POZ

A Woman’s Journey

Connecting with others has helped activist and artist Ivy Kwan Arce navigate life with HIV.

March 28, 2022 By Alicia Green

Ivy Kwan Arce had been living in New York City for less than a year when in 1990, a poster on the subway caught her attention. It read, “Women don’t get AIDS—they just die from it.” The bottom of the poster included a list of HIV risk factors for women.

“I had dated somebody who was a drug user for a short time, so I decided to get tested,” says Kwan Arce, an HIV activist and artist.

At age 25, Kwan Arce didn’t know much about the U.S. health care system. Born in the United States to Chinese parents, she spent her early life in Bolivia. English was her third language.

But Kwan Arce eventually located a doctor, who gave her an HIV test. The positive result changed her life forever.

The doctor didn’t know where to refer her, so he suggested she take another look at the poster she’d mentioned seeing. He thought it might list some resources.

“It happened to be an ACT UP [AIDS Coalition to Unleash Power] poster, so that’s how I ended up at the ACT UP meetings,” she recalls. “There was nowhere else to go. Up until that point, I was constantly told [HIV] wouldn’t affect women.”

***

Kwan Arce’s story is like that of many women diagnosed with HIV or AIDS at the beginning of the epidemic. Back then, even as cases among women rose across the United States, women were often overlooked and sometimes isolated.

During the early 1980s, many people believed that only gay men could acquire HIV. The research and information provided by the Centers for Disease Control and Prevention (CDC) initially focused primarily on this population. Women living with HIV had limited resources and lacked proper support.

At the same time, Asians, Pacific Islanders and Native Americans living with and affected by the virus were categorized as “other” in HIV and AIDS data. These groups also received little to no help from the government to fight the epidemic in their communities. Language barriers and other obstacles often also prevented them from getting assistance or finding support.

At ACT UP meetings, Kwan Arce couldn’t find anyone else like her—an Asian-American woman living with HIV in one of the biggest cities in the country.

“I saw no Asian women and hardly any women who were positive,” Kwan Arce says. “That kind of stigmatized me and made me feel very singular.”

As a first-generation Chinese-American woman living with the virus, Kwan Arce faced her own set of unique challenges. Not only was English not her first language, but she was also unfamiliar with how to access services and navigate the health care system in the United States. When she was growing up in Bolivia, her parents never took her to the doctor. She also didn’t understand how insurance worked.

“I was new to this,” she says. “I never had even asked for [copies of] my records because I didn’t have practice going to a doctor’s office. I never really had yearly checkups.”

Kwan Arce continued attending ACT UP meetings to receive vital information. But she often felt isolated and overwhelmed. As a newcomer, she found it difficult to connect to other women living with HIV and was often mistaken for someone’s nurse.

She was also discriminated against at the advertising agency where she worked as a graphic designer after she was forced to disclose that she was living with HIV. When her bosses found out about her HIV status, they limited the type of work she could do, and she was eventually fired.

“I couldn’t do my job,” she recalls. “I went from someone who brought them a huge account to someone they feared. Suddenly, I felt like a danger to everybody.”

***

Kwan Arce felt all alone and broken. It wasn’t until she was introduced to the PWA (People With AIDS) Health Group that she finally felt seen.

Founded in 1987, the group provided people living with HIV support and access to experimental treatments. It also created a safe space for women with HIV. It taught women about treatment options, how to read their lab results, how to take part in clinical trials and how to prevent opportunistic infections.

“That alignment was really important,” Kwan Arce recalls. “It basically gave me the tools to ask for my labs and to review them, and the group was generous to explain them when I just couldn’t digest the concepts.”

PWA Health Group director Sally Cooper entrusted Kwan Arce with the creation and development of graphics and artwork for the group’s many events and materials covering different topics.

Although her work didn’t reach a wide audience, she is proud that her contributions served her community.

“It saved my life,” she says of the organization. “It was so essential. I don’t think I would have survived without it.”

The thing that brings me the most joy is my connection to people.

Kwan Arce thinks about how much things have changed for women living with HIV in the past 40 years. She appreciates that women today don’t have to suffer the same trauma as those who were diagnosed in the early days of the epidemic.

But she believes there remains a lot of work to do when it comes to teaching women about prevention, especially pre-exposure prophylaxis (PrEP), a pill or injection taken to prevent a person from getting HIV.

According to the CDC, among those for whom PrEP is recommended, uptake is about three times as high among men (25%) compared with women (10%). This is concerning because cisgender women account for 19% of new HIV diagnoses every year.

“The few PrEP [advertisements for women] I’ve seen I couldn’t tell if it’s a tampon or juice,” she says. “To tell people to take something when they don’t have the illness is a very complicated thing.”

She believes that conversations about prevention need to include more long-term survivors who are women. Otherwise, she worries that women will continue to be left behind and young women today won’t be as knowledgeable about HIV and PrEP.

***

When she looks back on the romantic relationships in her life, Kwan Arce believes she lucked out. She has had partners who were HIV negative and supported her through her journey.

In 1993, she married her husband, who has stood by her side for almost 30 years. “My husband would sit and help me go through data and learn how to understand it,” Kwan Arce says.

Although she had found love, Kwan Arce didn’t initially plan to be a mother. Memories of the harsh conditions her family endured back home in Bolivia and the fact that she was HIV positive made the prospect daunting.

“[Doctors] would say, ‘Don’t even think about having a child. You’d be so irresponsible,’” she recalls. “From 1990 to 1997, that was the message for women.”

Kwan Arce, who had been undetectable since the mid-’90s, eventually became pregnant. In 2000, she gave birth to her first son. He was born without HIV, but that didn’t mean motherhood was easy.

“I had to give him oral AZT for several weeks,” she recalls. “Child services had to be involved. They told me if I didn’t do it in front of them, they would take the child.”

***

The experience was mentally draining. If she made even just one mistake, she could lose her son to foster care. On top of that, she couldn’t breastfeed him. She endured the same situation when her second son was born in 2004.

Today, Kwan Arce’s children are ages 17 and 22. “They’ve been really great,” she says.

She recalls watching the HIV documentary How to Survive a Plague with her sons and the family of Catherine Gund, a fellow soccer mom and a veteran AIDS activist from ACT UP and DIVA TV. Although at first, Kwan Arce’s sons didn’t understand much about HIV, she used the film as a vehicle to educate them.

When Kwan Arce began taking her oldest son to her speaking engagements, he slowly started to understand the impact of his mother’s activism. But because her other son was much younger at the time, she explains, he was more removed from it all.

“I think now he feels overwhelmed by the power of the story because he can’t grasp it,” Kwan Arce says. “His approach is very different.”

However, in their own ways, her sons have come to terms with their mother’s status and the work she does.

Ivy Kwan ArceMegan Senior

In November 2021, Kwan Arce received the Research in Action Award from the Treatment Action Group (TAG) for her decades of activism. The award is presented annually to individuals who have made extraordinary contributions to the fight against HIV, hepatitis C and tuberculosis.

“It felt amazing,” she says. “I slept with my award because I don’t get that many awards.”

It wasn’t the first time Kwan Arce was recognized for her HIV work. Three years ago, Performance Space New York honored her as well.

During her three decades of living with HIV, Kwan Arce has been a vital part of her community. From 1995 to 1999, she served as a voting member on the HIV Planning Council of New York. She helped allocate appropriate funding to AIDS service organizations across New York City.

In addition, Kwan Arce played a part in the grassroots formation of important New York City–based HIV/AIDS organizations, such as God’s Love We Deliver and the Asian and Pacific Islander Coalition on HIV/AIDS (now APICHA Community Health Center).

She also spent several years fighting on the front lines with Rise and Resist, a direct-action group formed in response to the 2016 presidential election.

Although she’s pulled back a bit, Kwan Arce continues to do her part in the HIV community. Last year, with support from TAG, she organized an ACT UP health fair that provided HIV testing, COVID-19 vaccinations and PrEP information at a Reclaim Pride event in New York City. She also actively advocates for PrEP access.

Though she is proud of all the work she’s done for the community over the years, Kwan Arce says activism can be depleting and she has sometimes even neglected herself for the greater good.

“What has helped is that my children will call me out on it,” she says. “It happened a lot [when former President Trump was in office]. I would get caught in a lot of conflicting situations, and they would beg me to step back.”

***

In January, Kwan Arce was named one of 63 artists and collectives whose work will be displayed at the Whitney Museum of American Art in New York City as part of the 2022 edition of the longest-running survey of American art, the Whitney Biennial.

“I’ve never been in a museum showing on this scale,” Kwan Arce says. “It’s really exciting.”

Her artwork, made in collaboration with visual and performance artist Julie Tolentino, whom she first met at an event at the museum, will be a part of the 80th biennial, titled Quiet as It’s Kept. It will be on display from April 6 to September 5, with some exhibits and programs continuing until late October.

“Julie and I connected,” she says. “It was very emotional. Every time I meet an activist that I didn’t know back then, I thank them for the work they’ve done because it led me to knowledge [about HIV].”

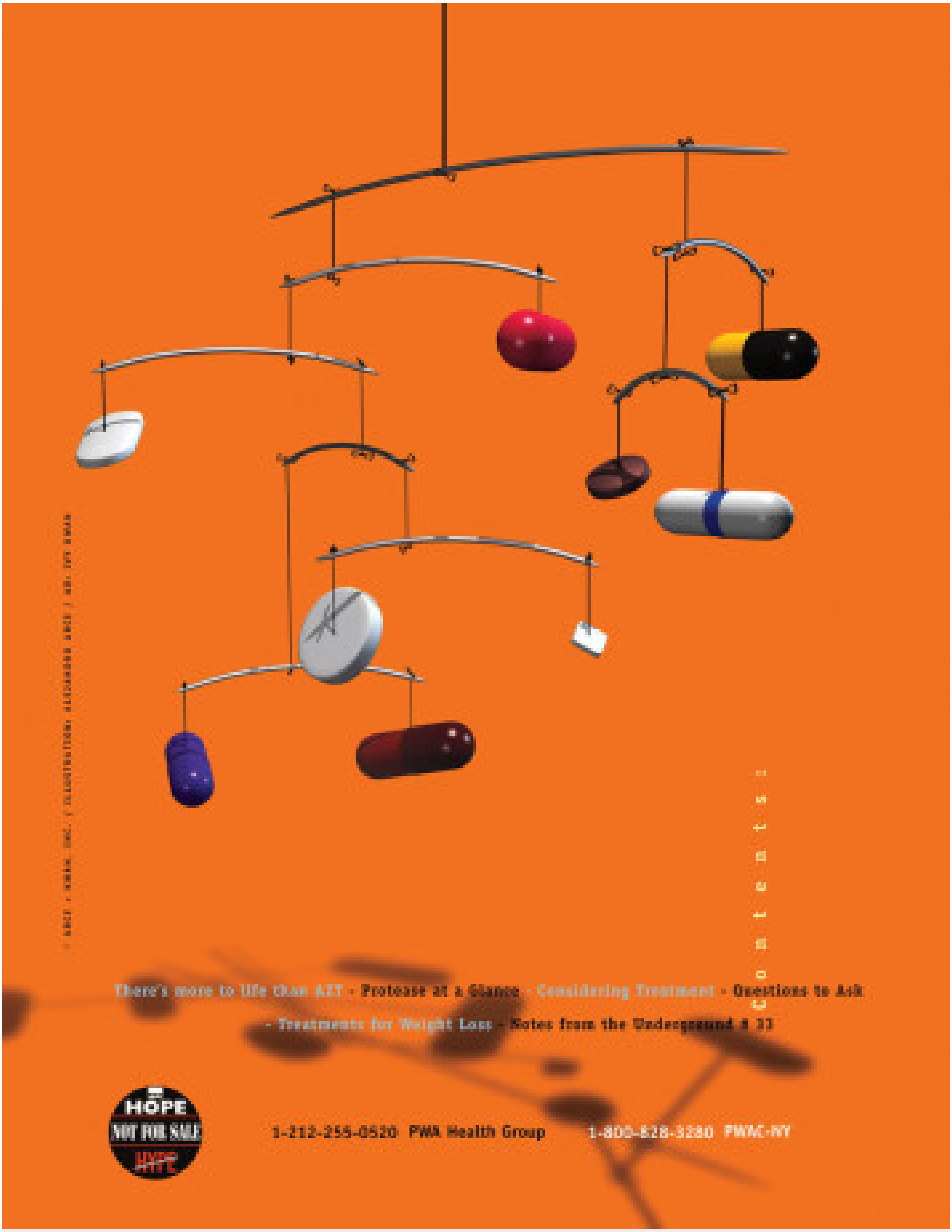
The pair’s contribution to the biennial challenges what art and activism can do while honoring the histories and experiences of people who have made an impact on others but who may not be commonly known.

The multi-experiential work consists of a poster, a light installation, a glass and mirror array, a web portal, an international talk following the 24th International AIDS Conference in Montreal and a durational performance at the museum in October.

Kwan Arce’s older son, Atom, will be a part of a Whitney Museum teen program that will debut midway through the show. As an homage to treatment activist Mark Harrington, a family friend and long-term survivor who is the executive director of TAG, Atom has created a bespoke T-shirt project titled #bornbeforethecure.

According to Tolentino and Kwan Arce, their multi-spoked artwork is “an effort to penetrate at multiple points to transmit and hold the many unseen lives and actions that resonate across generations, borders, identities.”

It’s fitting that the duo’s artwork centers people, especially those who aren’t always seen. As Kwan Arce puts it, “The thing that brings me the most joy is my connection to people. It really begins and ends with being able to have a connection. It’s the way I was able to survive.”



Graphic Kwan Arce designed for the PWA Health Group in the '90sCourtesy of Ivy Kwan Arc

© 2026 Smart + Strong All Rights Reserved.