AIDS Law Project delivers again on a transplant case

The initial call from Robert Burrowes Jr. to the AIDS Law Project of Pennsylvania last November was merely speculative. The 46-year-old did not think he really needed the help of a public-interest law firm, as he and his partner had the resources to hire a private attorney.

But within weeks, Burrowes contacted the AIDS Law Project again, because — like William Jean Gough, for whom the AIDS Law Project successfully appealed a liver transplant denial in 2004 — he had discovered that when you are HIV-positive and Medicare has denied your request for an organ transplant, there is almost nowhere else to go.

When the case made its way to Public Benefits Attorney Asha Ramachandran, she learned that Burrowes, a former professional chef who lives in Wayne, had been HIV-positive since 1987 and had hepatitis B since 1988. For many years, his antiretroviral treatment for HIV had kept his hepatitis under control, but, when the HIV regimen changed, Burrowes developed chronic liver disease requiring weekly therapy at the Hospital of the University of Pennsylvania. Eventually, Burrowes’ doctor told him that a liver transplant was the only hope for reversing his deteriorating condition.

In August 2009, Burrowes went to the Thomas E. Starzl Transplantation Institute at the University of Pittsburgh for a full medical review by the transplant team. By Aug. 26, all of the tests and reports had come back in support of a liver transplant at the earliest possible date. As Burrowes was preparing himself for the transplant, the hospital’s finance department sent him a notice of non-coverage stating that “Medicare is without guidelines for a liver transplant in the presence of HIV infection.”

Burrowes appealed this decision to an independent review organization that contracts with Medicare to review appeals. In mid-September, the reviewers ruled that the “proposed admission was not medically necessary.” As his need was clear and the transplant was in no way experimental, Burrowes began to wonder if the system was “just trying to stall me so that I’m dead so [they] don’t have to pay for it.”

Ramachandran just 12 days to prepare for the appeal hearing. Although she had never done a Medicare appeal hearing before, with the dedicated assistance of Certified Legal Intern Charles Bruce, Ramachandran prepared her case.

The national Center for Medicare Advocacy also helped Ramachandran get up to speed with its significant and invaluable assistance on both substantive and procedural issues.

In November, Burrowes filed a second appeal that was also denied, although this time, the reviewers agreed that the procedure was medically necessary. In December, Burrowes filed a Request for Hearing before an Administrative Law Judge. An expedited hearing was scheduled for February, giving attorney Ramachandran just 12 days to prepare for the appeal hearing. Although she had never done a Medicare appeal hearing before, with the dedicated assistance of Certified Legal Intern Charles Bruce, Ramachandran prepared her case.

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MESSAGE FROM THE EXECUTIVE DIRECTOR

Dear Friends,

Sometimes, our clients have to plead to save their lives. Even if they shouldn’t have to.

That’s exactly what happened to one of our clients, the subject of Good Counsel’s cover story. His doctor told him that his only hope for survival after years of chronic liver disease was receiving a new organ. A team of specialists at the transplant center reviewed and cleared him, which put him on the transplant list.

Then the hospital’s financial office said “no.” Medicare has no guidelines for HIV-positive organ recipients, so they feared the center wouldn’t get paid for the procedure.

We appealed on behalf of the client — and won.

“No,” of course, is a word our clients hear all too often. As in, “No, you can’t have this medication that will prolong your life because you’re not covered.”

Or, “No, you can’t live here because you have AIDS.” Or, “No, I won’t keep your HIV status confidential because I don’t think I have to.”

But ‘no’ in large part, is why the AIDS Law Project of Pennsylvania exists. We fight, every week, to turn some ‘no’ into a ‘yes.’ Most of the time, we’re successful. Sometimes we’re not. But that just motivates us to work harder.

We’re lucky to be able to boast of a string of successes, including defeating other insurance denials. Some are based on ignorance, others on outright bias. In our recent client’s case, the issue was money, or more precisely, a lack of understanding of how Medicare works, what it will pay for and what it won’t.

So part of our advocacy is education, explaining that people with HIV retain their rights, including the right to a medically appropriate liver transplant, despite their diagnosis. And we expect to be in this business for the long haul.

We do the good work of keeping people in their homes, getting them life-saving benefits, and helping them prepare for the future. We do this as our caseloads steadily increase, and the dollars to do battle dwindle.

The reason we continue on is that our work affirms our clients’ lives. Our work says to the powers-that-be that someone like our liver-transplant client is entitled to fair and equal treatment. And when clients are met with resistance or misunderstanding, we will plead for them. Especially because they shouldn’t have to.

Counsel

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
A HELPING HAND FOR THE BESENT & BEWILDERED

For many AIDS Law Project clients, troubles never arrive singly -- they bring the whole family of misfortunes with them. Take the case of Lorraine.

Lorraine is 47 years old and has HIV, breast cancer and high blood pressure. In the summer of 2009, Lorraine called the AIDS Law Project because she had gotten a letter from Pennsylvania’s Department of Public Welfare (DPW) advising her of a reduction to her food-stamp benefit.

Certified Legal Intern Vinh Su appealed the reduction to an administrative law judge. In August, Certified Legal Intern Deborah Richman took over from Vinh. In early October, Deborah was advised by DPW that Lorraine’s food stamps amount would not be reduced.

Meanwhile, Lorraine was also having problems with the Social Security Administration (SSA). According to the SSA, Lorraine had not reported her income from a job she held years earlier, although Lorraine contended that she called three times to tell them she had a job. Despite Lorraine’s protests, SSA determined that Lorraine had been overpaid and planned to withhold all of her monthly disability payments to pay off her overpayment.

Instead, Deborah was able to negotiate a repayment plan in which only $20 a month would be deducted from Lorraine’s check. But when SSA entered the $20-a-month repayment plan into its system it triggered another erroneous reduction to Lorraine’s food stamps.

Deborah was able to determine that the source of the problem was a computer glitch that prevented DPW’s computer software from correctly interpreting SSA’s data. The DPW software mistakenly interpreted the repayment plan as though Lorraine was ineligible for food stamps. By January, DPW resolved the problem.

In the six months that it took to straighten out these problems, the legal team found other ways to help Lorraine. Her budget revealed that she was paying $25 a month for Medicare Part D coverage, which Public Benefits Attorney Asha Ramachandran thought was too high. In December, Certified Legal Intern Charles Bruce switched Lorraine to a similar plan that was available without cost.

Lorraine’s budget also devoted 10 percent of her monthly income to paying off student loans and credit-card debt. The team is now working on discharging Lorraine’s student loans and negotiating with the other creditors to ease her current financial burden.

SSA TAKES AND — WITH MONTHS OF CONVINCING — GIVES BACK

Certified Legal Intern Gabbie Nirenburg was assigned a case in her first few days at the AIDS Law Project last August that called upon not just her legal skills but also her stamina. Ricardo (not his real name) had sought help from the AIDS Law Project because his Social Security payments had abruptly dropped after the Social Security Administration (SSA) decided that he had previously overpaid him by $3,000. It was true, as the SSA had said, that the 60-year-old West Philadelphian had worked as a janitor in a prior year. But the agency’s allegation that Ricardo had never given it a copy of his pay stub was false.

Gabbie started the process by filing a Request for Waiver of Overpayment Recovery with the SSA. Next, she called the SSA to convince the agency that it should stop tapping Ricardo’s monthly check until the waiver request was decided. The SSA agreed and Ricardo got his full check back again.

Then the SSA again started taking $5 a month. Gabbie again got the agency to stop. Then it happened again, and again and again. Every other month for seven months, Gabbie had to get back on the telephone to renegotiate the same deal.

The AIDS Law Project requested a personal conference with the SSA to discuss the waiver request. Gabbie accompanied the client along with Public Benefits Attorney Asha Ramachandran. At the conference, Gabbie had to prove both that Ricardo was not at fault in causing the overpayment, and that he could not afford to make any payments. Convinced by the evidence put before it, the SSA granted the waiver and paid back all the money it had deducted from Ricardo’s checks over the preceding months.
A dental settlement to smile about

Imagine being in excruciating pain for months because of an infected tooth that no one would treat. That is exactly what led one central Pennsylvania man with HIV, who receives Medicaid, to become a client of the AIDS Law Project of Pennsylvania.

In spring 2009, Mr. Smith (not his real name) went to a hospital emergency room seeking treatment for a toothache. The emergency room didn’t provide routine dental care, and Mr. Smith was told to find a dentist. After weeks of searching for a dentist that would accept Medicaid, Mr. Smith returned to the emergency room for relief. This time, he came away with the name of a dentist whom he was assured accepted Medicaid.

Mr. Smith called the dentist.

“Yes,” the voice at the other end of the phone reassured him, the dentist accepted Medicaid.

“Yes,” said the voice again when Mr. Smith asked if the dentist was accepting new patients. But as soon as he mentioned that he was HIV positive, Mr. Smith was told, “We don’t have the facilities for that,” followed by a swift hang-up.

Mr. Smith contacted his case manager, Stephanie Lloyd of the AIDS Resource Alliance in Williamsport, Pa. Lloyd, skeptical that such blatant discrimination continues to occur, called the dentist herself. “Hi! Are you accepting new patients who receive Medicaid?” she asked of the person who answered the phone.

“Yes” came a slow and cautious reply, followed by, “Did you — or somebody — just call here?”

“My client called and he’s HIV-positive,” said Lloyd.

“We don’t have the facilities to handle that,” repeated the voice before hanging up again.

In response to that brush-off, the AIDS Resource Alliance agreed to pay for a dentist for Mr. Smith, but between authorizing the expense and the new dentist’s schedule, an appointment was set not for more than two weeks later. By that time, the infection was so entrenched that pulling the tooth posed a serious health risk because of his compromised immune system.

Mr. Smith spent 10 more painful days on antibiotics before the tooth could be extracted.

The AIDS Resource Alliance also urged Mr. Smith to call the AIDS Law Project of Pennsylvania. Last summer, the matter landed on the desks of Deputy Managing Attorney Cathryn Miller-Wilson and Certified Legal Intern Jane Nylund, now a third-year student at Villanova University School of Law. In the fall, Certified Legal Intern Marisa Barriere took over Nylund’s cases and filed an AIDS-discrimination complaint with the Pennsylvania Human Relations Commission.

With the AIDS Law Project at Mr. Smith’s side, the dentist agreed to compensate him for his pain and suffering. Miller-Wilson also demanded that the dental office train its employees on a non-discrimination policy at regular intervals, as well as distribute materials and post signs about the policy in the waiting area. In a final act of fairness, the dentist agreed to reimburse the AIDS Resource Alliance for its payment to the dentist who treated Mr. Smith.

Despite his long ordeal, the AIDS Law Project’s client is, once again, all smiles.

Mark July 16 with an ‘X’ — our annual summer movie party

Center City’s coolest warm-weather fundraiser returns!

Join us for a Secret Cinema screening of “Madame X” (1966), starring Lana Turner, John Forsythe, Ricardo Montalban, Burgess Meredith, and Keir Dullea.

Turner plays Holly, a rich wife neglected by her diplomat hubby (Forsythe). She’s wrongly accused of murdering the playboy (Montalban) with whom she was having a torrid affair. To protect her young son, Holly runs away, hiding in an underground of debauchery. She’s tricked into returning home by a so-called friend (Meredith), who blackmails her family by threatening to reveal her true identity. Holly kills the cad in self-defense, is arrested, and — irony of ironies — her defense lawyer is her own son (Dullea), who doesn’t recognize her. Vowing to shield him to the bitter end, she identifies herself only as ... “Madame X.” Scandalous!

WHEN: 6 p.m. Friday, July 16, for beer, wine and hors d’oeuvres (included in ticket price); movie starts at 7:30 p.m.
WHERE: Digitas Health, 11th floor of the Wanamaker Building (100 Penn Square East) in Philadelphia, just east of City Hall.
PRICE: $20 per person (minimum donation).

To purchase your copy, contact the AIDS Law Project of Pennsylvania at 215-587-9377 or visit www.aidslawpa.org.
Legal Services in 2009

We helped 1,343 people with 1,955 legal matters. 94 percent of requests for help come from people with HIV/AIDS, while the remaining 6 percent comes from friends and family, case managers, attorneys, healthcare workers, students, employers and others. Overall, 74 percent of all clients live within Philadelphia County. Many clients have multiple issues.

OUR ANNUAL WORKLOAD

CLIENTS BY AGE

RACE AND ETHNICITY

CLIENTS BY GENDER
Haitian with HIV gets temporary reprieve on removal

The Jan. 12 earthquake that devastated much of southern Haiti and left an estimated 230,000 people dead also has had political aftershocks for many Haitians living in America, including a client of the AIDS Law Project of Pennsylvania.

Ms. T., who has been HIV-positive since 1997, left her mother and extended family in Haiti for Miami in 1992. Upon arrival, she applied for asylum and received a work permit, eventually moving to the Philadelphia area. Over the past 14 years, she has worked at a job with health benefits sufficient to manage her HIV and has raised a daughter who, since she was born here, is an American citizen.

However, Ms. T.'s life in America seemed built on an unstable foundation after her application for asylum was denied in 2006 and there was no other basis to keep her in this country under an old U.S. travel ban on HIV-positive immigrants. "I did not anticipate winning," is all Managing Attorney Yolanda French Lollis says of representing Ms. T in removal proceedings.

Losing would have condemned Ms. T. to return to a country where she would have neither employment nor health care. Worse yet was that she would have been separated from her teenage daughter, who would have remained behind in foster care.

On Jan. 15, three days after the earthquake, Ms. T.'s situation changed, if temporarily, when Homeland Security Secretary Janet Napolitano announced "temporary protected status for Haitian nationals who were in the United States as of January 12, 2010." Napolitano explained that the designation will allow eligible Haitian nationals in the United States to continue living and working in our country for the next 18 months.

"This means that the 100,000-200,000 Haitian immigrants whom the Department of Homeland Security estimates are now in the United States on a temporary basis or without authorization will not be subject to removal as long as there is no functioning country to which they can return, and provided that they do not have criminal records," according to the website of the Immigration Policy Center of the American Immigration Council (www.immigrationpolicy.org) on March 13. There are currently 535,000 Haitian immigrants in the United States, including 30,000 to 60,000 in Philadelphia.

Now, with the 18-month reprieve on removals and the almost simultaneous ending of the federal travel ban (see story this page), Ms. T. and her daughter can continue to live their American lives even as the AIDS Law Project looks for a long-term solution.

Federal HIV travel ban lifted

By James L. Rosica

It hasn't made sense for years.

Since 1987, the federal government has banned HIV-positive people from visiting or immigrating to the United States. At the time, little was known about the virus that causes AIDS, and officials decided HIV was a "communicable disease of public health significance."

What a difference two decades makes.

Last November, the Obama administration — completing a process started under former President George W. Bush to lift the ban for HIV-positive temporary visitors to the United States — said it would go further and completely remove HIV as a condition barring permanent-resident status.

This means medical screening for HIV will no longer be required for people who apply to get green cards. The decision went into full effect on Jan. 4, 2010.

The move has far-reaching effects on people with HIV/AIDS, including reuniting families, allowing people to come to the United States to escape repressive regimes, and permitting adoptions of HIV-positive children that otherwise had been blocked.

As Dr. Arlene Barbegovz, outgoing president of the HIV Medicine Association, told the Associated Press last October: "This long-overdue move brings the U.S. in line with current scientific and international standards of public health and will lessen the painful stigma and discrimination suffered by HIV-positive people."

"Good riddance to this discriminatory rule that had no basis in public health or sound science," she added.

The Centers for Disease Control and Prevention (CDC) summed up the thinking behind the decision: "Immigrants and refugees with HIV infection do not pose a risk to the public's health by entering the United States because HIV is preventable and is not spread through casual contact."

Before the change in the law, people who wanted to come to the United States as green card holders had to submit to a medical examination. That included an HIV-antibody test.

Applicants who tested positive for HIV became immediately ineligible for a green card unless the government granted an HIV waiver. The tall barrier to getting a waiver was that the applicant had to prove that she or he had enough money or health insurance to meet the cost of treatment for HIV infection. That requirement is now moot.

Because the HIV travel ban has been lifted, the International AIDS Conference can now be held in the United States. Scheduled for 2012 in Washington, D.C., the event brings together "scientists, policy makers, program officials, HIV-positive individuals and others from all over the world," its web site said. No international HIV conference has been held in the U.S. since 1990 because of the ban, according to AIDSmap News.

TRAINING AT A GLANCE

In the last quarter of 2009 and first quarter of 2010, the AIDS Law Project offered many opportunities to learn about AIDS and the law, including the three monthly in-house seminars on Leaving Your Job, Back to Work, and Housing: Tenants' Rights and Responsibilities. Here's a snapshot of the programs.

TRAINEE DEMOGRAPHICS
October 2009-March 2010

Who attended
62 law students
2 clients*
30 medical students
76 case managers
20 other health professionals

Off-site locations
New Cumberland, Pa.
Danville, Pa.
Cranberry, Pa.
Carlisle, Pa.
Various locations throughout Philadelphia

Most-requested topics
Standby Guardianship
Back to Work

Sponsors
Health Federation (a network of the community health centers in Southeastern Pennsylvania)
University of Pennsylvania School of Law
Drexel University Earle Mack School of Law
Penn State Law
Dickinson School of Law
Philadelphia Department of Public Health, AIDS Activity Coordinating Office
Drexel University College of Medicine
ActionAIDS

* Two individuals identified themselves as clients. Among the training attendees are others who choose not to publicly identify themselves as AIDS Law Project clients or as living with HIV.
**Mayor appoints Goldfein to Police Advisory Commission**

**Ronda Goldfein**, executive director of the AIDS Law Project of Pennsylvania, has been appointed by Philadelphia Mayor Michael Nutter to the Police Advisory Commission, a 15-member civilian oversight agency for the Philadelphia Police Department.

Goldfein was one of eight new members appointed by Nutter on April 20 to serve on the commission, a volunteer board formed in 1993 to, among other things, investigate complaints of police misconduct.

“My appointment is clearly the result of the AIDS Law Project’s reputation for fairless, trustworthiness and commitment to social justice,” Goldfein wrote in a memo to the AIDS Law Project staff on the day the appointment was announced.

In the first 11 months of 2009, the commission received 168 complaints, according to data on its website. In response to allegations such as abuse of authority, the commission conducts investigations, including hearings, and issues recommendations. The commission’s website is at www.phila.gov/pac.

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**Changes...**

**Welcome new board member**

**Stephanie Payne McBride** joins the AIDS Law Project of Pennsylvania board after lending her time, talents and two older children to several of our most successful fundraising events. A native of Los Angeles, she is married to writer, musician and friend of the AIDS Law Project, James McBride, and lives in Bucks County. A professional actor, Stephanie has appeared on stage in New York and in several films including *The Manchurian Candidate* directed by another friend of the AIDS Law Project, Jonathan Demme. Stephanie holds an MFA in writing from Vermont College of Fine Arts and teaches creative writing at The New School in New York City.

**Welcome new staffer**

**James L. Rosica,** Esq., one of the AIDS Law Project’s first Drexel Law field clinic interns in 2008-09, has returned to the AIDS Law Project’s fold as a part-time development associate. James, who graduated last year and is now a licensed New Jersey attorney, is assisting with fundraising, grant writing and public relations, including refining our Web presence. Before attending law school he was a newspaper reporter in Pennsylvania and Florida from 1993 to 2005.

**Congratulations**

The AIDS Law Project staff has been busy in recent months logging worthy achievements. Here are some highlights:

- Deputy Managing Attorney **Cathryn Miller-Wilson** wrote “Becoming Poor: Stories of the Real ‘Safety Net’ and the Consequences for Middle America,” an article in the Quinnipiac University School of Law Health Law Journal, Vol. 13, Number 1, at the end of 2009.

- In October 2009, Housing Staff Attorney **Rafiah Davis** joined the board of Haven Youth Services Inc. This nonprofit provides recreational, educational and social services to children who are affected by, or infected with, HIV/AIDS.

- Finance Director **Tiffany Hair** has been raking in honors as she completes her bachelor of arts degree at Rutgers University-Camden. She was the recipient of the Osher Reentry Scholarship, for people between 25 and 50 years old with academic promise who experienced an interruption in their education of five or more years. In addition, she received the school’s Alumni Outstanding Adult Senior Award for “a graduating adult student who has demonstrated outstanding leadership and service to the campus.”

Congratulations to all.

**... and bid farewell**

Spring is a time of new starts, and Criminal Records Resolution Paralegal **Rochie Johnson** will be keeping in step with the season as he settles into a case-management position at the Philadelphia Health Management Corporation. Meanwhile, bilingual Benefits Paralegal **Lauren Kluz-Wisniewski** is finalizing her choice of law school for this fall. Thanks to both of them for their service to the AIDS Law Project, and best of luck with their new endeavors.
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