What's Lost When an AIDS Walk Becomes a Health Equity Walk?

And what's gained when a long-running Palm Springs AIDS walk fundraiser changes its name to reflect expanded health services?

October 24, 2023 By Trent Straube

What's in a name? For the newly rechristened DAP Health Equity Walk, the better question is, What's not in a name? For starters, there's DAP Health itself. Launched in 1984 as Desert AIDS Project, the nonprofit became DAP Health in 2021. Then there's the AIDS walk. For 30 years, the annual HIV fundraiser in Palm Springs, California, was known as the Desert AIDS Walk. But this year, the event, scheduled for Saturday, October 28, has been rebranded with a name that, absent "HIV" or "AIDS," leaves some folks living with HIV—the very community the event was founded to honor and serve—feeling erased.

"How can decentering our lives and struggles be equitable?" asks Bridgette Picou, a licensed nurse in Palm Springs with several years of experience working with infectious diseases. "Speaking for myself as a person living with HIV," she says, "any time you change the name or the focus of events meant to celebrate, honor or remember people living with (and lost to) HIV/AIDS, it's a disservice. Folks living with HIV are both marginalized and stigmatized regularly. A title may seem like a simple thing, but it represents so much struggle and change and triumph over life and death."

"In Palm Springs, with its large LGBT community, Desert AIDS Walk affirmed that bond between the stigmatized and the donor, the ordinary person and a pharmacy or bank, and the people at risk with the people in care," says Jax Kelly, president of Let's Kick ASS (AIDS Survivor Syndrome) Palm Springs, who is living with HIV. Remembering AIDS walks of the past, Kelly recalls that "beyond rainbow flags were red ribbons. And then there were the memories, the testimonials and the eulogies. And after all that, we lay to rest Desert AIDS Walk. This is a requiem for Desert AIDS Walk."

And yet, the event's organizers at DAP Health—which provides health, sexual wellness and HIV services throughout Coachella Valley—promise that the HIV community, past and present, will be honored and represented in numerous ways during the Health Equity Walk. What's more, "the core of DAP Health has always been centered around HIV care, testing and prevention," says Steven Henke, chief of brand marketing at DAP Health. "This commitment remains unwavering, and our efforts to address the HIV/AIDS crisis continue to be at the forefront of our work."

Below is a highlight reel from last year's Desert AIDS Walk:

Henke shares that the 2023 walk will feature a special performance by the Palm Springs Gay Men's Chorus honoring those lost to the epidemic; a moment of silence for those lost to AIDS; a keynote speech by DAP Health CEO David Brinkman about the lessons of loss; and a memorial pavilion. Sections of the AIDS Memorial Quilt will be displayed at the pavilion, which will also include a Día de los Muertos table dedicated to Latino community members and a wall on which folks can leave remembrances.

Beyond the events of October 28, Henke points out that DAP co-presented the 2023 Aging Positively Conference in Palm Springs and that the ongoing DAP Talk series features long-term survivors. Via email, he offered context and background to the recent rebranding of the walk:

> "Earlier this year, DAP Health, whose goal it is to protect and expand health care access for all people—especially the marginalized, regardless of who or where they are, their health status or whether they have health insurance—made a successful bid to acquire the Borrego Health system, enabling it to now serve more than 100,000 patients of all populations, genders and ages (from newborns to seniors) at a total of 25 Southern California clinics located within 240 rural and urban ZIP codes from the Salton Sea to San Diego.
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> "To some, this expansion signals that the organization—founded as Desert AIDS Project in 1984 by a group of community volunteers determined to provide support, care and treatment options to gay men with HIV who had been ostracized by the mainstream and abandoned by their government—is drifting from its initial mission.
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> "In truth, HIV prevention, testing and treatment remain as central to DAP Health's work as it ever has been—and will forever remain so.
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> "Indeed, it is precisely thanks to the nonprofit's nearly 40 years of experience and proven success in the field of HIV/AIDS that it has been able to thrive and grow as it has. The agency's hard-won expertise in providing health care to one marginalized community has permitted it to transfer its unique, patient-centered model of care to a vast array of other such groups, including women, people of color, the poor, the undocumented, those with substance use disorder and more.
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> "By standing on the shoulders of all those lost to HIV/AIDS, and all those living and aging well with the virus today, DAP Health's broadened mission remains perfectly in line with that of its founders, whose singular goal was to provide for those dismissed by the mainstream. Expanding health care access is just one of the ways DAP Health honors the memory of those lost to HIV/AIDS."

C.J. Tobe, the chief of community health at DAP Health, offers personal reflection that parallels the organization's growth. "Most people don't know I once experienced the stigma and shame of being gay, that I live today with HIV, that I once was unhoused and that I long ago faced mental health issues," Tobe says. "I am a survivor who is as thankful as I am excited about the tremendous impending expansion of our community health department. I believe it is my and my team's duty and privilege to advocate and fight daily on behalf of every member of our diverse communities—but especially for those who are LGBTQ+ and/or living with HIV—so that they may get the second, third and fourth chances I received, which enabled me to see my bright future and to live my happiest and healthiest life."

Indeed, the U.S. HIV epidemic has evolved immensely since the 1980s. Lifesaving antiretroviral drugs became available in 1996; new populations and geographic regions emerged as being at risk; and scientific data led to the conclusion that Undetectable Equals Untransmittable (U=U, the fact that folks with HIV and a suppressed viral load don't transmit the virus sexually). So it only makes sense that the organizations and events catering to people with HIV would pivot to meet this changing landscape, including makeovers of logos, brands and names. But does omitting references to the virus go too far and, if so, for whom?

"Many long-term survivors, especially, feel that the focus on HIV and AIDS is being abandoned just as they are getting older and are experiencing more aging comorbidities made worse by their HIV," says Jeff Taylor, who has been living with AIDS for over 40 years and is the executive director of the HIV+ Aging Research Project—Palm Springs (HARP-PS).

Long-term survivors, he says, "bemoan this shift to normalize HIV and make it a part of primary care, and they fear losing access to the dedicated HIV specialists who have served them so well for so long as the providers themselves age out or leave primary care given all the tectonic shifts in health care since COVID."

Taylor says he understands that the newly expanded DAP Health would want to broaden its fundraising scope, especially since people living with HIV constitute a shrinking fraction of DAP Health's client population. But he also points out that Palm Springs is unique in that it is home to a thriving and aging HIV and LGBTQ population steeped in AIDS history. "One wonders if 'health equity' is as compelling a fundraising incentive as HIV/AIDS has been—especially in Palm Springs," he says.

"I have been around long enough to mourn the closing of an AIDS services office that was repurposed from a hospice once antiretrovirals stopped the flood of deaths," says Let's Kick ASS's Kelly, citing an example of the sorts of losses that accompany inevitable change. "I have grieved when neighborhoods were gentrified and bars were closed. I think Palm Springs needs to take a moment to reflect on what losing an AIDS Walk means. And let's share that grief so we can move on."

SIDESTORY

Other AIDS Name Changes of Note

Palm Springs' Desert AIDS Walk is now the DAP Health Equity Walk, but it's not the first name change to omit "AIDS" as part of a rebrand—nor the first to raise the ire and eyebrows of the HIV community. In some cases, people felt AIDS was stigmatizing or that it was outdated or constricting because nowadays fewer people with HIV progress to AIDS. Others countered that their AIDS diagnosis was a badge of honor and that they preferred to respect the history inherent in the term. As Paul Kawata, the executive director of NMAC (more about that below), put it during his own rebranding dustup: "The politics of HIV and AIDS can be difficult. Sometimes, you have the best of intentions, and it still goes wrong." Below are examples of other name changes:

- Blueprint to End AIDS: In 2014, when New York State Governor Andrew Cuomo unveiled a plan to end the state's epidemic, it was referred to as a Blueprint to End AIDS by 2020. The following year, a POZ feature underscored the awkward and often misused term in the title and asked "Is It Time for the End of 'AIDS'?" Fast-forward to 2023 and it's commonplace to read of city, state and nationwide plans for Ending the HIV Epidemic—or, as the federal government refers to its plan, EHE.

- DAP Health: Launched in 1984 as Desert AIDS Project, the Palm Springs–based nonprofit became DAP Health in 2021. According to a timeline on the DAPHealth.org, the change reflected its expanded mission and "more clearly conveys our commitment to the greater good and the diversity of…people calling DAP Health their health care home. It also retains and honors our founding, with the letters DAP."

- NMAC: Originally known at the National Minority AIDS Counsel, the organization, like many others, now goes by its initials. Another example: Gay Men's Health Crisis—the country's oldest AIDS service organization—is now simply GMHC.

- USCHA: Speaking of NMAC, the organization spearheads an annual gathering of the HIV community, held in a different city each year. In 2020, the plan was to change the name from

the U.S. Conference on AIDS to the U.S. Conference on HIV. Community protests ensued. The result: U.S. Conference on HIV/AIDS.

- The Walk to End HIV: In 2014, after 27 years as AIDS Walk Washington, the fundraiser in our nation's capital, which benefits Whitman-Walker and other local groups, became the Walk to End HIV. "Changing the name is a way to focus attention on getting us to that ultimate finish line," said Don Blanchon, WWH's executive director at the time, "providing care for all who are HIV positive and getting to zero new infections." Similarly, the Minnesota AIDS walk is now MN Walk to End HIV.

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http://beta.docker.realhealthmag.com/article/lost-palm-springs-hiv-aids-walk-becomes-health-equity-walk