My name is [redacted], I live in Seattle. And I'm alive because of ACT-UP.

I usually see my doctor a week after getting my labs done. At the office after having my vitals checked his assistant leaves and closes the door behind her. Taped to the back of the door is the current HIV Drug Guide … they are arranged by classification. As I scan the various options for treatment, I have realized that I have become resistant to entire classes of medications.

As a long-term survivor of over 35 years, my current HIV regimen is three pills, twice a day, multiple tabs. I am literally at the end of the line for treating my HIV. I only have two options left. Gazing at the chart of different classes of drugs I go down the list, crossing each one off in my mind. My doctor consults me as fear begins to set in. There isn't a day in the week that I don't think about where I am in treating my HIV. I share with him that he is one of the longest enduring relationships that I've had in my life. And how important the relationship has become in treating my HIV.

Trust.

As a queer white male and elder in community, I believe we need to have all options be made available for others living with HIV in Washington State.

Access, access, access. No more hurdles. No more barriers.

"We only answer to the State Legislature."

Well, here we are.

In reference to the big elephant - $$$ - Budgeting on the backs of those most vulnerable and the poor. Take from the poor to give to the poor.

Stress.

I haven't shared this with too many people, only my closest friends and a few colleagues and mentors. As a member of the Washington HIV Justice Alliance – the last few years has left me having to step away due to the stress, to focus on my mental and physical health.

My community and those closest to me were beginning to see the impact the stress was having on me.

Doing what I need to do to take care of myself.

“No one considers the historical trauma on individuals and subsequent generations despite revolutionary treatments and how they find themselves unable to escape the conflation of queerness with death, desire with danger or the racism and transphobia of the dominant HIV response that cleaved the momentum of progress away from trans, immigrant and BIPOC communities. … Including the fear-based HIV stigma and sex phobic HIV prevention campaigns and the destructive effects that stigma has had on feelings of self-worth, on intimate relationships, and on their understanding of community.” – Tony Valenzuela (Between Certain Death and a Possible Future)

I am very concerned that members of community who already struggle … will be left behind yet again … unnecessarily. I fear people who already struggle to establish trusting relationships will continue to slide backwards towards invisibility. This only creates additional barriers in accessing lifesaving medications in communities that are already difficult to engage.

One segment of community should not have to work harder than another to get the same access to HIV Care services or treatment. The reality is that they do. And this only reinforces a class system, a tiered system of those who have access and those who do not.

There is an eerie parallel as I reflect on treatment options in the 80s and 90s when those who had more resources those who had more options, were mostly well to do gay white men. Do we really want to repeat that moment in time?
Do we want to instill that fear onto another generation?
I say that because we already know that those most marginalized, BIPOC and those living with complex issues such as MH/SUD and unhoused are bearing the brunt of new infections. The government has failed so many of our people, for so many years (especially marginalized communities; sex workers, people who use drugs, incarcerated folx and trans women).

Step Therapy (once fail, twice fail) is not an appropriate practice or approach for treating HIV because the use of an ineffective drug can lead to viral resistance or non-adherence. It can also render another drug in a patient’s treatment regimen ineffective.

Everything we as Washingtonians have been working towards … reducing stigma, reducing the profound racial and ethnic disparities in new HIV infections, and reducing barriers will be undermined.

This is a health justice issue.

These guidelines (pre-auth/step therapy) run counter to the goals in the Federal HIV treatment guidelines in the National HIV AIDS strategy to start antiretroviral treatment as soon as possible following diagnosis, to avoid lapses in treatment and to help individuals take their medications as prescribed.

Some things to consider moving forward.

Historically we know that marginalized populations are underrepresented in all data sets. Take steps to ensure that is not being perpetuated.
Don't defer to the HCA spell out what data you want to see and who would be most impacted by these decisions.

Address the needs of those with the greatest disparities first. According to the HCA, the most expensive people to treat on Apple Health are PLHIV and those with Diabetes, primarily Gay and BIPOC communities. As a PLHIV that means I'm too expensive to be kept alive. This is a health equity issue. And any expert or authority that doesn't place US at the center of our health and wellbeing has lost touch with a vital feature of health and wellbeing … US.

We already know the gaps in MH providers/professionals in Washington State are severe. Is the next gap in care those treating PLHIV? In community we know that several top HIV doctors already have or will be retiring. What are some options in addressing these gaps? Recruitment from local colleges, loan forgiveness in return for a commitment in serving people with the greatest need and the realities on the ground in those communities that are historically underserved. People who are reflective of those they are serving.

How do we ensure that reimbursement rates and prior authorizations and paperwork isn't overburdening those doctors who treat us (PLHIV)?

I often say; “peers are the most underutilized asset in every community”. Peers must be integrated in every sector to help alleviate an already overburdened system. Peer navigators, peer support specialists and certified peer counselors are some that come to mind. And of course, STIGMA is reduced when we share our stories. And no one will have a greater impact on reducing stigma than those living with HIV. (U = U) And ending the HIV epidemic will never happen unless we center the stories and experiences of those communities most impacted by HIV.

Nothing About Us Without Us.
The current epidemic already has a vise grip on the most marginalized.
Join us in moving forward – living in a healthy and just society where all lives are valuable despite the places and spaces, they find themselves.
And that we do no harm working towards Ending AIDS in Washington State.

In Solidarity,
[redacted]