"Annus Horribilis" and The War on Science: Thoughts on Resisting and Rebuilding

Thank you, Mike, for the generous introduction, and thanks to the CROI organizing committee for the humbling invitation to give the Martin Delaney Presentation this year.

Marty was a hero of mine. I first learned of his activism during the steep HIV/AIDS learning curve I found myself desperately climbing after my diagnosis with AIDS-Related Complex in November, 1985. I was a 24-year-old, deeply closeted bond trader on Wall Street, and knew nothing about AIDS.

I eventually found my way to a small but extraordinary library run by the People With AIDS Coalition, and it was filled with all the back issues of PI Perspective, Marty's voice at Project Inform, with its slowly growing list of possible treatments showing test-tube potential, along with Marty's activism, primarily focused on the FDA.

Marty's work handed me my first kernels of hope since my diagnosis.

Within a few years, as a member of ACT UP New York's Treatment & Data Committee, I found myself fighting shoulder to shoulder with Marty, alongside Mark Harrington, Jim Eigo, and others, as we ran a bicoastal pincer move against Tony Fauci, pushing him to endorse Jim Eigo's proposal for Parallel Track, our primary demand of the FDA, crafted to provide early access to experimental drugs in their last phase of development.

The New York activists had been meeting with Fauci to hammer out how the program would work, and Marty provided a tsunami of moral persuasion during a fateful trip Fauci took to San Francisco in June of '89, grippingly described in Tony's recent memoir.

Marty brought Tony to the apartment of a partially blind person with AIDS, who begged Tony to, "please get me some ganciclovir. Why do I have to make a choice of stopping my AZT and dying sooner versus staying on AZT, living a little longer, but going blind without ganciclovir?"

Fauci announced his support for Parallel Track the next day at a Project Inform community meeting with Marty backstage. The New York Times ran a front-page story on the announcement a few days later, and the FDA caved immediately. Before the end of the year, thirty-five thousand people with HIV were taking ddI via Parallel Track prior to the drug's approval. The victory put AIDS activism on the map as America's movement du jour.

Now, I know that this presentation is often used to emphasize the imperative need for community involvement in the fight against AIDS. But I'm pretty sure that almost everyone in this room already understands and feels this in your bones. And we also know that that wasn't always the case.

In fact, the last time I spoke to a room filled with this many HIV medical experts was way back in 1990 at the opening ceremony of the International AIDS Conference in San Francisco. Some of you with gray hair like mine might remember it. I spoke about the growing and frightening divide between the scientific community and AIDS activists. We were demanding a seat at the table, and many of you were freaked out by our anger and radical protests.

But thanks to bridge-builders like Tony Fauci, Mathilde Krim and others who advocated for constructive dialogue, we slowly started working together.

We learned from you and adjusted our demands accordingly. You learned from us and adjusted clinical trials and access programs.

We became more like you. Science became our shared religion. And some of you became more like us, joining us in coalition, working towards various goals.

Years later, we are now so comingled that when new epidemics hit, like Ebola, Monkeypox, and COVID, we all jump back into action as one, unified voice – unwilling to let our collective power go unused against the new threat, beautifully expanding our shared history of fighting HIV into the wider realm of infectious disease busters.

Each time this happens, it's felt to me like we're an aging rock band, getting back together for yet one more tour, dusting off our guitars and drums, or in this case, our political and media connections.

And here we are now, fighting another battle – the Trump administration's war on science.

The Lancet got it right with an editorial in December titled "2025: an annus horribilis for health in the USA." We all knew Trump's second term would be worse than his first, but few of us were prepared for the level of destruction, and the speed of it, that started immediately after his inauguration.

Historians point to how authoritarian movements have repeatedly attacked science and other elite institutions in order to stifle opposition. But here? In America – a country with a post-war record of scientific achievement that's second to none?

Most of us probably remember specific, where-were-you moments when the enormity of destruction hit you in a visceral way. Maybe your NIH grant was cancelled. Maybe your university's government grants were suspended en masse. Maybe it was when an AIDS denialist and leading antivaxxer was approved by the Senate to oversee all our federal health agencies.

Or maybe it was any week last year as this administration and its ruthless base waged a terrifying and relentless war against the very existence of trans people. All of us can certainly commiserate about feeling stunned this past year, followed by deep sadness.

I know I first felt it just a few days after the inauguration. Tony Fauci called me, in disbelief. "Have you heard anything about PEPFAR being shut down?" he asked. "No," I replied, "that can't be right."

Funding had been put on hold. All partner organizations had been told to stop providing HIV treatments to their patients. PEPFAR's data systems were taken offline. Within a week, USAID's website was taken down.

The world's richest man, Elon Musk, tweeted, "USAID is a criminal organization – time for it to die." It's already small budget, just $10 billion a year, was eviscerated. It's worth noting that Musk's wealth grew last year by $300 billion.

Even though media outlets were overwhelmed trying to report two or more outrages per day, our community did a remarkable job raising the alarm about PEPFAR and USAID. With the last remaining whiffs of his soul, Marco Rubio backpedaled, announcing limited waivers for some of the stop-work orders. But without USAID in place, many of the waivers were delayed.

Nicholas Kristof started reporting on the first deaths from the closures, mostly in children. We know that when HIV treatment is suddenly stopped, one's immune system quickly returns to its pre-treatment nadir. Opportunistic infections can seize the opportunity, resulting in a quick death.

I started losing sleep thinking about these patients. I was remembering the night sweats from the first few years after my diagnosis, when I reached my own CD4 nadir of 103. The soaked sheets. The understanding that these fevers were a manifestation of the war going on between my immune system and the virus. The understanding that I was *feeling* the virus.

Now I was imagining hundreds, if not thousands of people in Africa, waking up on soaked sheets, feeling the virus for the first time in many years, suddenly robbed of the hopeful futures they had looked forward to just weeks earlier. Try to imagine that fear.

It filled me with rage. How could rich and/or powerful men – Musk, Rubio, Trump – intentionally cause this?

And then another blow. On February 14th, DOGE summarily axed thousands of civil servants from our healthcare agencies – the largest cuts in our government workforce in history. According to an analysis by the *New York Times*, the NIH suffered a workforce reduction of 18% last year.

These cuts had nothing to do with cost-cutting. They were political, targeting women and people of color in leadership roles, including institute directors, and any job tinged with concerns about health equity. And the new guys in charge, the COVID backlash nutters, took their vengeance out on NIAID in particular.

Again, I was filled with rage. Every AIDS activist I know felt the same. Our heroes in the civil service who had dedicated their lives to fighting AIDS were targeted. They deserved to leave NIAID on their own terms, with retirement parties packed with thankful colleagues. Maybe it would help a little now if they heard from us. Please join me in thanking Cliff Lane, Emily Erbelding, Sarah Read, John Beigel, Tara Palmore, Jill Harper. and last but definitely not least, Carl Dieffenbach.

Two and a half years ago, I had the huge honor of being asked to join the NIH search committee to find a new NIAID director after Fauci's retirement. I remember having bouts of imposter syndrome as I read dozens of extraordinary resumes, most over thirty pages long, each listing dozens of published studies and multiple leadership roles. *My* resume is still two-pages long, with a single degree – a BA from Oberlin, not that there's anything wrong with that.

Regardless, I'm incredibly proud that I played a role in forwarding Jeanne Marrazzo's name to the acting NIH director for his consideration. The small-minded men who illegally pushed her out probably didn't expect her response. She'll see you in court.

Beyond Jeanne's shining example, how has the broader research community been doing with its response to MAGA's war on science? The grades are mixed, but I think we've been doing a lot better recently than we were early last year.

When the NIH cancelled over $780 million of grants in response to Trump's executive order targeting DEI, the rush by grantees to remove targeted keywords from grant descriptions got more news than any strongly worded statements that pushed back. One can appreciate the harm-reduction nature of this approach, but it looked like acquiescence.

Jeremy Berg, the former editor-in-chief of *Science*, commented on all of this by pointing to one the first tenets of historian Timothy Snyder's important book On Tyranny – do not obey in advance.

Thankfully, plaintiffs, led by the American Public Health Association, took the NIH to court, and were soon joined by a group of Democratic state attorneys general. Even with a setback in the Supreme Court, those cases are producing results. Many of the grants have been reinstated, and many more are being re-reviewed.

As the year went on, we saw repeated acts of individual courage that demonstrated clearly to the American public that the scientific community maintains a strong ethical compass.

"After much contemplation and reflection on recent developments and perspectives brought to light by Secretary Robert F. Kennedy Jr., I find that the views he and his staff have shared challenge my ability to continue in my current role at the agency and in the service of the health of the American people. Enough is enough."

That's a snippet from the remarkable resignation letter written by Demetre Daskalakis in August. He was joined by other senior leaders of the CDC, like Debra Houry, Daniel Jernigan, and Jennifer Layden, all protesting the firing of CDC director Susan Monarez. The resulting media story lasted almost three weeks, capped by damning testimony before the Senate health committee by Drs. Monarez and Houry.

Along with the 484 NIH employees who courageously signed the Bethesda Declaration, this kind of standing up has been one of our community's finest hours.

I got looped into the behind-the-scenes activism that led to AAP vs. Kennedy, the first federal case to target RFK Jr. directly. Bravo to the American Academy of Pediatrics for stepping up so boldly. The case, driven by an energetic lawyer, Richard Hughes, has a better than 50/50 chance in shutting down the deadly clown show that ACIP has become.

I've also been in the loop after Michael Osterholm and Rochelle Walensky launched the Vaccine Integrity Project to counter ACIP.

It's been a marvel to witness the passion of all the scientists and lawyers fighting back against RFK Jr.'s war against vaccines, reminding me of the same passion AIDS treatment activists had during the early ACT UP and TAG years.

Can we be doing more? Most definitely, according to the activists who follow this much more closely than I do, groups like Stand Up for Science, Defend Public Health, launched by my former TAG colleague, Gregg Gonsalves, and the Science and Freedom Alliance.

While they applaud the courageous acts by many individuals and a few institutions like those I've just mentioned, they are deeply concerned by the silence of many, many others. The old, entrenched view holding that scientists should avoid politics, or the newer view that they should just keep their heads down until this all blows over, are both sadly prevalent.

Political historians are pretty clear that during pivots towards authoritarianism, strategic silence only makes things worse.

Regardless of these handicaps, I think we've all witnessed reasons for hope in recent months.

Our court cases have born some fruit. More of our societies have signed onto strongly worded statements defending vaccines, mRNA research, and calling for the resignation of RFK Jr. We've won bipartisan support for a total rejection of Trump's radical proposed cuts to our federal science programs. The NIH, and NIAID specifically, received budget increases!

And PEPFAR, while severely battered and bruised, is still standing, mostly thanks to CDC staffers who got a majority of the money flowing again after USAID was gutted.

And the larger resistance is stronger than ever.

The No Kings marches keep getting bigger and bigger.

An entire community, the great city of Minneapolis, rose up against the largest deployment of Trump's extra-judicial paramilitary force, bringing more passion, stunning organizational skills, tens of thousands of glove warmers, and more courage than any mob MAGA can muster. And they won.

Many of our major cities have community groups that are deep into planning how to duplicate Minneapolis's movement.

It feels like a tipping point. If each of us takes even the smallest step towards defending science, we'll add to the current momentum.

By the way, none of our public facing resistance has hurt us. Recent polling from both Pew Research and Research America show that about 8 in 10 Americans have a fair amount or a great deal of confidence in scientists, an increase from the year before.

So what more can we do in the months and years ahead? Resistance comes in many forms. Obviously, I love the flashy stuff, from street protests to enough-is-enough public resignations, or the named plaintiffs in federal court.

But equally important is the often hidden, keep-the-lights on approach of the thousands of public servants who were not let go, and are not being forced to cross an ethical line. It should be a major goal of our resistance to save as much of our core institutions as we can, so that they can be more quickly rebuilt once the opportunity allows.

Those unnamed, unrecognized CDC employees who kept PEPFAR alive are just as important as their superiors who sacrificed their jobs in the name of science.

Our academies and societies can up their game with some ongoing coordination to quickly respond to every anti-science policy or statement this administration comes up with. We shouldn't just roll our eyes at each new piece Bhattacharya manages to get published. We should respond, as a community, every time, so that the administration's nonsense doesn't become normalized.

On an individual level, if you haven't dipped your toe into any activism thus far, you could try the very easy step of signing up for updates from Stand Up for Science, and Defend Public Health. That's standupforscience.net and defendpublichealth.org.

We need to start planning now for the great rebuilding. If we are lucky in 2028, new pro-science leadership will take over HHS, NIH, FDA, and the CDC. All will require some rebuilding. Which of our big organizations will start now drafting the health-related chapters of Project 2029?

Personally, I'd like to work with others on pushing all the Democratic presidential candidates to commit, as part of their platforms, to a resurrection of USAID and PEPFAR.

But how do we summon the energy for the work ahead? There were moments last year that felt pretty hopeless. It reminded me of some of the darkest early AIDS years, especially 1993. Remember the Berlin AIDS Conference, and the depressing results from the Concorde Trial?

Some of us wondered, was it all for naught? The activists had racked up years of policy victories and huge budget increases for AIDS research, but we were losing the war. The death toll just kept on rising.

Amazingly, as if we were on autopilot, we kept at it. We couldn't yet see a light at the end of the tunnel, but giving up felt far more frightening than plowing on. And besides, you still wanted to be in the room if the great pivot finally arrived, and it did, three years later.

Thirty years ago, on July 11, 1996, I remember standing just behind the right section of seats, in a standing-room-only conference room in Vancouver that was about the same size as this room, trusting, intellectually, the data I was seeing on David Ho's slides, but emotionally, feeling very wary.

Four months later, my undetectable viral load result still feels like a miracle. As someone who got anemic on 1,200 mg of AZT monotherapy, and now takes this single pill once a day, with a safety profile far better than a baby's dose of aspirin, the miracles haven't stopped. Juluca, if you're wondering. Thank you, Viiv.

I have to believe that the pendulum that has been swinging against us this past year will, if we fight for it, eventually swing back.

You are a community that gives us miracles. With empathy as your driving force, you've saved millions of lives. Your history will pull that pendulum back.

From the French team who discovered the virus, to the scientists at Burroughs Wellcome and the National Cancer Institute who discovered AZT's antiviral potential, to the pediatricians who worked on ACTG 076, saving millions of infant lives, to the chemists at Merck who synthesized Crixivan, making HAART possible, to Bob Grant, the father of PrEP, to the investigators behind HPTN 052, leading to U=U, to the virologists and chemists at Gilead behind the potential gamechanger, Lenacapavir, and the basic researchers who defined and discovered the vulnerability of HIV's capsid protein, research that was often funded by NIAID.

Speaking of which – to Tony Fauci's nearly four-decade leadership of NIAID, which funded the basic research that led to many of the miracles I've just listed.

And finally, to the frontline doctors and nurses that took care of us, and suffered with us, or are new to this community, building on a legacy of remarkable care, ready to witness a future cure.

It’s a huge honor to be in the same room with hundreds of you, and to be able to say thank you. Thank you for everything you’ve done in the fight against AIDS.

Please take care of yourselves and each other in the fight ahead. Always prioritize your own mental health. Find joy with your close friends and family. Go deeper this week when you meet up with old or distant colleagues. I know this old activist needs a good hug, so this is my mass prior consent for hugs if you see me and want to say hello.

Let’s start strategizing for the fight ahead. Thank you.