The MAC AIDS Fund awarded PACPI \$35,000 to strengthen the program's activities by providing additional care and services to address the medical adherence, mental issues, substance abuse, childcare, education, and employment needs of the PACPI-HP participants. We hope this additional support to the program allows us to evaluate its success in hopes of expanding it to additional clients.

CDC Presentation – PACPI was honored to present the Perinatal HIV Enhanced Case Management Program to healthcare professional and HIV/AIDS advocates at the 2009 CDC National Prevention Conference in Atlanta, GA.

PACPI named to the National Perinatal HIV Prevention Stakeholders – PACPI has been invited to join a national discussion on development of models to help prevent transmission of perinatal HIV. In particular, the Perinatal Enhanced Case Management program, the Perinatal Rapid Testing Implementation Initiative in Illinois, the 24/7 Perinatal HIV Hotline as well as the work to change laws in Illinois puts us at the forefront of the discussion on best practices.

Thank you for your support!

PACPI gratefully acknowledges the many donors who join us in caring about women and children affected by HIV/AIDS. Every gift plays an important part in the ongoing success of our mission. We are proud to count the following foundations, corporations, community organizations, and individuals among our most valued supporters.

The listing reflects gifts received between January 1, 2009 and December 31, 2009.

GRANT SUPPORT FROM CORPORATIONS, FOUNDATIONS AND COMMUNITY ORGANIZATIONS

\$100,000 and above

Pediatric AIDS Chicago

Support for care and support service to HIV-positive pregnant women

\$25,000 - \$49,999

Hektoen Institute

Support for perinatal surveillance data collection and analysis

M·A·C AIDS Fund

Support for the continued development of the PACPI Housing Program

\$10,000 - \$24,999

Dr. Scholl Foundation

Support for the Perinatal HIV Enhanced Case Management Program

\$5,000 - \$9,999

Children Affected by AIDS Foundation

Emergency support to five PACPI families

Paris Presents, Inc.

General Operating Support

\$1,000 - \$4,999

DIFFA Chicago

Excellence in Care Award for the Perinatal HIV Enhanced Case Management Program

Francis W Parker School

Proceeds from annual Parkerpalooza student summer concert

John Snow, Inc.

Support to train HIV case managers through the Perinatal HIV Case Management Training Program

Seder Family Foundation

Unrestricted

Simon Blattner Family Foundation

Unrestricted

Trigan Investments, INC

Unrestricted

\$999 and under

Kowalkowski & Labuda
Support to the PACPI AIDS Run/Walk Team

Littelfuse, Inc.
Unrestricted

Rosenson Foundation
Unrestricted

Salvi, Schostok, & Pritchard, P.C.
Unrestricted

Taylor Plumbing Incorporated
Unrestricted

Women's Association of Glenview
 Community Church
Unrestricted

MATCHING GIFTS & EMPLOYEE GIVING CAMPAIGNS

Ameriprise Financial Employee Giving Campaign
 Community Shares of Illinois
 Merck Partnership for Giving
 Tyco
 United Way

GIFTS-IN-KIND

AIDS Foundation of Chicago (AFC)
 Kersti Azar
 Jaime Dircksen
 Hasbro
 Yvette Kilpatrick
 Power 92
 Dr. Scott Resnick
 Elizabeth Sharpe
 Cathryn Smeyers
 Susan Socher
 Eryn Weber-Shifrin

INDIVIDUALS

PACPI gratefully acknowledges the following donors for their generous gifts made between January 1, 2009 and December 31, 2009.

\$1,000-\$5,000

Daniel Johnson & Julia Parzen
 Tom & Margot Pritzker
 Susan Socher

\$500-\$999

Dr. Patricia Garcia, MD, MPH
 Harold Rosenson

\$100-\$499

Alice & Bob Abt
 Andrew & Mona Albert
 Thomas Berbas
 Douglas Chilcott
 Jim Christensen
 Karen Christensen
 Cathe Evans-Williams
 George & Heather Fisher
 Patricia Freysinger
 Michelle L. Fried &
 Melissa Roderick
 Susan Gevirtz
 Richard & Nancy Giannini
 Kenneth Granat
 Konstanze Hickey
 Anne Hutchins

Jennifer Janovetz
 Debbi & Mitchell Klein
 Sharon Lear
 Barry & Teri Lind
 Alan & Barbara London
 Madeleine Msall
 David Munar
 Robert & Sue Novasel
 Mary Pappas
 Bill Pope
 Cheryl Pope
 Urvi Purohit
 Evelyn Reynolds
 Cheryl Roberts
 Norma Rolfsen
 Janet & Philip Rotner
 Edward Seeger

Nancy Silverman
 Anne Statton
 R.M. Traut
 Fred & Lynne Weber
 Eryn Weber-Shifrin
 Leonard Weiss
 Lorraine & Steven Weiss

\$99 and Under

Barbara Abraham
 Elliot Abraham
 Dara Adkinson
 Steven & Mary Anderson
 Edward Avila
 John Bartlett
 Lawrence Bernstein
 Stephanie Bortko

Bryant Boyd
Cecilia Boyd
Johnathon Briggs
Michelle Busse
Rosemary Campbell
Sarah Deardoff Carter
Jovita Coria
Theresa Coria
Brian Dibblee
Alyzza Dill
John Dillon
Michael Dinneen
Michael & Suzanne
Donovan
Samantha Donovan
Peter Edmonds
Steve Fee
Jerry Feldman
Frank Fishella
Jane Fresne
Elizabeth Fry
Irwin & Cathy Gafen
David Gantt
Andrea & Jack Garland
LaTrina Garner
Frederick Geldmyer
Hilda Geldmyer
James Geldmyer
Robin Gold
Elena Luz Gomez
Raquel Gonzalez
Andrea & Marcus
Gottlieb
Isabel Grantham
Cathy Gray
Shannon Greenholt
Kristy Haskett
Lauren Healy
Robert Hearne

Effenus Henderson
Natalie Herard
Thomas Hines
Sanjuana Jaime
Amanda Janulis
Patricia Jeffords
MaryBeth Joyce
Anna Koivisto
Briana Kelly
David Kim
Peter Knoll
Mark H. Kusatzky
Heather Lasche
Judy Lai
Jeffrey Lemerman
Edward Letchinger
Louis Levine
Laurie Linxweiler
Patrick MacMahon
Rachael Jean Marusarz
Kristin Mays
Yanantali Mejia
Jessica Meylor
Daniel Nevez
Betty Ann Panagakis
Linda Pape
Daniel Pasette
Igor Petrushchak
Marta Petrushchak
Heather Pines
Ryan Pollyea
Rebecca Pope
Beth Primps
Alexandria Ramirez
Vanessa Ramos
Lucy Rios
Lizette Rivera
Barrett Robinson
Julio Rodriguez

Manuel Rodriguez
Wanda Rodriguez
Kathryn Roe
Christina Rogawski
Inga Ruzhitsky
Zachary Samson
Steven Sanabria
Barbara Schechtman
Ann Schramm
Elleson Schurtz
Devin Schwarz
Connie Scott
Arnold Shkolnik, MD &
Carol Waugh
John & Joan Siff
Abigail Silva
Cathryn Smeyers
Brian Smith
Julio Soriano
Craig Spital
Amy Statton
Edward Statton
Marley Stein
Linda Sticklen
Will Tanzman
Allan Taylor
Deane Taylor
Jennifer Tison
Leslie Wallin
Edward & Natalie Weber
Gretchen Weiss
Craig Wells
April Whitworth
Jo Anne Willis
Carolyn Wilson & Robert
Swedlow
Ben Woo
Kristen Zelasko

Every effort has been made to ensure the accuracy of our donors. If your name has been misspelled or omitted, please accept our sincerest apologies. Please direct your comments to Cecilia Boyd at 312.334.0972 or cboyd@aidschicago.org. Thank you.

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.

Pediatric AIDS Chicago Prevention Initiative

Board of Directors

Dr. Patricia M. Garcia, Northwestern Memorial Hospital
Board Chair

Lynne Weber
President

Dr. Daniel Johnson, University of Chicago Hospitals
Vice President/Secretary

Simon J. Blattner, III,
Treasurer

Debbi Klein
David Ernesto Munar, The AIDS Foundation of Chicago
Barbara Schechtman, Midwest AIDS Training & Education Center
John Seder
Deane Taylor, The CORE Center

Staff

Anne Statton
Executive Director

Cecilia Boyd
Development & Media Coordinator

Gretchen Weiss
Program Coordinator

Perinatal Enhanced Case Managers

Dolores Benton
Gail Bronson-Redmond
Leticia Maldonado
BeLinda Richardson
Lucilia Rios

Prenatal Class Instructors

Rosa Camacho, RN, RNC, ACRN
Pamela Haerr, RN, BS, CPNP
Shelley Scott, RD, LDN
Brenda Wolfe, RN, CNS, ACRN

Interns

Alyzza Dill - University of North Carolina, Chapel Hill
Chelsea Maddox - Adler School of Professional Psychology
Nahed Sobhy - Chicago State University, College of Pharmacy

**PEDIATRIC AIDS CHICAGO PREVENTION INITIATIVE
OPERATING FINANCIAL HIGHLIGHTS
FINANCIAL YEAR, 2009**

