Exposed Document Links HIV Leaders to 'Betrayal of People with HIV'

January 10, 2025 By Mark S. King

When Jeremiah Johnson was perusing the Gilead Sciences website last November, as one does when tracking one of the most insidious assaults in history against people living with HIV, an item he found buried deep in Gilead's pulldown menus literally took his breath away.

"My heart sank," recalled Jeremiah, director of the national HIV advocacy organization PrEP4All. "It felt like I was witnessing some kind of advocacy fraud."

Iconic HIV treatment activist Peter Staley put an even finer point on the discovery. "The document saddened me," Peter told me. "It felt like a shocking betrayal of people living with HIV."

The item Jeremiah discovered was a notice that Gilead would be filing, within days, an amicus brief signed by a list of a half dozen HIV community leaders. The brief would be in support of Gilead and against the plaintiffs in an ongoing lawsuit that claims Gilead did great harm to people living with HIV.

Jeremiah and Peter immediately began reaching out to people on the list, beseeching them to withdraw as a signatory before the brief was filed. They received no substantiative responses – but the item about the amicus

brief quickly disappeared from the Gilead site. The brief was filed on November 25, 2024, and, as promised, with the community names attached.

This is when this all came to my attention. I was just as shocked, as much by the document itself as by the line crossed between HIV advocates and the pharmaceutical industry. Never before have our own advocates joined pharma in a legal action meant to defend pharma's atrocious acts against people living with HIV.

I managed to reach some of the signees. Their responses ranged from frustrating to arrogant to saddening. Before we get to those community leader names, here's a quick refresher about the lawsuit in question.

The Terrible, Horrible Thing Gilead Did and How People with HIV Suffered and Died

Once upon a time, Gilead introduced a very successful HIV treatment drug, a compound known as

TDF. Let's call it "the original drug." It was widely used by patients but had some troublesome side effects, like kidney damage and osteoporosis, especially when used with booster regimens (a booster is a drug that helps the other medications stay in your body longer). At about the same time, Gilead had a second drug they were testing, known as TAF, that was a bit further behind in the pipeline.

Before long, Gilead's own early research showed that the TAF drug – we'll call it "the new version" – looked very promising in testing and showed safer results. There was only one problem. Gilead's patent on the original drug wasn't going to expire for another nine years and they really wanted to squeeze every buck out of that patent before introducing the new version. So, Gilead stopped its promising research on the new version and bided its time. For years.

Meanwhile, people with HIV taking the original drug suffered through broken bones and hip replacements and kidney complications. Oh, and some of them died.

Yeah. Gilead allowed that. And it gets worse.

Once the patent on the original drug was nearing its end, Gilead restarted their research into the new version and, lo and behold, the results were stellar. They moved to rush the new version to market.

Here's another detail that will make your skin crawl: as part of the marketing for the new version, Gilead really leaned into how awful the side effects of the original version were. You know, those terrible side effects that they had known about for years.

Gilead even commissioned a study to determine how many patients would suffer broken bones or even die unless they switched to the new version. The grim results: an estimated 16,000 people would die and 150,000 people would suffer kidney and bone injuries over a nine-year period.

(The original drug TDF is one of the two drugs in Truvada, our first PrEP medication, but don't freak out – Truvada PrEP doesn't have a booster and is used by healthier, HIV negative folks, so we haven't seen any of the worst-case toxicities happen in this very different context.)

Let's review. Gilead paused promising research into a new version of a drug because the company wanted to keep making money off the patent for the original drug – even though they knew the original drug was causing great physical harm to people living with HIV. Then, when the patent for the original drug was close to expiring, they introduced the new version and actually used the harm the original drug caused people as a tool to market the new version.

Peter Staley sums up Gilead's actions fairly simply. "This is a level of evil we have never seen," he told me.

That brings us to the lawsuit against Gilead. Filed in California, it was brought by HIV treatment activists and on behalf of 24,000 people nationwide who used the original drug and had, or risked, unnecessary side effects.

Those are the facts. You can read more about the damage caused by the original drug (TDF) in a front-page story in the Los Angeles Times. Or you can read how Gilead knew the first drug was hurting people and held off the new version (TAF) anyway in a front-page story in the New York Times. Or you can read Peter Staley's guest editorial in STAT Magazine that lays out the whole dirty business.

Now, let's look at the amicus brief filed by Gilead and the names that are on it.

The Amicus Brief, the Signatories, and Their Responses to My Questions

As part of the ongoing legal proceedings in California in this lawsuit, an amicus brief (a "friend of the court" document that supports one side or the other) was filed. The brief argues, essentially, that if pharma has to fight a lawsuit every time they have a new version of a drug coming to market, it would create a "chilling effect" on innovation, meaning research into new medications.

In other words, don't pick on us, says Big Pharma, or we'll take all our marbles and go home.

That argument has no basis in fact. "Pharma has used that tired old argument since the days of ACT UP," Peter Staley reminded me. "And yet we have more HIV medications and drugs in development today than ever before. That argument is a smoke screen."

Yet somehow, Gilead managed to convince a handful of community leaders, most of them retired from the field, to sign the amicus brief. Once retired, it is worth mentioning, an organizational director no longer has to answer to its Board or constituencies for their actions.

"It's questionable if it's in the best interest of people living with HIV for our leaders to rush to the aid of pharma," Dorian-Gray Alexander, an HIV activist from New Orleans, told me. "Especially when something, as in this case, has been exposed. They sat on a newer, safer drug for the sake of profit."

"Seeing well-known names sign on to this legal brief in opposition to tens of thousands of people living with HIV felt like an attack on everything our field is supposed to stand for," recalled Jeremiah Johnson.

"They should have spoken to their own constituents about this issue," Juan Michael Porter II, an HIV advocate living in New York City, told me. "Had they done that, they would have found that the community was not okay with them joining the amicus brief. They would have found out how people feel about Big Pharma playing around with patents to get as much money as they could off the bodies of people living with HIV."

Here are the signers of the amicus brief:

Global Coalition on Aging

Liver Coalition of San Diego

National Minority Quality Forum

Partnership to Fight Chronic Disease

Organizations like these, awash in Big Pharma money, are often a clever way for pharma to sprinkle around their key messages and push their legislative agenda through the guise of community work.

C. Virginia Fields

Ms. Fields served as CEO of Black Health until she retired in 2024. Black Health has received many millions of dollars from Gilead over the years.

Ms. Fields did not respond to my request for comment.

Community Education Group

This organization, a long-time Gilead grantee, was founded by A. Toni Young thirty years ago. Ms. Young sent me this response to my request for comment:

> “After consideration, I’ve decided not to make a comment.”

HIV and Hepatitis Policy Institute

Pharma appears to fund this outfit entirely. Carl Schmid serves as founder, director, and Board Chair, and primarily posts press releases featuring pharma key messages. As of this writing, Mr. Schmid has not yet retired.

Here is Mr. Schmid’s response to my request for comment:

> We joined as amici given our concerns that the appellate court’s opinion could have on future drug development. That ruling, if left to stand, carries implications for the future of all drug development – not just HIV drugs. The basis for our concern is articulated in our brief – the duty to market issue and the potential

liability for a drug manufacturer for not proceeding with development of a potential drug. Assume you will cover both sides of the issue in your article. We have no further comment on this matter.

"It was not surprising at all to see Carl as a signatory," Peter Staley told me. "His entire organization might as well be a subsidiary of Gilead, paying Carl to play in the policy sandbox of Washington, DC."

Dr. Eugene McCray

Dr. McCray served in the Division of HIV/AIDS at the CDC until he retired in 2020. It is deeply concerning, given his signature, that Dr. McCray serves as Board Chair for AIDS United.

Dr. McCray did not respond to my request for comment.

Phill Wilson

Yeah, this one hurts. Phill's decades of leadership served our community well. He retired as founder and CEO of the Black AIDS Institute in 2018.

"Phill's name was a huge gut punch to me," Peter admitted. "He's a hero of mine. I'm saddened by what this might do to the last chapter of his story. This is not how you want to go out," he added.

Phill was the only signee who agreed to speak with me. Our conversation stunned me more than once. You're going to hear all about it.

First, here's how Big Pharma has silenced dissent over the course of the HIV epidemic. Spoiler alert: money and jobs.

Big Pharma's Long Game to Conquer the HIV Community Arena

Pharma has flooded our HIV organizations and program budgets with cash and our magazines and AIDS Walk programs with ads and sponsorships, in amounts that are utterly inconsequential to them but more than enough to buy as much influence as gratitude.

"I think we would be able to speak as a community a lot more freely if more of the funding and support came from means other than pharma," Dorian-Gray Alexander said, citing the "co-dependent" relationship that has developed between community and pharma. "But we can't be fooled," Dorian-Gray warned. "Pharma has all the leverage."

There’s another strategy pharma has employed – quite literally.

From grassroots activists to clinicians to public health workers to more than one White House AIDS Czar, our community talent pool has been depleted by a hiring spree pharma has been on for years. It is a strategy that puts our friends and former co-workers on the other side of the equation, blurring the line between advocacy and commerce.

“There has been a concerted effort by pharmaceutical companies to hire HIV advocates and clinicians,” Juan Michael Porter II told me. “And the thing is, they’re smart to do so. A lot of the people they are hiring are burned out from having been mistreated, underpaid, and undermined for years. But let’s be clear that these hires are not simply because the individuals are impeccable: It’s part of a strategy to allay any accusations that ‘big pharma is a bad guy.’”

“It’s a strategy,” Juan Michael added, “and it changes the dynamic for the worst by using activists as a shield against criticism.”

It can certainly be argued that we benefit from having allies working within pharma. But we all know pharma is getting the better end of the bargain here — while creating a sense of fraternal kinship between HIV advocates and the very people we must sometimes advocate against.

All of this investment solves a few dilemmas for pharma. The corporate jobs tend to silence dissent. It also puts trusted community faces in the front of the store window. And the dynamic comes in handy when favors need to be asked.

During my phone call with Phill Wilson, Phill mentioned that a Gilead executive initially reached out to him about the amicus brief. That person is a trusted friend who had enjoyed a highly-regarded career as a clinician and community advocate before being hired by Gilead. You can see how the roles might get a little cloudy, between whether talk of the amicus brief was simply a friendly request, a legal strategy, or a corporate ask.

Do I believe that Phill Wilson deliberately colluded with Gilead by signing a document he knew was not in our best interest? No. I believe that Phill agreed to a request from someone he trusted without speaking to any of the other players involved. The resulting damage is the same.

So, what was Phill thinking? I asked him.

My Phone Call with Phill Wilson

Phill was the only signatory on the amicus brief who agreed to speak with me. I appreciate his willingness to take my questions and have his say. We spoke for an hour on the call, recorded with his permission.

I began by sharing with Phill that his name on a legal document on behalf of pharma came as quite a shock to the activists working on this suit.

“Let me back up and give you some history,” Phill began. “There are multiple HIV/AIDS epidemics going on in the world and the people impacted by them have different needs. There is a white and wealthy epidemic in America and then there is a Black/brown/poor epidemic. So, when I was approached about this issue, I approached it, quite frankly, as ‘how does this impact Black communities?’ There used to be maybe twenty pharmaceutical companies involved in the AIDS space. Today there are two. Black communities suffer from the reduction of efforts to fight the pandemic.”

I pointed out that pharma has always warned that activism might chase them out of the HIV arena – and yet it never, ever has. There are also multiple pharmaceutical companies that are very much involved in HIV research and sales. The drug pipeline is robust.

I walked Phill through the history of Gilead’s actions and what the lawsuit charges because I wanted to be sure Phill knew the depths of Gilead’s offenses.

“I didn’t sign on to the amicus brief to suggest that pharma in general or Gilead itself in this particular case always operate in ethical ways,” Phill responded. “I am not defending the process of the delivery of these two drugs. I do believe that part of the calculus of developing drugs, you know, always involves a profit analysis.”

As I understood his answer, Phill had just pardoned Gilead’s unethical behavior because they needed to make money. When asked why he had been unresponsive to Peter Staley’s many attempts to discuss the document he signed, Phill responded, “I did not respond immediately because I had made a commitment already and I was less likely to change my position.”

I was stunned that Phill felt more strongly about his commitment to Gilead than to the HIV treatment activists who were begging for a moment of his time.

“Peter’s name carries a huge amount of weight,” Phill assured me, before stunning me again. “In other times, I would have invested a lot more time and energy in doing a lot more due diligence on this,” he said, citing busy life events that have distracted him in recent months. “This particular time, I didn’t do as much due diligence as I might have.”

For much of our call, Phill alternated between Gilead’s talking point about the lawsuit risking a “chill to innovation” and his contention that pharma could abandon the field if we pick on them because, well, he says so. Not because he researched the lawsuit, or spoke to the plaintiffs, or otherwise performed a shred of due diligence before signing the amicus brief, because Phill acknowledged he did none of that.

Since the issue of pharma funding is central to this scenario, I asked Phill if he was, in any way at all, benefiting from Gilead dollars.

“The answer is no,” Phill stated emphatically. “I am no longer involved with the Black AIDS Institute. I retired.” Then he reconsidered his statement. “In April, at a biomedical summit in Seattle, I did a Gilead plenary where I was compensated,” he explained. Then Phill mentioned a

large dance event he produces every year and said Gilead is their major donor.

Honestly, I am still processing this conversation. It certainly clouds, if not complicates, the monumental community legacy of Phill Wilson.

Some Final Thoughts and Yes I Am Very Angry

People with HIV are dead. Thousands of others suffered needlessly. The lawsuit contends that Gilead's actions contributed to it. And now some of our own community leaders have signed on the dotted line in defense of Gilead. This is infuriating. Our long-departed friends, the ones we marched beside and buried and mourned, surely are turning in their graves.

Pharma has transformed the HIV community landscape. It has erased the lines between what is a friendly request and what is a conflict of interest, between what is an advocate and what is a sales rep, between who is a friend and who is a player. We are all in the suffocating embrace of Big Pharma now.

Has Gilead broken our spines as easily as its drug destroyed our bones? Where the fuck is our courage?

Peter Staley can still conjure a tone of optimism. "Look who did not sign that document," Peter reassured me. "Some of our groups who are heavily funded by Gilead are continuing to do the right thing. NMAC is not on that list of signers. AIDS United and the Black AIDS Institute are not on that list. Housing Works isn't. There are grains of hope here, and we can regrow our community with them."

"I've always urged organizations to take pharma money," Peter added. "It's our money. We paid for it. But they will never buy my advocacy or my voice."

The question is whether we can maintain our principles in spite of a well-financed effort to lure us into giving up pieces of ourselves.

Mark
