



## Two Pills Saved My Life. Two Shots Could Have Saved His.

By Kevin Cummines

I HAD A headache on September 19, 2012. It was annoying, an added hurdle to the grind of my week. I was annoyed at Kyle, my boyfriend, because he probably gave me the flu. That's what we thought he was battling. We avoided each other that week. He was sick, and I was music directing a show that weekend. An actor and playwright, Kyle also had his own shows in development. Neither of us had time to be sick.

When Kyle's symptoms became much more severe, I toyed with forcing him to go to the hospital. Something clearly wasn't right, but I decided to give it one more day. Kyle was stubborn, and I didn't have that fight in me.

Kyle died that night. I was potentially next.

We were sero-discordant. He broke my heart a few times because of it. He worried about hurting me, being unable to commit. He worried about giving me HIV. He worried about everything and said nothing. That's how he was. I never worried. I knew he was the man for me the first time I saw him. Four and a half years and many break-ups after we met, we were back together and stronger than ever. I asked him to marry me, and he said yes. I imagined an amazing life together: artistic, impoverished, kinky, frustrating, playful, rare times of quiet...for better or worse, I was ready. He was a giant bundle of awesome. He was indomitable. His personality was massive, his presence powerful. He was my love, my hero, the man to join me in raising my daughter, the man I would support until my dying day.

Kyle's viral load was undetectable. He was the healthiest person I knew. It never crossed my mind to police our aches and pains. I never imagined

meningitis would steal my future from me. I never imagined meningitis would kill him.

The New York City Department of Health and Mental Hygiene sprung into action after Kyle's autopsy. Within an hour I was treated for the bacteria that killed him. Two pills. Eight dollars. One dose. So cheap, my insurance wasn't even bothered. We treated my daughter as well, just to be safe. But as the weeks passed, the casualties rose from this particular strain of meningitis, which killed within three days of the onset of symptoms, far faster than normal, and untreatable for most once symptoms began.

The reports were conflicting all over the media. But I watched as man after man was lost from our community, as the disease spread beyond gay men, to the West Coast, through colleges, and beyond. I watched family after family live the pain I lived, the pain Kyle's friends, families, and business partner lived. I watched an easily-preventable, easily-cured tragedy unfold — easily preventable because a vaccine could wipe the danger away with two doses.

The vaccine is inexpensive, often free. One shot if you're HIV-negative, two if you're positive. No side effects for most. Between fits of collapsing in tears as I continued to process Kyle's death, I told everyone I knew to get vaccinated. Yet, I waited nearly a year to be vaccinated, hoping something would take me...I wanted to be where Kyle was. That's all I ever wanted to begin with. I wanted to bask in his smile again. I wanted to stare back into those eyes, the color of grass with flecks of brass, more so in his right eye. I wanted the unrealistic desires of a grieving man. But I took the shot. I had no side effects. I felt no different after receiving the vaccine.



Kyle Spidle

Well, that's a lie. I felt angry. Angry for not knowing the symptoms of meningitis. Angry for not better protecting my family and the man who was the center of it. Angry at the world, the country, social media, the government, the city, for not telling me the vaccine existed, for not requiring us to get it, for not showing me that a free shot with no side effects would save my life, my daughter's life, my future husband's life. I was angry that his business collapsed, that his business partner lost it all, that his life work would be left unrealized, that his parents were devastated, that his nephews would grow up without him. You name the injustice, I was angry about it. I was angry that two pills might have saved his life, and two shots in the arm could have prevented all of this.

This is your wake-up call. Get vaccinated. It's easy. It's cheap. It's likely free or low cost from most clinics and departments of health. It's the right thing to do to protect yourself and those you love. If you are a legislator, this is also your call. This is life or death for your constituents. **My life was saved because New York City knew what to do. Call your representatives because we need public policy to address this, and**



## **Wait, What? Police Can Arrest You Simply for Having Condoms in Your Pocket?**

*By Chelsea Miller, Community Coordinator, GMHC*

**THE TRAGIC DEATHS** of Mike Brown and Eric Garner captured headlines around the world and ignited a movement against aggressive and discriminatory policing practices. In New York City, people are often illegally stopped, frisked, and arrested on suspicion of prostitution charges for merely possessing condoms. The New York Police Department (NYPD) employs a “condoms as evidence” policy that disproportionately affects youth who are lesbian, gay, bisexual and transgender (LGBT), especially youth of color, and who are living with or at high risk for HIV and AIDS.

In fact, New York City (NYC) spends more than \$1 million a year to distribute free condoms, while the NYPD concurrently criminalizes and confiscates them. The condoms as evidence policy jeopardizes the use of the most basic and effective tool to prevent HIV infection. It also not only threatens New York Governor Andrew Cuomo's Plan to End AIDS by 2020, but also the National HIV/AIDS Strategy.

**we need it now.** The vaccine is cheap and available. Two and a half years into this whole widower business, I'm ready to fight for my people. Nobody should have to suffer as we have.

Even today, I imagine a life with Kyle. I imagine working through his mood swings, his fears, his failures. I remember how infuriating he could be, how ridiculous his expectations could get, how closed he would become at the slightest sign of conflict. I imagine still feeling inadequate next to his devastating beauty, and learning to accept that he loved me even though I didn't deserve it. I imagine teaching him to express his fears to my face. I imagine us going through what every couple goes through heading towards the twilight of old age, a twilight we'll never realize. I imagine the man I loved so much beside me forever. I remember the best of times, his head on my chest as he slept, or the way he smiled at me when nobody was looking. I remember how his body felt in my arms. I still feel the true and honest love I always felt for him. Two pills saved my life. Two shots could have saved his. ■

Policies at the intersection of racism, criminal justice, and HIV, including condoms as evidence, further endanger the health of black men. Black men who have sex with men (MSM), particularly youth ages 13 to 29, have the highest rates of new HIV infections in the United States. A growing body of research shows that stop and frisk disproportionately targets communities of color. For example, in NYC black and Latino residents comprised up to 90 percent of people stopped by the NYPD from 2002 to 2011.

How are police able to identify condom carriers in the first place? In New York and throughout the country, law enforcement unconstitutionally “stop and frisk” “suspicious persons.” Law enforcement should only “stop” a person when they reasonably suspect that a person has committed or is about to commit a crime. A person can only be frisked, or “patted down,” when officers reasonably fear for their safety. On March 2, New York Police Commissioner

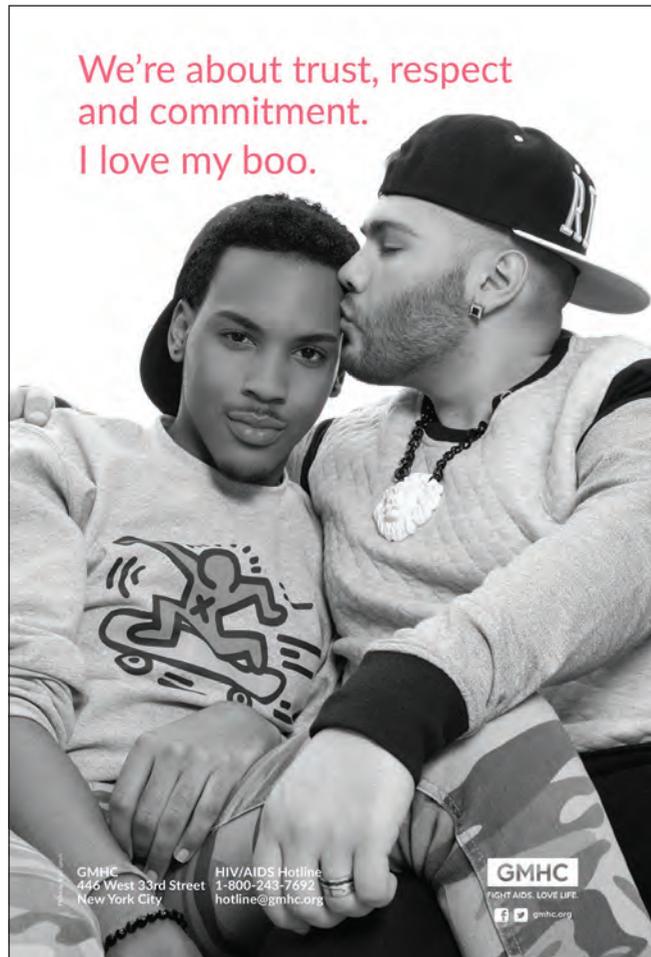
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## I Love My Boo

By Kelsey Louie, CEO, GMHC

**WITH THE UPCOMING** U.S. Supreme Court decision on same-sex marriage and nationwide protests about violence against African American men, public discourse about racism and homophobia has reached a tipping point in this country. Both continue to drive the HIV epidemic across the nation. In fact, in New York City African American and Latino men and women comprise 75 percent of new HIV infections, and of those, over half are among gay and bisexual men. To combat the epidemic in populations hardest hit by HIV, homophobia, and racism, GMHC first launched “I Love My Boo” in 2010, a prevention campaign that celebrates positive images of young gay men of color. Instead of presenting hyper-sexualized gay relationships and unrealistic images of chiseled bodies, I Love My Boo features real young men focused on the beauty of love and intimacy.

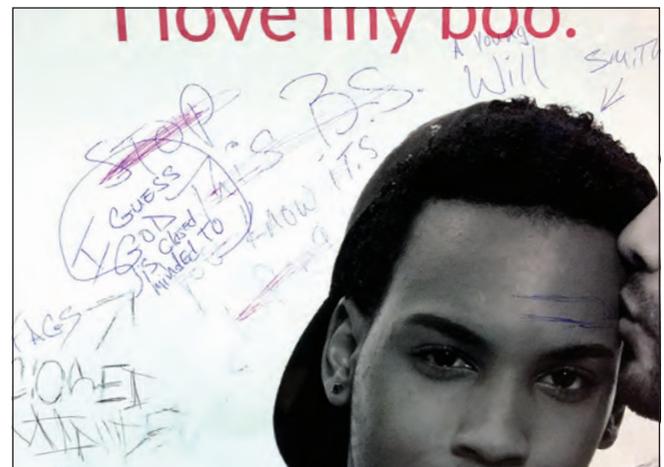
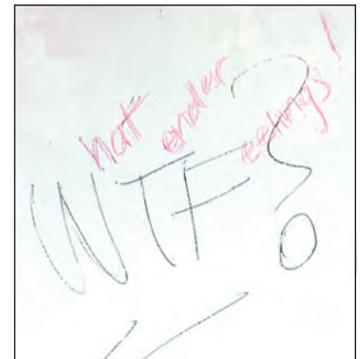


Originally featured in the bathrooms of gay bars, I Love My Boo was re-launched on December 15, 2014. **With over 270 posters in subway stations throughout New York City, it was seen by approximately 1.6 million people.** Now located in the heteronormative public sphere, the new I Love My Boo directly challenges homophobia and asks the public to critically think about love and support across racial and sexual orientation boundaries.

Since the launch of the new campaign, many posters were vandalized and defaced with derogatory and homophobic language. More importantly, while there has been hate, there has also been overwhelming support. I Love My Boo posters has fostered much-needed, public discussion about homophobia and racism in New York City and around the country. Even more essential, thousands of young gay and bisexual men of color have seen themselves reflected in messages supporting their health, well-being, and relationships. ■

Left: Original “I Love My Boo” subway poster.

Right and below: Examples of vandalized posters.



**Wait, What?** *continued from page 2*

Bill Bratton circulated a memo to Police Command ordering federal court mandated changes to its unconstitutional stop and frisk policies. Nationwide, Human Rights Watch found that these aggressive policing practices in four major U.S. cities, including NYC, actually fuel the HIV and AIDS epidemic based on how the NYPD inhibits outreach workers who distribute condoms by charging them with prostitution related offenses.

Condoms are one of the most reliable, accessible, and inexpensive HIV-prevention tools. People who need them most shouldn't leave their latex behind to avoid being prosecuted under false pretense for prostitution-related offenses. Marc Antonio is a member of the Action Center at Gay Men's Health Crisis (GMHC) in NYC, a program that helps people living with HIV and AIDS raise awareness and advocate for improved quality of life for themselves and their communities. He identifies as a black MSM directly affected by this issue:

You know, when white citizens or white New Yorkers see the police, they feel at ease. But

for men of color, like myself, we're always questioning, "Am I going to be singled out? Am I going to be suspected of something or falsely accused?" It's always on my mind. I do carry lots of condoms on me, not only for personal use, but also to give out to friends. I shouldn't be accused of being a prostitute just because I have condoms.

In 2014, the NYPD revised its policies of confiscating condoms in some prostitution-related cases. This is a small victory, but it does not go far enough. This policy has a chilling effect that ultimately harms those most at risk for HIV—black MSM. The ultimate solution is legislation that completely eliminates the use of condoms as evidence. Carrying condoms should never result in harassment, arrest, or even criminal charges. The only evidence that having condoms in your pocket should provide is that you're doing the right thing to protect your own, and the public's, health. ■



## **Dr. Kahn vs. The Delivery Guy: My Personal Fight Against Mandatory Mail Order Pharmacy**

*By Lyndel Urbano, Manager of Government Affairs*

**I GREW UP** in a small town where my father would fill every prescription at our local pharmacy. Our pharmacist, Dr. Kahn, was like a member of our family. He provided critical guidance on potential drug interactions, and he would even consult with my doctor about any new prescriptions before filling them just to make sure everyone was clear about my treatment. As a kid, I was more focused on the candy Dr. Kahn gave me every time my father brought me to the pharmacy. But looking back, I'm thankful that he gave so much to ensure my care was safe and effective, simply by doing the job he was trained to do.

When I moved to New York City as an adult, I didn't hesitate to go to a small, local pharmacy that my friends raved about. I loved my experience there. Just like Dr. Kahn, my new pharmacist would ask me about the medications I was taking, fill my prescriptions on time, and even deal with the convoluted health insurance bureaucracy on my behalf. The safety and peace of mind provided by my

relationship with my pharmacist made living with a long-term, chronic illness so much easier.

That all ended in January 2013 when my pharmacist told me that I needed to contact my insurance provider because it would no longer authorize him to refill my prescriptions. My insurer told me that I would either need to enroll in its mail order pharmacy, or pay the full cost for each prescription I filled at my local pharmacy. Given the cost of my medications, I had no choice. I consider myself "lucky" for even being warned about this change in advance. Many HIV-positive clients I work with at Gay Men's Health Crisis (GMHC) have been blindsided and switched to mail order without any notice at all, causing them to go days or even weeks without their anti-retroviral medications.

My right to privacy, especially about my health and medications, is paramount. When the mail order pharmacy representative I spoke to over the phone explained that I would have to use either UPS or

FedEX to receive my medications, I was immensely concerned. When I explained that I lived in an apartment without a doorman who can receive the package, the representative coldly suggested that I either take the delivery day off from work, have the medications delivered at work, or have them delivered to my doctor's office.

None of those options were acceptable. It was not possible for me to take a day off from work every month just to receive my medications, and I should not have to choose between protecting my privacy and allowing someone in the mail room at my workplace to receive my personal packages, even if that was an option. Additionally, my doctor's office would not accept deliveries on my behalf. Fortunately, after speaking to a mail order pharmacy supervisor I was given permission for my medications to be delivered to my mailbox by the U.S. Postal Service without requiring a signature. I breathed a sigh of relief.

For the next two months, I called the mail order pharmacy to fill my prescriptions and they arrived on time. But whenever I asked about drug interactions, I was read scripted and incomplete responses over the phone by "specialists" who were unable to pronounce the names of my medications. On the third month, I received an orange slip in my mailbox asking for a signature for the delivery. As a result, I had to take time off from work to wait in line at the post office.

The following month, I arrived home to my neighbor shaking a bag of medication in front of me and saying, "This arrived for you. The post office put it in my mailbox." I was gripped with anxiety. Did she look in the bag? Is she going to tell anyone else about my illness? In response, I immediately requested an exemption from having to use the mail order pharmacy, but my request was rejected. I appealed. It was rejected. I appealed again and again for a total of three months, to no avail.

From then on, every time I re-ordered my medications I constantly worried about protecting my privacy and needing to unnecessarily take more time off work. Recently, a GMHC client who is also being forced to use a mail order pharmacy mirrored my personal experience:

All I ask is for some control over my own privacy, and who knows about my illness, and what medications I am taking. I would rather pick up the medications at a pharmacy. That way, I would have control over who sees my medications. On several occasions I have not

received my medications on time, and twice, including this month, my medications were left in my neighbor's mailbox.

These experiences prompted me to contact the New York State Attorney General's (AG) Health Care Bureau to request assistance for myself and the dozens of GMHC clients being affected by mandatory mail order. After I provided documentation of my appeals and rejections, the AG's office successfully negotiated a one-year exception that allowed me to fill my prescriptions at my local pharmacy. Over the past few years, some GMHC clients have also had to take that extraordinary step to get short-term exceptions. Many others have not been so lucky.

In September 2013, I read an article in *POZ* magazine that updated a story written by Larry Kramer about his mandatory mail order experience. It mentioned class action lawsuits filed by the patient advocacy group Consumer Watchdog in federal court in California against two insurers, United Health Care and Anthem. The lawsuit alleged that obligating people living with HIV or AIDS (PLWHA) to use mail order pharmacies was discriminatory. Eventually, Anthem and United agreed to a settlement that forced them to allow PLWHA to opt out of mandatory mail order, without acknowledging fault.

***My insurer told me that I would either need to enroll in its mail order pharmacy, or pay the full cost for each prescription I filled at my local pharmacy.***

United now allows PLWHA to opt-out by submitting requests in the mail, over the phone, or online. Anthem, however, does not have a formal process and patients must call customer assistance to opt out. Despite some success with United and Anthem, many PLWHA who use other insurance providers are still being forced to use mail order pharmacies. Recently, a third insurer, Aetna, was also sued in federal court by Consumer Watchdog. The lawsuit alleges that Aetna's Qualified Health Plans offered on California's health exchange are discriminating against PLWHA.

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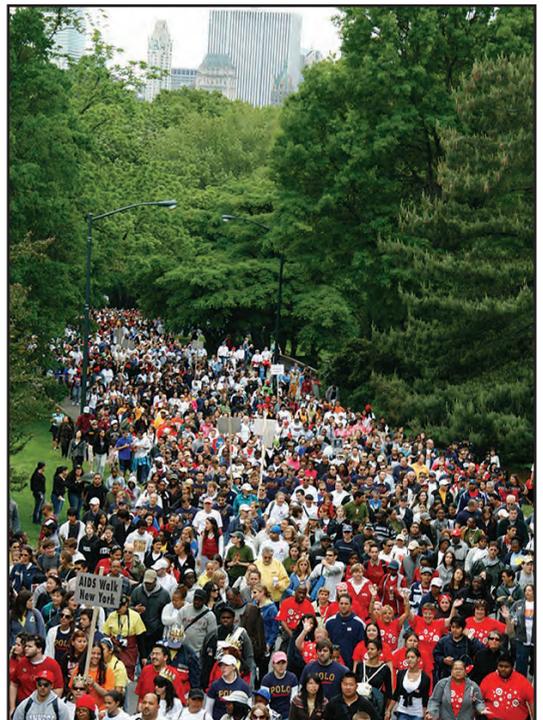


In response to the Anthem settlement, the New York State AG sent a letter to 15 major insurers asking them to also allow PLWHA to opt out of mandatory mail order. The U.S. Department of Health and Human Services (HHS) has also issued a final regulation that requires insurers, beginning in 2017, to offer alternatives to mail order pharmacies. However, that regulation allows the insurer to charge an extra fee to those who opt out.

My one-year exemption from mandatory mail order will end soon, long before the new HHS regulation takes effect. Locally, I am helping to lead a broad coalition of patient interest groups in New York State fighting to pass a bipartisan bill that finally prohibits insurers from forcing patients to only use mail order pharmacies.

Patients should have a choice. For some, mail order may be their best option, but that has not been my experience. I value having the choice and peace of mind that comes from working with my trusted, state-licensed, local pharmacist. I should not be forced to do anything that jeopardizes my privacy or health, and neither should anyone else. ■

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