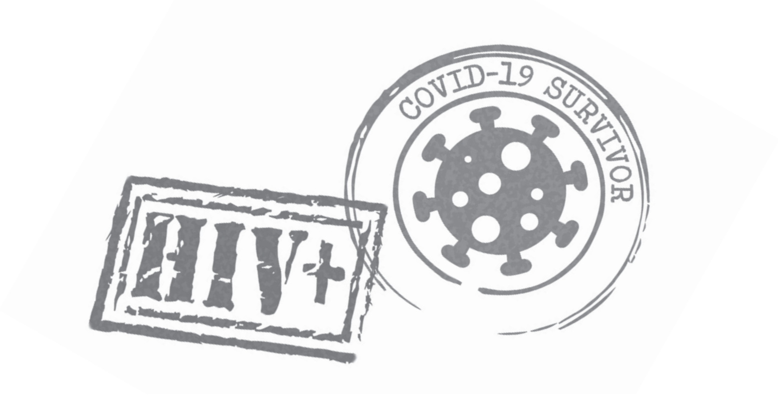
MY UNEXPECTED LIFE

an international memoir of two pandemics, HIV and COVID-19



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The events in this book reflect the author's recollection. Dialogue has been recreated from the author's memory, and a few names and identifying characteristics have been changed to protect the privacy of those depicted. Nevertheless, it all happened.

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“If you think you are too small to make a difference,
try sleeping with a mosquito.”

—Dalai Lama XIV

“If you can’t find somethin’ to live for,
you best find somethin’ to die for.”

—Afeni Shakur

Rebecca also attended, as did a handful of other positive women I'd met through WORLD. I wasn't sure what I expected to find when I landed in Acapulco. I was just glad to be traveling again, and open to whatever might lie ahead.

How naïve I was.

A Kidnapping in Mexico

Acapulco, Mexico, 1993

Mexico: North America
Population: 127.6 million
Capital: Mexico City

Trying to drown out the shouting of conference attendees below and quiet my overwhelmed mind, I sat in the path of the daylight flooding my hotel room window for a long moment, my feet still on the adobe tile. The air conditioning was on high, but the warmth of the Acapulco sun felt like a much-needed hug. When I'd first been told I'd tested positive, I hadn't thought I'd live long enough to watch Oprah the next afternoon. Yet here I was, almost a year and a half later, at an international conference for people living with HIV.

Shy by nature (although I fake confidence), I was hesitant to go out and face the sea of angry activists outside my room. Some still looked and sounded healthy. Others appeared closer to death than anyone under eighty ever should. The stale stench of illness hung in the air amid the sweaty Act Up T-shirts, and the slap of flip-flops around the pool became our soundtrack. Punctuated now and then by shrieks of, "Oh my God! You're here! You're still alive!" or "Come here, princess, you look faaabulous!" Which might be said to a muscular six-foot-tall man.

These warriors were unlike the HIV-people I'd met so far. They were very pissed off. Not simply disenfranchised or disappointed or frustrated, or even like the perky ones determined to make their remaining years happy. These people felt the world owed them, and as I listened, I tended to agree. They were advocating for themselves and our global community in order to live. For access to better health care, affordable treatment and, perhaps most importantly, for their dignity to be acknowledged and the stigma and discrimination to end. Their activism went beyond the stereotypical marches, memorials, or campaigns. They were demanding a seat at the table alongside the decision makers. They wanted representation on local, national, and international advisory boards of pharmaceutical companies, medical networks, and governmental bodies, including the United Nations.

"You know, Mike Merson's going to be here," one lanky guy with spiky red hair said from across the breakfast table.

"Uh-huh." I nibbled some salty bacon and noted the slogan on his T-shirt: *SILENCE = DEATH*.

"You know who that is, right?"

"Um. No, not really," I said, looking back up into watery green eyes, like olives floating in gin.

"Girlfriend! Where have you been?" he yelped. "He's the head of GPA—you know, the Global Programme on AIDS at the WHO?"

I shrugged.

"Sorry, World Health Organization." He pronounced each word from the acronyms slowly, as if I had a hearing impairment.

"Of course," I said, pretending I'd known all along. "So is he going to speak or something?"

"Yeah, he's going to speak, all right. And so are we! We have some serious things to say to him, like, 'How dare you bureaucrats and doctors play with our lives, you arrogant prick?'"

"I see. Well, I'm sure that's going to be quite a session!"

I sat there imagining what I assumed to be a distinguished-looking doctor having it out with angry people fired up with more passion than their immune system could contain. I couldn't see how it would end well for these hard-core activists, but kept my mouth shut.

I was intimidated by their knowledge. Not only of the illness but also the history of the epidemic, and the workings of the bureaucracies guiding, or neglecting, the responses. I'd begun to educate myself, but hearing them discuss macrophages as eloquently as they dissected Big Pharma profit margins, I felt out of my depth.

Giving in to my survival tactic of silent watchfulness, I felt very much an outsider at the opening of this conference. What kind of nonstop chaos had I fallen into? I wanted to learn more about HIV, but mostly to know more about these people who wanted direct input into the decisions shaping their futures. Our futures.

My future.

Mothers, for example, wanted research trials to provide childcare so they could participate. The scientists apparently hadn't thought of that, and as a result, few women were enrolling in studies. So how could we be sure medications being tested on men would even work for half the population? I had so much to learn.

The fiercest activist I'd met so far was Bellona, who, like me, was a small, blue-eyed blonde. Five years younger, she not only spoke publicly about living with HIV, but was also candid about being a lesbian—not an easy label to wear in her rural Midwestern hometown. She'd been fighting like hell since having been infected in her early teens. Her mother's boyfriend had raped her, and that was a burning rage she'd never extinguish. But she also told me funny stories, which drew me to her gentler side. My favorite was about when she'd gone to her first support group and found herself surrounded by gay men. They listened, hugged her, and offered reassuring words. And, at the end of the night, one took her in his arms and said, "Bellona, darling, it's all going to be okay. Really, it is. Just don't *ever* wear that belt with those shoes again!"

She was already more involved and knowledgeable than I was and could help guide me through the madness. She'd been to one of the first world conferences, in Amsterdam, when the networks of people with HIV began to form. She knew many of the individuals and had trenchant opinions on them all. Her biting humor was a balm in the blistering rage that surrounded us.

At first, I'd wanted to go to the conference primarily for the opportunity to travel again. By 1993, scores of countries around the globe had imposed travel restrictions for people living with the virus (even today, many still do). In order to visit one, a test was required; if it was positive, the visa was denied. If the rules were somehow skirted but officials found related meds in your luggage, you'd be packed home on the next flight and blacklisted forever. This despite the fact that the HIV-1 retrovirus already exists in every country and continent. It is not airborne, it does not live long exposed to air, and it is extremely fragile. It's actually not that easily transmitted. It requires intimate contact with infected bodily fluids.

In short, such restrictions do nothing to stop the spread and everything to increase the stigma against positive individuals. As such, traveling again was a privilege, and I appreciated it that much more. Mexico was selected for the conference because it did not impose such restrictions. This trip was a glimmer of hope: maybe I could have a mostly normal life. My passport was my most prized possession. I still hoped I'd be able to use it frequently.

Also, I was eager to meet people with HIV from other countries, to see if their experiences were the same. Even as a child, I'd always been drawn to the new kid in school. If they came from another country, I felt I'd hit the jackpot. Though long since lost, one of my favorite childhood possessions was a handmade valentine from an Iranian boy whose family had escaped the revolution in the early 1970s. He'd written my name in Farsi with the script I'd later recognize as Arabic. I'd never seen my name written in another alphabet, much less cut out of red construction paper and pasted onto a blue background. I used to trace my fingers over this magical-looking depiction of my name so often, the edges became worn like those in a favorite book of poems. How a boy my age could know so many different things from a world so far from mine fascinated me. What he knew, of course was his own language, script, and culture, but I was too young to grasp that. My curiosity about the world beyond my hometown was piqued and has yet to subside.

The quiet Persian in grade school had been gentle and mysterious. But many of the participants at this conference scared the bejesus out of me. Some were so militant in their demands I found them off-putting. Like a diner straining to hear the daily specials in a crowded restaurant, I tried to decipher the messages swirling around me, picking out a voice here and there to lock on to. Mostly, though, there rose a wall of vocalized irritation that I didn't have a way to make sense of.

Others seemed passionate in a way I could relate to though, because their fire stemmed from a place of hope—a desire to change things, rather than simply rage and accuse. They were *doers* and *fixers*. I tried to get closer, to absorb a dose of that strength. They sat quietly together in small groups, working on documents to circulate. Or drafting press releases. Or simply strategizing ways to make our collective voice clearer, so those who most needed to listen might actually be able to hear us.

The newer ones among us were lost, trying to navigate this new world of international activism. For me, that meant learning a new vocabulary. Acronyms were darting around like sandflies at the beach. GNP+. WHO. GPA. ICW. USAID. ICASO, CDC. ICASO, Picasso, Mi Casa, Su Casa. What the hell?

Many of those acronyms didn't sink in, but I discovered four were key. The first was the WHO—the World Health Organization—part of the United Nations, which, at that time, coordinated the response to AIDS. The second was the program within the WHO called GPA, or the Global Programme on AIDS.

WHO and GPA were easy enough to remember mostly because the activists had cast them as the enemy, the high and mighty medicos who would figure this all out *for* us rather that *with* us. And, though it looked like the WHO was about to reorganize and create a different program, which would certainly yield yet another acronym, I held on to those two abbreviations.

The other essential acronyms pertained to two international networks of people living with HIV who were trying to galvanize a collective voice, to build a stronger lobby to influence folks at the WHO. This conference had been organized by one of them: the GNP+: The Global Network of People Living with HIV. Acronym three. The other was the ICW, or International Community of Women Living with HIV. Acronym four. Like the GNP+ but exclusively for women. GNP+ and ICW worked together, and one of their goals in Mexico was to elect a new board of directors for each network and move the agenda forward in concrete ways to match the pandemic's rapid evolution.

They didn't want to merely write letters to the WHO. They wanted to ensure that the voices of positive people were given equal weight with the opinions of the scientists, doctors, and politicians who ran the international response. These individuals had gathered from around the globe to discuss our plight and plan for a less marginalized, longer, healthier future. Before we left Mexico, two people from each region of the world were to be selected to serve on the board of the GNP+. This was not your rich uncle's corporate board where people got paid to meet and greet. The appointment came without a salary (though some expenses might be covered if you were lucky). Members would become one of the global faces of HIV. While it was an honor to serve, these roles would entail personal and financial cost. Once a person went public with their status, anonymity could never be retrieved.

Between the many buffets of tame and tasteless food, there were how-to workshops on advocating for our needs, understanding treatment options (few though they were at the time), managing your doctor, and so on. There were support groups for women, for men, for parents, and even support groups for support groups! I heard speakers and attended panels. More interesting, however, were the stories in the hallways.

One day, in the shallow end of the swimming pool, a woman from Zimbabwe told a small gathering of female attendees about her travels from Africa to Mexico. She'd been questioned repeatedly by immigration officers across two continents, about why she was traveling. And thus, publicly humiliated at every turn. These government officials always made a showy affair of wrapping her luggage in industrial-strength trash bags so it would not "contaminate" other suitcases. She was assigned seats at the back of the planes on long-haul flights and told to stay there. To not get up to stretch her legs or to use the restroom. To not even ask for a blanket or pillow. Over the course of two days, she flew from Zimbabwe to South Africa to Brazil and then on to Mexico. She was treated like a leper, and she took it, because she was determined to speak her mind here.

A handful of women—one from Germany, another from Mexico, a few from various countries in Africa—told us they'd recently had babies who without medical intervention, miraculously, were not born HIV positive. Some of the Africans said that *not* breastfeeding—which was recommended—was simply not an option. Where they lived, a woman who didn't was already an outcast. So they could never risk drawing attention to themselves and their babies by raising suspicions as to why they weren't nursing.

Of course, that was only one issue for those living in developing nations. There was also having to haul water in rural areas and then boil it, which required a stove, which not everyone had. I learned that many of the early medications (none of which I'd had to take) required refrigeration. Again, a huge problem, because not everyone has access to reliable electricity.

I'd already traveled a fair bit before my diagnosis. But never in order to learn the reality for someone dealing with such issues, so these stories were illustrative of life beyond my privileges. I'd never gone hungry or been unable to afford a safe, warm place to live. These issues, and more, compounded and accelerated the fatality rates in developing nations. There was so much I'd been taking for granted.

Another impressive speaker was one of the first women diagnosed in the United Kingdom (U.K.). Kate had co-founded the first women's group there, Positively Women. Later she helped start the International Community of Women Living with HIV (ICW), the sister organization to the GNP+. She'd been diagnosed nearly a decade earlier and I was astonished she'd survived so long. She was a striking beauty. Half Indian, half English, her enormous blue eyes were set against olive skin and black hair. I may have had a girl crush on her, but I certainly developed an activist crush.

One night she came out to the edge of the pool, where a bunch of us were lounging. Eyes bloodshot, slurring her words, smoking and waving a glass of liquor in her hands, she made her way toward us. "Thaaas it," she said, "Can't do this… anymore."

"Why? What happened? What are you talking about?" we asked, pulling our feet from the pool, or rising from our lounge chairs to form a circle around her.

"The lasssss one died. The lasss woman I started Positively Women with… has died. Sss no one left. I jusss don' have it in me… to continue."

I watched her swollen eyes spill over with tears and feared she might collapse right there on the patio. She looked broken, exhausted. So frail and tiny. I wondered if I'd ever see her again.

I knew why she was crying in that particular moment. But it also started to sink in that many of these people were angry not just because of the issues, but because they were tired. Tired of their friends dying. Tired of being told no. Tired of being rejected. Tired of fighting for their lives.

As I watched Kate slump in exhaustion, I felt my thinking shift. Maybe I could play a role. Maybe I belonged in this movement as well. If I could work with people like her on concrete issues, perhaps we could help make life better for women in our situation—at least for future generations, if not for ourselves.

Between these hallway and poolside discussions, I managed to attend a few of the actual conference sessions. Unfortunately, I remember little of what was said. Dr. Michael Merson, director of the WHO Global Program on AIDS, a nondescript man in his fifties, made his speech, and not a word sank in. My brain was on overload. Most of what he said floated away like passing clouds.

What I do remember clearly was the day a near-riot broke out during one of the plenaries. The group had been discussing, in English, the financial state of the GNP+ and the fact it was in debt. The Spanish language translators had not quite caught the gist of the conversation, however, and were relaying a discussion of "*la muerta*" of the organization and its members.

One of the Spanish-speaking delegates stood, removed his headphones and in broken English demanded, "Stop speaking of our precious lives as if we were mere statistics. We are here. We are alive this day. Stop to disrespect our humanity! *Por favor*."

Startled glances flew around the room like a game of laser tag, each of us looking for someone who might calm the insulted man. Pairs of heads leaned together. Soon, giggles erupted as we realized the translators had confused *debt* with *death*, sending us all into an unintended tizzy. Calm was restored, and the drone of speakers resumed.

On the last night, we held a Miss GNP+ contest. Most of the contestants were guys in drag. I lent my favorite black leather belt to one to secure his toga—ultimately the winning costume—only to watch him take a celebratory leap into the pool. My belt was ruined. Oh, well. At least I helped him win. I was already beginning to collaborate and, to my surprise, having fun in the process.

The music for this closing event was DJ'd by Yolanda, a wry woman from Trinidad. I heard Caribbean carnival music for the first time. "The Ballad of Hulsie X" and another called "Tayee Ayee" that employed beats I'd never heard before. Calypso. Soca. Steel pan. No wonder these grinding rhythms propel the famous carnival spirit and parades of Trinidad and Tobago. I couldn't keep my hips still. We danced into the night and celebrated our lives, crazy and challenged though they were.

Meanwhile, unbeknownst to me, another event was occurring nearby that would go down as one of the wackiest on the timeline of AIDS activism.

From our poolside vantage point, the tops of heads could be seen through a window in a suite overlooking the pool area where we were dancing. There, several of the more militant activists had skipped the party to waylay Dr. Merson. As the man in charge of the global response to the pandemic, he had disappointed the more seasoned activists. They felt he owed our community a fuller explanation of his intentions. There were rumors that a new United Nations (UN) entity was being set up to replace his program, and these activists wanted to make sure people with HIV would be involved from the outset. Not as puppets in a tokenistic way, but as respected decision makers in our own right.

Merson's hotel room was blocked at the door by the very people he was tasked to help. They canceled his taxi and told the airline he'd miss his flight. His luggage stood outside his room untouched, until eventually he retrieved it under the watchful eye of a man wearing that same *Silence = Death* tee. Lights from his room stayed lit long after the party outside wound down as the activists and the bureaucrat deliberated. The sky turned lavender shades of sunrise, then rose overhead, and eventually sank down again for the evening. But Merson listened. He vowed to take the messages back to the WHO and others at the UN to see if things couldn't be different in the future.

The redhead I'd met at breakfast my first day—the one with the olive martini eyes—and other activists demanded that never again should the medical community alone make decisions on a much broader-reaching social and health issue. HIV was more than a virus; it epitomized a chasm in society—an unwillingness to discuss sex and sexuality or to respect those deemed "different" by the mainstream "norm". The gay rights movement had merged with AIDS activism.

The downside of the union was that the epidemic was labeled as a "gay disease," associated with what many perceived to be immoral behavior, compounding the stigma. The upside was that this powerful lobby used years of organizing skills to change the face of patient rights for many illnesses to follow.

From that impromptu kidnapping, a movement was born. That night set into motion GIPA, or The Greater Involvement of People Living with HIV or AIDS. The term had first been coined years earlier, as a part of the Denver Principles in 1983, although it wouldn't be formalized until 1994. After those living with and facing the day-to-day reality of the disease joined forces to shape the global agenda, more informed decisions might be made. While I'd been shaking my booty, these activists had been blazing a trail I'd soon walk, and widen, in my own small way.

Ultimately, I agreed to be nominated for the board of the GNP+. I don't think any others even stood for the position, so I was easily voted in. I'd never before been on the board of anything. I mean, I was class president once, but that was in the sixth grade. I'd run on a platform of "legalizing" chewing gum. My brain, however, was three steps ahead, committing me to tasks I felt compelled to take on simply because someone had to. My inner activist apparently was eager to emerge, so she gave herself a coming-out party in Mexico.

There was no guidebook, no rules. We were all making it up as we went along. But I always like a challenge, and the possibility of more travel was enough for me to agree. The job would be unpaid, but I was already working as a temp, so I wasn't exactly tied up in any fast-track career. Somehow, I'd make it work.

I'd arrived from San Francisco as just another woman living with HIV, but returned with a purpose. I had new friends, renewed vigor and—let's not forget—a new appreciation of Caribbean music! Along with Eric Sawyer—a pioneer in the movement as one of the founders of Act Up and later Housing Works—and Stefan Collins, a community outreach worker from Canada, I was now a North American board member of the Global Network of People Living with HIV and AIDS. I felt that I mattered and knew, with relief, that I was not only not alone, I was in excellent company.

Poster Child

Yokohama

Japan: East Asia
Population: 126.3 million
Capital: Tokyo

The best part about flying west from Japan *to* California is that, with the right flights, you can arrive before you left. The flip side is going to Japan *from* California, the jet lag from crossing the international dateline is so disorienting it takes days to clear the fuzz from your brain.

So as I rode up the escalator at the 10th International AIDS Conference, after my very long journey across the Pacific, I had to do a triple take to be sure I wasn't imagining things. There, at the top of the escalator, I spotted my face. Not just a snapshot, but a larger-than-life three-by-five-foot photograph. A friend stood next to the it, pointed to it, and said, "Hey, Martina! Look at you. You look great!" Only then did I realize he wasn't talking about me, in person, but about the image. In less than a year of international activism, and two years after my diagnosis, I'd somehow become a poster child for AIDS.

about the author

MARTINA CLARK holds a BA in International Relations and an MFA in Creative Writing and Literature. She worked for the United Nations system for two decades and now teaches writing, critical reading, and global politics for College Now at LaGuardia Community College/CUNY. She has been living with HIV for more than half her life—29 years and counting—and survived COVID-19 in 2020.

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