



AIDS Activists Pass the Baton

Events commemorated the 40th anniversary of the Denver Principles.

August 14, 2023 By Mathew Rodriguez

To some people, the passing of a baton is a symbolic gesture—or merely a metaphor. But on a Wednesday evening at the Dupont Circle Hotel in Washington, DC, at an event commemorating the 40th anniversary of the landmark manifesto known as The Denver Principles, activists representing the elders of the HIV movement passed literal batons to people representing those now on the front lines of the fight against the virus.

A total of 15 batons were handed off that evening. First, Richard Berkowitz, a coauthor of The Denver Principles as well as the 1983 safer-sex manual “How to Have Sex in an Epidemic: One Approach,” passed a baton to Linda Scruggs, a co-executive director of Ribbon, the national organization that coordinated the event.

Then, in succession, Helen Schietinger, a nurse who in the 1980s coordinated the University of California San Francisco’s Kaposi Sarcoma Clinic and who helped bring people to Denver in 1983, passed a baton to a representative from the Latino Commission on AIDS, after which activist and author Sean Strub (the founder of POZ) passed a baton to Ronald Johnson, the current chair of the U.S. People Living with HIV Caucus.

From there, more batons were passed: literally, to auxiliary partners who helped sponsor the event, as well as symbolically, to supporting partners who represented the grassroots organizations that continue the on-the-ground work kicked off in Colorado’s capital 40 years ago.

Berkowitz said it was “moving” to see the legacies of the gay men who wrote the principles live on in the work being done today. “Passing the baton to people fighting the battles we began was more than symbolic,” he told POZ. “It showed how we created something that made the world a better place, not just for those with HIV but for anyone facing life-threatening illnesses.”

Strub added that the passing of the batons was reflective of the evolution in HIV leadership in the years since the 1983 Denver gathering. “It was also reflective of how what, for many, began as a narrow silo of activism against HIV and its attendant challenges” has morphed into an “intersectional, broad human rights movement and racial justice lens through which this work is pursued today,” he said.

Several times throughout the ceremony, people repeated the chant “Nothing about us without us.”

That phrase, a common refrain in AIDS activist circles, is used so often it sometimes feels rote. But at this event, the words took on a new meaning. For what are The Denver Principles if not an articulation, through the lens of AIDS, of this exact sentiment?

It was at the Fifth Annual Gay and Lesbian Health Conference in Denver, in June 1983, that a group of people with AIDS from around the United States first shared these principles with those in attendance. The very top of the document, which serves as a sort of preamble, reads: “We condemn attempts to label us as ‘victims,’ a term which implies defeat, and we are only occasionally ‘patients,’ a term which implies passivity, helplessness, and dependence upon the care of others. We are ‘People with AIDS.’”

In July 2022, Ribbon’s director of programs, Shauna Cooper, alerted others in the organization that the anniversary of the principles was approaching. Ribbon waited for others to announce events to commemorate the anniversary, but by March, no one had. That’s when Ribbon’s Scruggs, a Black woman living with HIV, spoke by phone with Ronald Johnson, the policy fellow at AIDS United. They decided to, as Scruggs put it, honor the “40 years of work that advocates, legislators, stakeholders and everyone has done that really embodied the principles.”

“It was the boulder that was thrown that activated the activism of HIV in America,” Scruggs told POZ.

Though the ceremony that included the passing of the batons took place on June 14, it was not the only related event that Ribbon and its partners organized. To include people both nationally and globally, organizers planned a week’s worth of events accessible from anywhere, including an online film festival of movies concerning the history of the AIDS epidemic, such as *And the Band Played On*, as well as virtual panels.

Implicit in the principles’ preamble is the critique that such words as victims and patients were chosen for people with AIDS and not by them, and it’s that spirit that continues to empower people with HIV and other chronic illnesses. It’s also that spirit that drove Scruggs, Ronald Johnson and Ribbon co-executive director Vanessa Johnson to conceive of this ceremony honoring the principles, highlighting the progress made in the fight against HIV during the past 40 years and looking forward to the work yet to be done—which can happen only if people living with HIV are at the center of the conversation.

“1.2 million people can’t be at a table at any given time,” Ronald Johnson said. “But their voice needs to be at all of the tables possible.” Johnson, who is living with HIV, said he owes his own outlook on activism to the guiding light of the principles. “The Denver Principles, as Sean Strub has said, are indeed our North Star that grounds us and guides us at the same time.”

When they were launched in Denver, the principles were meant to serve as guidelines for how to talk about people living with HIV. When they were first spoken aloud, Ronald Reagan, the president at the time, had yet to say the word AIDS publicly. Amid a political climate in which the government not only didn’t fight for people with HIV but denied their very existence, the assertion of the principles was all the more powerful.

This event, which took place just across the street from the Capitol Building and featured prominent lawmakers, including Representative Barbara Lee (D-Calif.), who tweeted a photo of all the participants in the baton-passing event (see page 6 for photos), helped prove just how effectively The Denver Principles landed HIV in the national conversation.

“Having events in our capital to honor the work of those abandoned by our leaders when AIDS began was both an acknowledgement of that tragedy as well as a tribute to the courageous contribution we made in the face of that,” Berkowitz said.

To coincide with the event, the Ribbon Organizing Center for the HIV Age Positively Initiative (ROC4+Aging) presented a policy brief that reckons with what the HIV epidemic looks like now versus 40 years ago.

Prepared by the initiative’s Policy Action Group, the brief underscores the reality that half of the people living with HIV in the United States are 50 or older, a fact that would have been unthinkable when the epidemic was in its infancy in the 1980s. By 2030, the policy brief explains, 70% of people living with HIV in the United States will be 50 or over, which means policies about people with HIV must include people over 50 and policies aimed at aging Americans must include people with HIV.

“Forty years ago, aging was not even considered a possibility,” Vanessa Johnson told POZ. “And so we have this whole cohort of people we have to remind that just because we’re over 50 or 60 or 70, we still have rights.”

Ribbon and its partners call Congress to action, suggesting specific policies to address the unique challenges that people with HIV over 50 experience. In the brief, they propose passing legislation to create centers that would address HIV care, chronic disease management and geriatric care; increasing the budget for research dedicated to HIV and aging; and developing programs to train the health care workforce to meet the specific needs of America’s aging HIV-positive population.

There was a poetic quality to the political call at the center of this event. If the first articulation of the principles was a demand for dignity for people living with HIV, then the work, according to this event’s organizer, is to carry on that work as people with HIV continue to grow older, especially in a country that tends to sweep the concerns of older people under the rug.

In that sense, the event was a call to be seen as more than people living with HIV. “As long as we have folks in office who don’t understand that we are human beings, we are going to be forever fighting,” Vanessa Johnson said. “It’s going to be a forever fight, but if we keep fighting, there might be spaces where we have some relative peace before we have the next fight.”

Taking the stage to demand dignity for all people with HIV, regardless of age, was a fulfillment of the tenets first outlined 40 years ago. “What we did this past week is comparable to those 11 men taking the stage in Denver in 1983,” Ronald Johnson said. “We’re here, HIV is still here and we have to respond.”

This look back coincided with the Biden administration's calls for more funding for the Older Americans Act, a clear sign that the current president, an octogenarian, is willing to consider the needs of aging citizens. However, as the organizers underlined, saying "the needs of older Americans" without including "the needs of older Americans with HIV" is not progress, nor does it help to abate the ongoing HIV epidemic.

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