

# Patient Perspective



*The story below is from a series of articles created by CISCRP as part of their educational awareness campaign to increase public understanding that those who volunteer to participate in clinical trials are genuine “Medical Heroes.”*

## A Painful Loss and “Unbearable” Images Inspire Healthy Volunteer

A perfect storm of wrenching emotional events set Kymone Freeman, 39, on a mission to help eliminate AIDS—and to participate as a healthy volunteer in the search for a vaccine.

Kymone, a playwright and poet from Washington, DC, had seen friends die from AIDS. When his favorite uncle died from AIDS at age 54, Kymone was stricken with grief at losing the man “who was like a father to me.” His uncle’s illness and death were made even more painful and poignant because his family knew little about AIDS and refused to accept the diagnosis.

“The family reaction was one of denial,” says Kymone. “They tried to pretend that he just got sick and passed away from anything but AIDS. They wanted to keep that quiet.”

“But I refused to honor that because he personally told me he had AIDS and he told me how he got it.”

Sadly, Kymone’s uncle had to face his last days without the comfort and solace of his beloved family members. “My family would not visit my uncle in his final days in the hospital because they feared they would contract the disease,” says Kymone. “They wouldn’t even let me visit him.”

For Kymone, that experience brought home the tragedy of AIDS. Another powerful event occurred in 2004 when Kymone went to Kenya for a month. Kymone had become involved with the American Friends Service Committee (AFSC), a Quaker program which sponsored a Youth Leadership trip to Kenya. Kymone had received a fellowship because of his activism in other areas.

“The youth leadership conference in Nairobi was an intense experience,” says Kymone. “As part of our education, we visited AIDS clinics in Nairobi and the countryside. We went to orphanages

that housed children who had lost their parents to AIDS.

“All the symptoms of AIDS were aggravated by poor living conditions and poverty, which was just devastating,” says Kymone. “Seeing people who were dying without comfort and beyond help was unbearable.

“That opened my eyes to the worldwide AIDS pandemic,” says Kymone. “That and my uncle’s death led me to be an outspoken activist about an AIDS vaccine I came to realize that a vaccine was the best hope for addressing this issue.”

Kymone also learned that his home, Washington DC, had one of the highest rates of new AIDS diagnoses in America. “Much of that is among people of color,” says Kymone. “People gave lip service to curing AIDS, but there was no major outcry.”

## Tough Decision to Become a Healthy Volunteer

In 2007, Kymone attended a presentation given by the National Institutes of Health (NIH) explaining an upcoming clinical trial for a potential AIDS vaccine.

“I always have my ear to the ground about AIDS issues, and the NIH had set up an event in the Town Hall explaining the AIDS vaccine testing,” says Kymone. “It was a wonderful presentation and there was no pressure.”

Part of Kymone’s motivation to take part in the vaccine trial stemmed from his distrust of pharmaceutical companies. Kymone is convinced that companies know they make greater profits from treating—rather than preventing—AIDS, which means there will be less effort put toward developing an AIDS vaccine. “I believed in the vaccine,” says Kymone.

While Kymone was convinced that he wanted to participate in the clinical trial, his long-term girlfriend was adamantly opposed. Kymone’s desire to become a healthy volunteer almost destroyed their relationship.

“When I told my girlfriend I was thinking about doing the trial, it caused a lot of problems,” he said. “It came at a high cost at home. She was really against it,” he says.

“It didn’t end the relationship—she’s pregnant now with my son—but it definitely caused problems,” he says.

Kymone admits that he was initially anxious about taking part in an AIDS vaccine trial as a healthy volunteer.

“It was intimidating; before I started the test, the site staff gave me a whole list of potential side effects,” says Kymone.

The NIH site staff described the treatment’s potential side effects to Kymone. At first he was intimidated by the list of possible harmful effects. Then, says Kymone, the NIH staff took the time to discuss and explain the potential effects and the likelihood of their occurring. Their patience and willingness to spend time in discussions with him overcame Kymone’s initial reservations.

“Fortunately, I didn’t have any of them. I used to talk to other people I met at the testing center, and no one else I knew had any either.”



“The only side effect that I had during the trial was that I caught a cold the two times the vaccine was introduced. But it was winter, so possibly it was just a common cold I would have gotten anyway,” says Kymone. “I didn’t get especially sick.”

Kymone recalls that participation, which took place over about nine months, was not difficult or time consuming.

“I went to the site about once a month and would get a shot or give a blood sample to see how my body was responding,” he says.

“I couldn’t be tested by actually being exposed to the AIDS virus, but the goal of the trial was to see whether the body would simulate the antibody response. That’s the great leap of faith.”

As the founder of the annual National Black L.U. V. (Love Unity Vision) festival, which provides free AIDS screening for attendees, Kymone is no stranger to public attention. However, he did face some backlash when he became one of the participants featured in the NIH/NIAID Vaccine Research Center’s advertising campaign.

“People came up to me and offered condolences because they thought I was HIV positive,” he says. “They would say, ‘I’m sorry that you have AIDS.’ I said, ‘No, that’s not what the sign says!’ But they saw my face there and made the connection. I’ve had to deal with that. There’s so much ignorance.”

Kymone’s trial ended, and while he is glad that he participated, he’s not currently planning to get involved in another.

“I’ve been there, done that, and I think I’ve done my part,” he says. “I don’t want to become like a lab rat, or have anyone accuse me of trying to make money from being in trials. I did it because it’s the right thing to do.”

“Now I have credibility because I’ve done it. I can stand and argue with anyone with AIDS,” he says.

Kymone is still active about giving information about clinical trials, and he encourages others to consider taking part.

“What I’d say to anyone who is thinking about it is, ‘Educate yourself, educate yourself. Involve your family and friends in the decision.’” ■