HIV May Increase the Risk of Long COVID. Why Aren't Major Advocacy Groups Addressing It?

A search of many HIV/AIDS advocacy groups didn't find any informative information or resources about long COVID on their websites.

December 8, 2023 By Miles Griffis and The Sick Times

At the beginning of the SARS-CoV-2 pandemic, Philip Shubin went to the emergency room when he was infected with COVID-19. At the hospital, he said he was treated like a pariah and went home expecting to die. The visit reminded him of being hospitalized in 1996 with an AIDS-related lung cancer called pulmonary Kaposi sarcoma, which led to the loss of his right lung. The arrival of antiviral medications saved him from dying of AIDS-related complications, but he lost his entire social circle during the crisis.

"I'm a survivor of two pandemics," Shubin said during a Long Covid Justice webinar last year about the intersections between HIV, long COVID, and COVID-19. His acute case of COVID-19 led him to be diagnosed with long COVID, dysautonomia, and myalgic encephalomyelitis (ME), which made him bedbound, he explained. "All of my doctors keep referring to my original case of COVID as 'mild'," he said. His is acute case lasted a week and he has since been debilitated for years with long COVID."This terminology needs to change, there is nothing 'mild' about the condition."

As we enter the fifth year and another surge of the ongoing SARS-CoV-2 pandemic, our understanding of HIV's overlap with COVID-19 and long COVID is building, but stigmas surrounding both illnesses have impeded research funding and support. People living with both have described the serious lack of adequate care for long COVID and ME, and the low quality of life they experience.

Advocates say that the government is not doing enough to support people with long COVID, nor are most well-funded LGBTQ+ or HIV advocacy groups, even though long COVID may be burdensome for their communities. Recent studies suggest that HIV may be a risk factor for long COVID and that people with HIV have an elevated COVID-reinfection rate. Yet The Sick Times reviewed websites from several major HIV and LGBTQ+ advocacy groups and found very little information or resources about long COVID.

The overlap of HIV and Long COVID

“Several (but not all) studies suggest that HIV is a risk factor for long COVID,” Michael Peluso, an infectious disease physician at the University of California, San Francisco who has studied both HIV and long COVID, wrote to The Sick Times. “There are several reasons why this might be, but they can be summed up as HIV (even undetectable HIV) causing a background level of immune disturbance that is compounded by COVID.”

All of the things that are thought to contribute to long COVID in people without HIV — including inflammation, reactivation of other viruses like Eppstein Barr virus, mitochondrial dysfunction, and immune perturbations — could be further exacerbated by pre-existing HIV, Peluso explained. But many studies on this connection have been too small to draw definitive conclusions, he wrote. “I would like to see more investment in larger studies that can tackle these questions, in the form of NIH grants or foundation grants.”

Still, some research based on health systems data has suggested that people with HIV are more likely to have more health issues after COVID compared to people without HIV. One preprint found that people with HIV were more likely than HIV-negative people to have diabetes, heart disease, blood clots, and mental health problems after COVID. Another showed that people with HIV who had Covid were more likely to have these types of complications compared to people with HIV who did not get COVID.

The second study “really supports the idea that the combination of HIV and SARS-CoV-2 infection may be a perfect storm for some people,” Peluso wrote.

Peluso and collaborator Annie Antar, an assistant professor of medicine at the Johns Hopkins University School of Medicine, are currently working on a larger study funded by amFAR, The Foundation for AIDS Research. The study will assess immune dysregulation in people with HIV and long COVID.“We know that living with HIV is a chronic inflammatory state,” Antar said. “We’re very curious to see how that intersects immunologically with COVID and long COVID.”

In the meantime, Peluso wrote that “outside of avoiding COVID altogether, the single best thing that a person can do to avoid getting long COVID is to be up to date on their COVID vaccines.” He advised people with HIV who get COVID to discuss with their doctor whether they should be treated with a COVID antiviral like Paxlovid, which may slightly reduce the chances of long COVID.

Lack of Recognition From LGBTQ+ and HIV Advocacy Groups

Despite some clues like the CDC and Census’s Pulse Household Survey suggesting that long COVID may have higher rates in transgender and bisexual communities — likely due to pre-existing health disparities — many of the largest LGBTQ+ and HIV advocacy groups in the United States still aren’t urgently educating their community about long COVID or taking precautions to curb the spread of COVID-19 at their in-person gatherings.

For example, the National LGBTQ Task Force — an advocacy group that founded its conference Creating Change during the AIDS crisis — failed to institute any mandatory COVID-19 precautions during its in-person conference this year, leading to heavy criticism by disability and chronic illness advocates, I reported for Them. “The organization has forgotten its history and the history

of the people it supposedly represents," writer and activist Emmett Patterson wrote of the event in the Bay Area Reporter.

Numerous other LGBTQ groups and Pride organizers have also abandoned common sense COVID-19 precautions for their in-person events during the rush to "get back to normal." While acknowledging that long COVID can affect anyone of any orientation, gender, or age, some advocates have felt abandoned by queer and leftist groups that they believed would help advocate for members of their community most affected by the pandemic. Or at the very least, that they would help sound the alarm.

To examine this gap in advocacy, The Sick Times searched the websites of several major LGBTQ advocacy groups for information and resources about long COVID. We looked at the Human Rights Campaign, The Trevor Project, PFLAG, Los Angeles LGBT Center, The Center, and the LGBTQ Task Force; the search, as of December 4, 2023, found almost no mention of long COVID. GLAAD had one mention of long COVID in an announcement about vaccination while the Human Rights Campaign mentioned the diagnosis in an in-memoriam for a trans person of color, Morgan Moore, who died of "criminal neglect from his parents" in 2023.

Similarly, a thorough search of many HIV/AIDS advocacy groups including Elton John AIDS Foundation, AIDS United, Black AIDS Institute, and AIDS Healthcare Foundation didn't find any informative information or resources about long COVID on their websites. UNAIDS, however, had numerous mentions of long COVID. A search of Positive Women's Health Network mentioned long COVID once in a recent newsletter and linked to a long COVID Justice survey in 2022.

The burden of educating these communities about long COVID and COVID-19 has since fallen on advocacy groups with fewer resources, especially as the Biden administration largely ignores long COVID crisis and the ongoing pandemic altogether. Last month, Long COVID Justice — an intersectional long COVID advocacy group —partnered with Trans Equity Consulting for a webinar, Long COVID is a Trans Issue. The event featured a presentation by Sari Reiser, a researcher at Harvard T.H. Chan School of Public Health, sharing results from a 2022 study that found numerous health disparities exacerbated by COVID and long COVID according to a survey of over 2,000 transgender people.

The stigma around long COVID and ableism within the HIV community are two major reasons why COVID-19 and long COVID aren't adequately addressed by larger advocacy groups, said JD Davids, co-director of Long COVID Justice, who has long CoVID and ME.

People who have gone through the trauma of acquiring other illnesses and conditions deserve to have resources and support in tackling a new health crisis that is disproportionately affecting their communities, Davids said. But the organizations best positioned to create such resources and support fail to acknowledge the continued COVID-19 pandemic, he said. "To truly understand that reinfection increases the risk of chronic illness, and even death, would be to acknowledge the institutional roles in preventing COVID in the first place."

Towards Broader Disability Politics

The intersections between long COVID, HIV, and many other associated conditions and health crises have led some advocates and scholars to push for bigger-picture research and support for the people most impacted.

It's common in disability movements for people to "organize around their specific disability," as shown by patient advocates now organizing around long COVID, said Sami Schalk, an associate professor of Gender and Women's Studies at the University of Wisconsin Madison and the author of "Black Disability Politics." But moving forward, "connection to a broader disability community would be beneficial," Schalk added.

Schalk sees parallels between the long COVID and AIDS crises: in both, with limited support from the medical community and government, patients have been forced to organize and advocate for themselves. "I think we are in a moment where approaching disability justice and disability identity in a very coalitional way is incredibly important," she said. Building a larger movement is vital "especially as more of us become disabled."

The overlaps of long COVID and HIV are complex and are still not fully understood, but it is clear that broadly educating the public about COVID-19 and long COVID would be beneficial for all people.

To start, education around long COVID and its many crossovers with other diagnoses would do a great service in helping the public understand the risks of COVID infection. Annie Antar said that everyone should do follow-ups with their primary care doctors around three months after their acute COVID infection to screen for symptoms of long COVID or other associated conditions that arise following COVID-19 infection. She says information about long COVID should be applied widely and featured in more public service announcements. "If we don't mention long COVID whenever we talk about COVID, it just disappears from people's minds."

While major advocacy groups aren't yet discussing long COVID, smaller grassroots organizers are and their work is having an impact. Besides the many important webinars and resources provided by Long COVID Justice, The Reunion Project, an HIV advocacy group that organizes annual summits, hosted a webinar this summer on long COVID in people with HIV.

During the AIDS crisis, Philip Shubin said he took to the streets with ACT UP to demand funding for HIV/AIDS research and found that using his voice was a powerful tool to help change the way people think and act. "Today, I find myself in a similar position with long COVID and ME/CFS," he said, "I am compelled to fight for respect, research, and funding."

This article was published by The Sick Times, a new website chronicling the long COVID crisis, on December 5, 2023. It is republished with permission.

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