# Foreword

September 1, 2019 By Sean Strub

When the first issue of POZ was published in 1994, all of us involved knew we had created a home in print (and, later, in pixels) for an important community voice that had the potential to change the course of the HIV epidemic and the lives of our readers.

We were proud of the beauty of its art and design, the audacity and ambition of our advocacy journalism and our commitment not only to speak truth to power but also to speak truth—often difficult truths—to one another and to the community.

We sought to model self-empowerment ideals, not just in the pursuit of our right to health care but also in the fight for our right to our sexuality, quality of life and dignity. In those early years especially, POZ gave voice to the different acute emotional responses of people living with HIV (PLHIV) to the protease and post-protease moments, the "Lazarus effect" and survivor's guilt.

We championed the project of rebuilding our lives and movement amid massive personal and generational trauma that persists to this day. We did this while enduring constant heartbreak as people who were central to POZ's early voice and unique identity, including Stephen Gendin, Jeffrey Schaire, Michael Callen, Pedro Zamora, Ilka Tanya Payán, David Feinberg, Kiki Mason, LeRoy Whitfield and so many others, were dying all around us.

The key to POZ's success has always been that our readers trust what they read in POZ more so than information they get from HIV/AIDS organizations, other media, the government, drug companies and even their own families and personal doctors. Speaking and listening to one another is what launched the PLHIV self-empowerment movement in the early '80s, a movement to which POZ is the journalistic heir.

I certainly never thought POZ would reach a quarter-century milestone, let alone that I would be here to witness it. But the occasion provides an opportunity to consider the activist context that led to the creation of the magazine. Many of us most responsible for POZ's legacy, including myself, Stephen Gendin and longtime editor-in-chief Walter Armstrong, were part of ACT UP, whose spectacular street theater, angry demonstrations and sophisticated advocacy are what first come to mind for many when they think of 1980s AIDS activism.

As much as POZ reflected that cultural zeitgeist, it also was—and is—grounded in the PLHIV self-empowerment movement, which predated ACT UP's 1987 founding. In my view, that movement also was more radical and far-reaching, causing a ripple effect in patient self-empowerment that has influenced health care throughout the world. Like POZ's editorial mission, that earlier

advocacy centered on PLHIV, who looked toward one another for support and strength. Both prioritized connecting PLHIV with one another, creating power and change by building community.

In the early 1980s, the existing health care and social service delivery structure didn't serve people with AIDS, especially gay men, injection drug users, people of color, sex workers and poor people. We were left to die. Pioneering people with AIDS organized and wrote The Denver Principles manifesto (which codified ideals promoted by the women's health movement) to assert our right to a central role in the decision-making that so profoundly affected our lives. We created a parallel health care system of AIDS service organizations. There were no approved treatments, so we created buyers clubs to produce our own or to smuggle promising drugs from other countries. Research was slow or nonexistent, so we organized community clinicians to collect data from their patients through a community clinical trials network. With the PWA Newsline, the People With AIDS Coalition in New York pioneered our own media.

ACT UP activism was boisterous and demanding, driven in no small measure by white male privilege and mostly focused externally on the institutions of power, rather than the self-empowerment movement's internal focus on other PLHIV. ACT UP challenged the White House, Congress, the National Institutes of Health, the Food and Drug Administration, the media, pharmaceutical companies and others, successfully overhauling drug development and approval processes and expediting access to effective treatment.

Yet when drug development became the advocacy priority in the late '80s and early '90s, the feminist-inspired self-empowerment grassroots advocacy that preceded ACT UP began to fade from prominence within the AIDS movement. Getting PLHIV together with one another to provide peer support, develop our own strategies and speak with collective voices wasn't a priority for the emerging AIDS Inc. infrastructure.

Support for PLHIV networks declined as effective treatment was introduced in the mid-'90s, when POZ started. The community-created peer-to-peer service delivery system we developed moved incrementally toward the more dominant "benefactor/victim" service delivery paradigm.

By the late '90s, PLHIV began to be seen less as whole people deserving of support and sympathy and instead, through an increasingly racist lens, as an inherently dangerous population that posed a threat to society and needed to be monitored and controlled. Newly diagnosed PLHIV today are more isolated than in the early years, and HIV stigma is worse than ever, something most people who don't have HIV find startling.

Fortunately, PLHIV are responding as we did in those earliest days, organizing with our closest allies to create a flourishing PLHIV self-empowerment movement. New and growing PLHIV networks have brought us together to define our own agendas, to select and hold accountable leadership of our own choosing and to speak with collective voices.

Today, we are fighting far more than a virus. We are carrying forth the mandate issued by Vito Russo in 1990 when he declared "after we kick the shit out of this disease," we're going to "kick the shit out of this system, so that this never happens again." I am proud that POZ continues to be

at our side in this epic struggle upon which so many lives depend.

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