No One Is Coming For You, For Me

We were going to change the world. But the world ended up changing us.

April 26, 2024 By Mike Barr

TL;DR: After months of back-and-forth with some of the last independent-thinking HIV physicians and immunologists still working, Mike Barr has arrived at a conclusion he didn't want to reach: no one is coming. Not for his generation. Not with the research they actually need. The HIV establishment is captured, siloed, pension-waiting, and Covid-defected. The questions that matter — about quinolinic acid, gut repair protocols, routine nutritional analysis — are going unasked. This is a dispatch from that realization.

- The ACT UP generation now: Pot-bellied from Biktarvy. Metabolic syndrome from cART. On ever-lengthening lists of QOL meds. Faring not significantly worse perhaps than HIV-negative peers — but unequivocally no better-- and almost always poly-polypharmacy out the ying-yang, and no one questions why.
- The research landscape: Siloed, captured, retirement-age, Covid-defected. The few independent thinkers left are not talking to each other. There is no clearing house. There is no amfAR that believes what it's selling.
- The unanswered questions: Why is no one measuring quinolinic acid or kynurenic acid in people living with HIV? Why no gut repair protocols? Why no routine nutritional analyses — the way we once checked T-cell counts obsessively every three months?
- The conclusion: We are on our own.

[IMAGE: Something evoking a generation — a protest, an empty meeting room, a long hallway — not clinical, not hopeful, just honest]

A Mayday Call

I suppose we could just continue to muddle along. And more than likely, that's what will happen.

My ACT UP/New York generation — the ones I know best — is transitioning into old age. Those who've made it this far: pot-bellied from Biktarvy. Metabolic syndrome not from HIV but from cART. On an ever-elongating list of "QOL" meds — for depression, for cholesterol, reflux, anxiety,

insomnia, impotence.

That's not to say we're faring appreciably worse than our HIV-negative brethren, something I alluded to in an earlier post. (And the ones aging absolutely the worst are the physicians.)

I grow old, I grow old. Shall I wear my trousers rolled?
— Butchering Prufrock, sorry

It's just that after the past month or so of confabbing with one of the very last HIV physicians to think independently, I am throwing up my hands. Because so has he. Well, that meeting — and then the back and forth, back and forth, with a handful of HIV immunologists in whose hands our fate seemed to rest. Or at least, from whence was to spring our last, best hope.

In a word or two: it isn't pretty.

Channeling my inner Larry. Missing Joe. Even Derek.

I had started a blow-by-blow account of the week of emails and literature searches. But as my projects are wont to do, it quickly metastasized into something in serious need of organization and pruning. So it sleeps here as a draft awaiting caring attention.

We Are On Our Own

Even among the small number of scientists and thinkers — and long-ago activists and community organizers — who are not dependent on Gilead or ViiV or the rest for their funding or living standards, the proverbial left hand is not talking to the right.

Most of the HIV researchers are of retirement age — treading water until the pension kicks in. Others jumped ship for the Covid research funding bonanza. The younger ones, even the best intentioned and brightest, are working in silos. There is all this clinical experience and knowledge outside of government, outside of the strictest bounds of internal medicine and ID and immunology, that they do not avail themselves of. Are even oblivious to.

The government-funded researchers tack to the safest candidates, the most conservative study designs, and products that come with a deep-pocketed commercial backer. Yeh, talking about you, dasatinib.

Please — someone tell me there is a non-profit I am unaware of that is compiling and cross-referencing all the different potentially productive pieces, making sure their producers are aware of each other and communicating. A clearing house. A switchboard.

I just don't see it.

The amfAR Moment

I cannot help but think back to an early amfAR meeting I was called into in autumn 2013. They were getting ready to launch their "Countdown To A Cure" campaign. $20 million by 2020. Twenty million dollars. Notable that the marketing team — not the science team — headed up the meeting. "Kevin's not on board with this yet, but he'll come around," the marketing head promised us. She knew as well as anyone that he wouldn't want to jeopardize his Soho House life. No one at 120 Wall Street ever believed what they were selling. It was Trumpism before Trump. Everybody

now only thinks about money. Even in HIV/AIDS.

What's Coming Instead

We will die on the dance floor from a sudden MI. Just like the old days. Only this time it won't be the GHB — it'll be the Tivicay.

Or our depression — misunderstood, then misdiagnosed, then mistreated — will imperceptibly morph into dementia. And we'll be carted off to an HIV-themed memory center somewhere. Maybe Palm Springs or Provincetown, for the luckiest MSM among us. I doubt we even have things like that in place. And what about the women?

Why is no one measuring quinolinic acid or even kynurenic acid in people living with HIV? Why no gut repair protocols? Why no routine nutritional analyses — the way we once checked T-cell counts and viral loads obsessively every three months? Folate, B12, amino acids, essential fatty acids, magnesium, zinc, selenium, copper, manganese, antioxidant status, glutathione — at the very least.

The Conclusion

We all had such promise once. We were going to change the world. But the world ended up changing us. I suppose that's what happens to revolutions.

The wind blows the water white and black.

If you find my writing useful or moving — please consider making a small donation here. Or booking a phone or video consult with me — up to 45 minutes for $125 — here. We can go over labs, health concerns, or just reminisce.

Mike Barr, a longtime POZ Contributing Editor and founding member of the Treatment Action Group (TAG), is a science writer, functional medicine practitioner and herbalist in NYC. Reach out to him here. Or sign up for his curated, professional-grade supplement dispensary — 30% off your first order, 25% off all auto-refills — here.
