

A Celebration and a Renewed Sense of Purpose

After 30 years, the AIDS Law Project mission is still evolving, still vital

In the early days of the AIDS Law Project of Pennsylvania, new hires were warned that their clients might die.

Despite the grim landscape at the time, the small but dedicated staff soldiered on. They helped clients get public benefits and health insurance. They fought the stigma and discrimination that sadly was the norm at the time.

Now, it is with equal measures of wonderment, exhilaration and gratitude that we find ourselves observing our 30th anniversary.

"When we were founded in 1988, the idea was to provide some support, some dignity, to people who were not going to survive," said **Ronda B. Goldfein**, who joined the AIDS Law Project in 1992 and became its third executive director in 2000. "We're now helping people live healthy lives and plan for their futures."

Managing Attorney **Yolanda French Lollis** joined the AIDS Law Project a few months after Ronda and has seen its mission change

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Contigo Photos + Films

John Jarboe of The Bearded Ladies Cabaret performs at PEARL: A 30th Anniversary Celebration on Oct. 11. For more photos from PEARL, go to **Page 5**.

Court Approves \$17 Million Aetna Settlement

The U.S. District Court for Eastern Pennsylvania in Philadelphia on Oct. 16 approved the \$17 million settlement of a class action lawsuit against Aetna Inc. over an HIV privacy data breach.

Aetna agreed Jan. 16 to the settlement after a faulty mailing revealed the private medical information of

thousands of its customers in what is believed to be the world's largest privacy breach of its kind.

The court approval clears the way for settlement checks to be mailed to class members, probably by early January.

In July 2017, current and former customers of Aetna were alarmed when

they received letters in envelopes with a large transparent window that accidentally revealed the recipients had been prescribed HIV medications.

Among those who got the mailing was "Andrew Beckett," a Pennsylvania resident who became the lead plaintiff

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INSIDE

REFUGEES SEEK STABILITY

After years in a refugee camp in Ghana, a family needs help navigating the immigration system in the U.S. **Page 2**

OWNING HER NAME

More than 40 years after transitioning, a transgender woman seeks official identification as her true self. **Page 3**

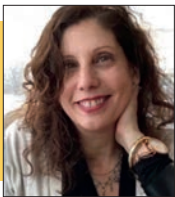
30 YEARS OF VICTORIES

A timeline of the battles the AIDS Law Project has fought since 1988. **Page 4**

HAVE A HEART

Hearts on a Wire, which publishes a newsletter for transgender and gender variant inmates, fights a ban at two state prisons. **Page 6**





FROM THE EXECUTIVE DIRECTOR

Steadfast In Protecting Privacy For 30 Years

As much as we know there should be no shame in HIV, we also recognize that it is not safe for everyone living with HIV to be open about it. State and federal confidentiality laws were created to ensure that the fear of disclosure didn't dissuade people from getting tested and treated for HIV.

For 30 years, the AIDS Law Project has been committed to protecting the privacy of people living with HIV. A client contacted us in August 2017 after receiving a letter from Aetna with a large transparent window revealing that he was prescribed HIV medications. It turned out that the letter was sent to 12,000 Aetna customers who were prescribed HIV medications for treatment or as PrEP, a pre-exposure prophylactic that prevents HIV.

We knew we had to take action. The AIDS Law Project of Pennsylvania, the Legal Action Center, and Berger & Montague, P.C. filed a federal class action lawsuit in August 2017 in Philadelphia.

After the lawsuit was filed, more than 500 people contacted our office to tell us that as a result of the letter, they felt forced to discuss their HIV status and sexual orientation with family, friends, neighbors, church members and employers. Class members on PrEP reported embarrassing conversations about intimate matters to explain their potential risk of HIV.

The case was settled for \$17 million on Jan. 16, 2018, and the court granted final approval on Oct. 15. We expect that the checks to class members will be sent no later than the beginning of January 2019.

While this may be the largest privacy breach we ever worked on, every case in which a person's private medical information is at risk of unwanted disclosure is important to us. Disclosure, intentional or accidental, has devastating consequences. Our clients have lost their homes, jobs and families once their HIV status was shared without their permission.

Until we can create an environment where our clients don't need to fear the stigma and discrimination that is often a part of living with HIV, we will remain steadfast in protecting their privacy.

Ronda

NAVIGATING

Family Gains A Footing In A New Country

REFUGEES GET HELP FINDING THE PATH TO CITIZENSHIP, STABILITY

Fleeing the violence of a civil war in Liberia that eventually claimed about 250,000 lives, the man moved his family to a refugee camp in Ghana in 1997.

The family stayed in the camp until 2004, when they were able to come to the United States on refugee visas, initially settling in Philadelphia.

Hoping to solidify his family's place in their new country, the man applied on his own for a permanent resident visa, or green card. He was shocked when he was rejected under the so-called HIV travel ban, which since 1987 had barred entry to the U.S. by people living with HIV or AIDS.

"He didn't have any idea," said **Yolanda French Lollis**, the AIDS Law Project's managing attorney, who met him when he sought help in 2009.

Yolanda was able to get the man a waiver from the ban and his green card was granted. (The HIV travel ban was rescinded in 2010.)

In 2015, the man returned to the AIDS Law Project seeking Yolanda's help to become a citizen. At the same time he revealed another problem his family faced.

His daughter, now 19, was born in a refugee camp, where birth certificates are not issued. Her only official identification

was the I-94 arrival record created after she left the refugee camp at age 5.

Her father kept the document in his wallet. He lost his wallet two years ago, and she could no longer prove she was in the country legally. If she had been picked up, she could have been detained or even deported.

To make matters worse, although she had graduated from high school and been accepted to a college, she could not get financial assistance.

"She was scared for her future," Yolanda said. "She didn't think she was going to get to go to college."

The only thing the family had was a United Nations document showing they had promised to repay her travel expenses to the United States. Utilizing her strong investigative skills, Yolanda tracked down records that showed our client's daughter entered elementary school in 2005 and was issued a student ID in 2016.

With those documents in hand, Yolanda requested that Homeland Security reissue the client's daughter her I-94 arrival record. She can now apply for a green card.

The young woman is now in college and looking forward to a bright future.

To top things off, her father was granted citizenship in August and is now waiting for the ceremony that will make it official.

GOOD COUNSEL BY E-MAIL

Want to get the newsletter electronically? Sign up at

AIDSLawPa.org/e-newsletter.



The Sky's The Limit With A New ID

TRANSGENDER WOMAN FACES BARRIERS
IN QUEST TO CHANGE NAME, TRAVEL FREELY

Although she had transitioned her gender more than 40 years ago, the woman had never gotten official identification in the name she had used all her adult life.

But she had come to a point where she wanted to broaden her horizons. As a transgender woman and a long-time survivor of HIV, she wanted to share her story to give strength to others in her situation, said **Adrian M. Lowe**, an AIDS Law Project staff attorney.

According to the Centers for Disease Control and Prevention, 22 to 28 percent of transgender women are living with HIV and an estimated 56 percent of black transgender women are living with HIV.

"She wanted to give hope to other trans women living with HIV," Adrian said.

She had opportunities to pursue her goal, having been invited as a panelist to international and national conferences.

The problem was she couldn't get to them.

New federal regulations that took effect in January require air travelers to have official identification compliant with the Real ID Act. Without ID that matched her true identity, she would always be limited in her ability to tell her story. She came to the AIDS Law Project for help.

The first step was to legally change her name to the one she had been using her entire adult life, which presented several hurdles.

As Adrian worked on her case, he learned she had a criminal record for sex work and a 12-year-old bench warrant she didn't even know about.

Luckily, she had never been convicted of a felony, which could have barred her from changing her name. Adrian helped her resolve those issues and then petitioned the Court of Common Pleas in Philadelphia for a legal name change.

But there was one more problem.

Pennsylvania requires name changes be published in two newspapers. Although the woman had a strong desire to interact with the transgender community, she didn't want to be "outed" to the general public because of the discrimination and violence transgender women often face.

Adrian requested an in-camera hearing to ask for a waiver of the requirement.

"She testified about friends she had lost to violence as a result of hatred towards transgender women," Adrian said.

The judge granted the waiver and sealed the record of her name change. Finally, Adrian and his client went to the Department of Motor Vehicles and she soon had an ID that matched her true self.

"She said she felt like she just won the lottery," Adrian said.

Family Back On Track After Benefits Secured

AFTER LAYOFF AND SOCIAL SECURITY DENIAL,
N.J. MAN TURNS TO AIDS LAW PROJECT

Despite living with muscular dystrophy and HIV, the 50-year-old Camden County man pushed himself hard to keep up with the demands of his work as a mental health case manager, a job he loved.

Then he lost his job to company-wide layoffs and things started to unravel.

He wanted to get back to work immediately in a similar position, but that proved elusive. The jobs he applied for required physicals and he failed them time and time again. His muscular dystrophy, a hereditary condition marked by progressive weakening and wasting of the muscles, had advanced since he was diagnosed about 15 years ago.

Reluctantly, he applied for Social Security disability benefits, but was denied and his family's finances deteriorated. Although his wife took a second job, they struggled to pay the mortgage on their house and eventually could not keep up. They were at risk of losing their home.

Unable to even help out much around the house due to his health, our client gradually slipped further into depression.

Then, in September 2017, he realized he needed help and

met with **Charlotte Hollander**, the senior staff attorney at our Southern New Jersey office.

Charlotte reviewed his medical records and realized what probably caused the denial from Social Security, which has specific criteria for what constitutes a disability based on various medical conditions. Although the records included his neurologist's assessment that he was "clearly disabled," they did not contain the battery of neurological and functional tests that would meet the Social Security Administration's criteria.

Charlotte discussed the criteria with the neurologist, who reexamined the man, did additional tests and updated his records.

The next step was to appeal the denial to the New Jersey Department of Disability Determination, a process that can take up to two years. It was time the man and his family didn't have.

At an initial review of the appeal in August, the department made a highly unusual decision, approving his application on the spot and granting him back benefits.

The man was elated.

"It had become a really bad situation," Charlotte said. "Now they can keep their house. It was a life saver."

30 YEARS OF VICTORIES

1988: We file several complaints against Pennsylvania physicians for secretly testing people for HIV.

1989: We file suit against a funeral home that used an empty coffin at the memorial service for the deceased. A jury awarded the mother of the deceased \$175,000.

1990: We file a complaint against 11 dentists who refused to treat patients living with HIV.

1992: A Bucks County dairy bar settles a discrimination suit we filed on behalf of a worker who was fired because he had HIV.

1994: Philadelphia signs the first consent decree in the country under the ADA after Fire Department emergency medical technicians refuse to treat a man with HIV.

1994: We take action against SEPTA and Rite Aid after a breach of confidentiality of employee prescription records. Rite Aid agrees to modify its billing procedures to prevent future disclosures.

1995: 12th Street Gym pays \$35,000 to settle an HIV discrimination suit.

1999: The Pennsylvania Legislature adopts the Standby Guardianship Law, drafted and proposed by the AIDS Law Project.

1999: A Delaware County man who was fired from his job because his partner had AIDS gets a financial settlement.

2001: A national transportation company pays financial compensation after its driver rejects the disability pass from our client, a man with HIV.

2001: Our client, a Peruvian man living with HIV, wins asylum in the United States, sparing him deportation.

2002: A bus company pays a financial settlement to a group of HIV activists it refused to drive to a rally in Harrisburg.

2003: A dentist pays a financial settlement to a man with HIV he refused to treat.

2004: A client gets a liver transplant after we appeal his Medicaid denial. HIV is removed from the state's list of "life-limiting conditions" as a result.

2006: Philadelphia agrees to financial compensation, a nondiscrimination policy and training after Fire Department emergency medical technicians refuse to treat our client, a man with HIV.

2006: We get the state to clarify that occupational licensing rules that exclude people with an "infectious, contagious, or communicable disease" do not apply to people with HIV, as the virus is not transmitted through casual contact.

2008: A sandwich shop pays a settlement to a worker it fired for having HIV.

2009: A financing company settles with our client after trying to back out of a promise to pay her health insurance premiums for life because she lived longer than expected.

2010: A client who had been kicked out of a personal care home because she has HIV wins more than \$60,000 in a trial before the Pennsylvania Human Relations Commission.

2010: We successfully sue a financial services company who paid death benefits to the ex-wife of our client's deceased partner, contrary to his wishes and even though they had been divorced for 25 years.

2011: We settle a case on behalf of a single mother of four living with HIV who was fired from her job at a snack-food manufacturer after her supervisors found out her status.

2012: We negotiate a settlement with a national health care staffing firm that rescinded a job offer from a nursing assistant after learning he has HIV.

2012: The Milton Hershey School pays \$700,000 to settle a federal AIDS discrimination suit we file after the school refused to admit our client, a 13-year-old honor student, because he has HIV.

2013: A home health care company pays \$15,000 to our client after a worker told his uncle to keep the kids away from him because he has HIV.

2013: We settle a case on behalf of a nursing assistant with HIV whose job offer was rescinded after he disclosed his status.

2014: A hospital pays financial compensation to our client who was recovering from surgery, when his doctor disclosed his status to a visitor.

2014: Our client, a worker at a residential facility for troubled youth who was fired for having HIV, is reinstated and

gets back pay and compensatory damages.

2015: With our assistance, criminal charges are dismissed against a licensed practical nurse from Lebanon County for not disclosing her HIV status before engaging in consensual sex.

2015: A Montgomery County hospital pays \$25,000 to settle

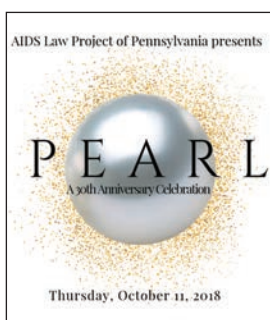


CELEBRATING 30 YEARS



Our 30th anniversary celebration at the Asian Arts Initiative drew almost 200 people.

Photo by Donald D. Groff



Far left: Bill Rusk, Dina Stonberg and Dennis Langan.

Below left: Teddy Fatscher of Brian Sanders' JUNK performs.

Below center: Executive Director Ronda Goldfein and board member Kim Silverman remember the 1995 lawsuit on behalf of Kim's brother, an AIDS Law Project client.

Below right: From left, paralegal John C. Marrero, Audrey Hoang Ai, Jonathan Agudelo, Sean Doan, Steven McManus, Matt Greene and Puneet Masson.

Photos by Contigo Photos + Films



a claim we brought on behalf of a woman who said she was denied bariatric surgery because she has HIV.

2015: A Philadelphia County physical rehabilitation center financially compensates our client, a woman who was denied paraffin wax treatment because she has HIV.

2015: A Lancaster County medical practice agrees to financially compensate our client after it kicked him and his family out of the practice because he has HIV.

2016: Following the end of DOMA and the beginning of marriage equality, we file an immigration waiver for a man with HIV who was at risk of being deported and separated from his US citizen husband.

2017: The Philadelphia Commission on Human Relations grants our client financial compensation in a claim against

a taxi company whose driver kicked him out for kissing another man.

2017: Our client receives \$30,000 from a northeast Pennsylvania residential care facility that fired him five days after he disclosed he has HIV.

2017: We settle a case on behalf of a Navy veteran with HIV who was denied aqua therapy at a physical therapy center.

2017: A chef living with HIV and his fiancé, who does not have HIV, get financial compensation in an agreement we negotiate after both were fired from a country club restaurant.

2018: Aetna agrees to a \$17 million settlement after we partner with the Legal Action Center and Berger & Montague on a federal class action lawsuit after a faulty mailing reveals the HIV-related information of more than 12,000 customers.

INSIDE THE AIDS LAW PROJECT

Hearts Newsletter Breaks Into Prison

Hearts on a Wire, a collective of transgender and gender variant people and allies inside and outside Pennsylvania's prisons, publishes a quarterly newsletter. When officials in two state prisons blocked its distribution, the AIDS Law Project stepped in to help.

The newsletter publishes stories, letters and resources for incarcerated people that are a lifeline for a highly marginalized community, both in the prison system and the broader community, according to **Adrian M. Lowe**, a staff attorney for the AIDS Law Project and a co-founder of Hearts on a Wire.

"It connects them to one another and the community outside," Adrian said. "It gives them hope."

Based on Hearts on a Wire's internal survey, 34 percent of its incarcerated members self-disclosed that they are HIV positive.



In May, Hearts on a Wire mailed copies of its 22nd issue to community members in Pennsylvania state prisons. It was rejected by two of them.

The AIDS Law Project challenged those decisions, arguing among other things that banning the newsletter without a legal basis violated the First Amendment rights of the intended recipients.

The Department of Corrections ultimately agreed that the appropriate process had not been followed and the newsletter was soon in the hands of those it is intended to help.

BOO! V • "SWINE AND PEARLS"

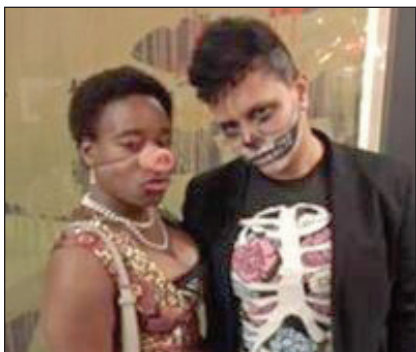


Photo by RJ Thornburg



Photo by Audrey Hoang Ai

Our annual Halloween party was at BAHDEEBAH DU on Oct. 26. Enlivening the festivities were, left, Kristina "Supa" Hill and Evan Thornburg; below left, Todd Flaherty and Audrey Hoang Ai; and below, Jennifer Segal, board member Bryn Michaels, Adam Williams and Shira Goldberg.



Photo by Bryn Michaels

BRIEFLY NOTED

CONGRATULATIONS: Blair

C. Dickerson, our intake attorney, was honored with a Tatnall School distinguished alumni award in October. The Tatnall School is an independent, coeducational college preparatory school in Wilmington, Del., founded in 1930. In 1972, Blair was the school's first African American graduate.



CONGRATULATIONS: Finesse

Ross, a member of our board of directors, received a much-deserved honor when she was named one of four Miss Philly LGBT Pride recipients, in honor of their loyalty to the community.

WELCOME:

Saybria Nelson

has joined the AIDS Law Project as an intake paralegal. She currently is a paralegal studies student at Peirce College. Saybria was a volunteer on our intake team this summer.



FAREWELL: Maggie Schepcaro

has left her role as an intake paralegal to study for a master's degree at Temple University Klein College of Media and Communication. We thank her for her contribution and wish her good luck in her studies.

THANK YOU: This summer we were lucky to have the assistance of two second-year law students from Temple University Beasley School of Law. **Josh Davis** worked on housing issues and **Grace Harris** worked on public benefits issues and HIV discrimination.

FROM THE COVER

Aetna Settlement Approved

Continued from Page 1

in the lawsuit, using the pseudonym of the fictional lawyer with HIV played by Tom Hanks in his Academy Award-winning role in the 1993 movie *Philadelphia*.

The AIDS Law Project of Pennsylvania, the Legal Action Center and Berger & Montague, P.C. filed the lawsuit in August 2017. The plaintiffs included people taking medication to treat HIV, as well as people who, like Beckett, take PrEP, a pre-exposure prophylactic that prevents HIV.

Aetna improperly shared with its legal counsel and a mail vendor the names of 13,487 customers who had been prescribed HIV medications, papers filed in support of the settlement allege. Of those, 11,875 people received the large-windowed envelopes revealing confidential HIV-related information, according to the papers.

Aetna agreed to pay \$17,161,200 to resolve the claims. All settlement class members will automatically receive a base payment of either \$75 to those whose health information was allegedly improperly disclosed by Aetna to its legal counsel and mail vendor, or at least \$500 (including the \$75 payment above) to those who received the large-windowed envelope.

Class members also had the opportunity to seek additional monetary relief of up to \$20,000 by documenting financial or non-financial harm.

The settlement includes the implementation by Aetna of a new “best practices” policy to prevent similar incidents from occurring in the future, and provides for attorneys’ fees and expenses.

After 30 Years, Still Vital

Continued from Page 1

with the times. While originally intended to exclusively serve people with HIV and AIDS, it now also helps people at risk of HIV, including the transgender community and those in the grip of opioid addiction.

“I’m excited that we’re still here, still providing quality services,” Yolanda said. “We respond to the issues in the community as they evolve.”

Aaron Skrypski, president of the AIDS Law Project’s board of directors, said the number of people the organization has helped is overwhelming.

“As we look to the future, the needs of our community and city are evolving, and the AIDS Law Project is committed to being at the forefront of that change,” Aaron said. “We will continue to fight for an end to HIV-related discrimination, while expanding our advocacy work with new vulnerable populations and — most importantly — being a place of refuge for anyone who walks through our front door.”

We observed our milestone with a series of events throughout the year, culminating with PEARL: A 30th Anniversary Celebration, a spectacular evening at the Asian Arts Initiative on Oct. 11, and BOO! V “Swine & Pearls,” our annual Halloween party at BAHDEEBAHDU on Oct. 26.

ABOUT US

WHAT WE DO

The AIDS Law Project of Pennsylvania is a non-profit, public-interest law firm. We publish *Good Counsel* semiannually for our friends, volunteers and colleagues committed to protecting the rights of people with HIV. Last year, we worked on 1,913 legal issues, nearly all from people with HIV. We help people navigate the legal system, the welfare system, the housing system, and the worlds of public and private insurance. We provide education and training to professionals who work with people with HIV.

WHO WE ARE

BOARD OF DIRECTORS

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STAFF

| | |
|-----------------------------|---------------------------------|
| Ronda B. Goldfein, Esq. | <i>Executive Director</i> |
| Yolanda French Lollis, Esq. | <i>Managing Attorney</i> |
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| John C. Marrero | Jeni Wright, Esq. |
| Sarah Schalman-Bergen, Esq. | <i>Of Counsel</i> |
| Blair C. Dickerson, J.D. | <i>Volunteer Attorney</i> |
| Mark Spencer | <i>Editor/Writer</i> |
| Paul Spencer | <i>Newsletter Designer</i> |

WHERE WE ARE

1211 Chestnut Street, Suite 600, Philadelphia, PA 19107
709 Haddonfield-Berlin Road, Voorhees, NJ 08043
Telephone: 215-587-9377 Fax: 215-587-9902
On the web: www.aidslawpa.org
On Facebook: [AIDS Law Project of Pennsylvania](https://www.facebook.com/AIDSLawProjectofPennsylvania)
On Twitter: [@AIDSLawPa](https://twitter.com/AIDSLawPa)

HOW TO HELP

Remember us at workplace giving time. When you donor-designate in your workplace giving campaign, remember your neighbors served by the AIDS Law Project of Pennsylvania.

United Way of SE PA: Specific Care Option #09067
Combined Federal Campaign: Donor Option #36027



OUR FUNDERS AND DONORS

Gifts received April 1, 2018 through Sept. 30, 2018

Major Funders, Grants and Contracts

AIDS Fund
AIDS Healthcare Foundation
Broadway Cares/Equity Fights AIDS
Health Federation of Philadelphia
MAC AIDS Fund
The Mayor's Fund for Philadelphia
New Jersey Interest on Lawyers' Trust Accounts (IOLTA)
Pennsylvania Interest on Lawyers' Trust Accounts (IOLTA)
Philadelphia Bar Foundation
Philadelphia Bar Association, Public Interest Section, Higginbotham Fellowship
Philadelphia Department of Public Health, AIDS Activities Coordinating Office (AACO)
The Philadelphia Foundation
Philly AIDS Thrift
Prevention Point Philadelphia
Union Benevolent Association

Gifts of \$5,000 to \$9,999

Eden Family Foundation
Mel Heifetz
Kline & Specter, P.C.

Gifts of \$2,500 to \$4,999

David Lee Preston & Ronda B. Goldfein

Gifts of \$1,000 to \$2,499

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Jose deMarco
Michael Ippoliti
Kent & Yolanda Lollis
Bryn & Jeffrey Michaels
Aaron Skrypski
Michael Weiss

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Philadelphia FIGHT
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Linda J. Scarazzini & Lisa Kyriakatos
The Wistar Institute
M. Michael Zuckerman & Jan Levine

Gifts of \$250 to \$499

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Jovan Goldstein
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Leslie Miller & Richard Worley
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Mark Segal
RJ Thornburg
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Bebe Kivitz
Tara Lessard
Joann Leszczynsky
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Judith R. Porter
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Gifts of \$49 and under

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Mark Davis
Daniel Dunlavey
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Susan Feagin
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Charles Jones
Constance Kirker
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Philip Sebastian
Brian Shulli
Howard Silverman
Raymond Simon
Dionysia Sioutis
Phyllis & Richard Taylor
Everett Wilde
Jennifer Yuan

Workplace Giving Campaigns

Abbvie
Amazon Smile
Arthur J. Gallagher Foundation
Combined Federal Campaign
Fidelity Charitable
Penn Virginia Corporation
Pew Charitable Trusts
United Way of SEPA
United Way of Tri-State

Gifts were made in honor of:

Steve Goldfein

Gifts were made in memory of:

Stephen Michael Petty

Gifts in Kind

AIDS Fund

Aramark PRIDE
BAHDEEBAH DU
Richard Barrios
Sonja Bontrager
CRW Graphics
Josh Davis
Cookie Diorio
Grace Harris
Matthew Mossman
Nuts To You
Pyramid Club
Finesse Ross
Mark Seaman
The Secret Cinema
Midge Shull
David Talento
Evan Thornburg
William Way LGBT Community Center

Gifts in Kind for PEARL & BOO! V

12th Street Catering
Asian Arts Initiative
BAHDEEBAH DU
José Benitez
Brian Sanders' JUNK
Contigo Photos + Films
CRW Graphics
Danny's Midnight Confessions
DJ Sharyn Stone
DJ Wrong
Eventsful
Faber
Farrow & Ball
Flying Fish Brewing Co. garnish
Julie Graham
Marcus Hill
John Jarboe & Heath Allen of The Bearded Ladies Cabaret
Peter Lien
Moore Brothers Wine Company
Megan Niño
Original XIII Ciderworks
Randy Ott
Oyster House
Passional & Sexploratorium
Philadelphia Gay News (PGN)
Pleasure Chest
Single Prop
South Jersey Party Rental, Ltd.
Mark Spencer
RJ Thornburg & Warren Muller
Tim Bellew Food
The Tot Truck