

A photograph of a forest floor with large trees and ferns. The scene is a dense forest with tall, dark tree trunks and a lush green undergrowth of ferns and moss. Sunlight filters through the canopy, creating dappled light on the forest floor.

40+ Years of HIV:

What's Changed, What Hasn't, What Shouldn't, What Must

Rebecca Denison

Writer / Activist

Who am I?





**“You’ll be fine” I told her.
“I’ll go with you”**

“AIDS is a
disaster!
Women
die
faster!”





Something about all of us in the struggle together filled me with a courage I hadn't felt before.

The Denver Principles - 1983

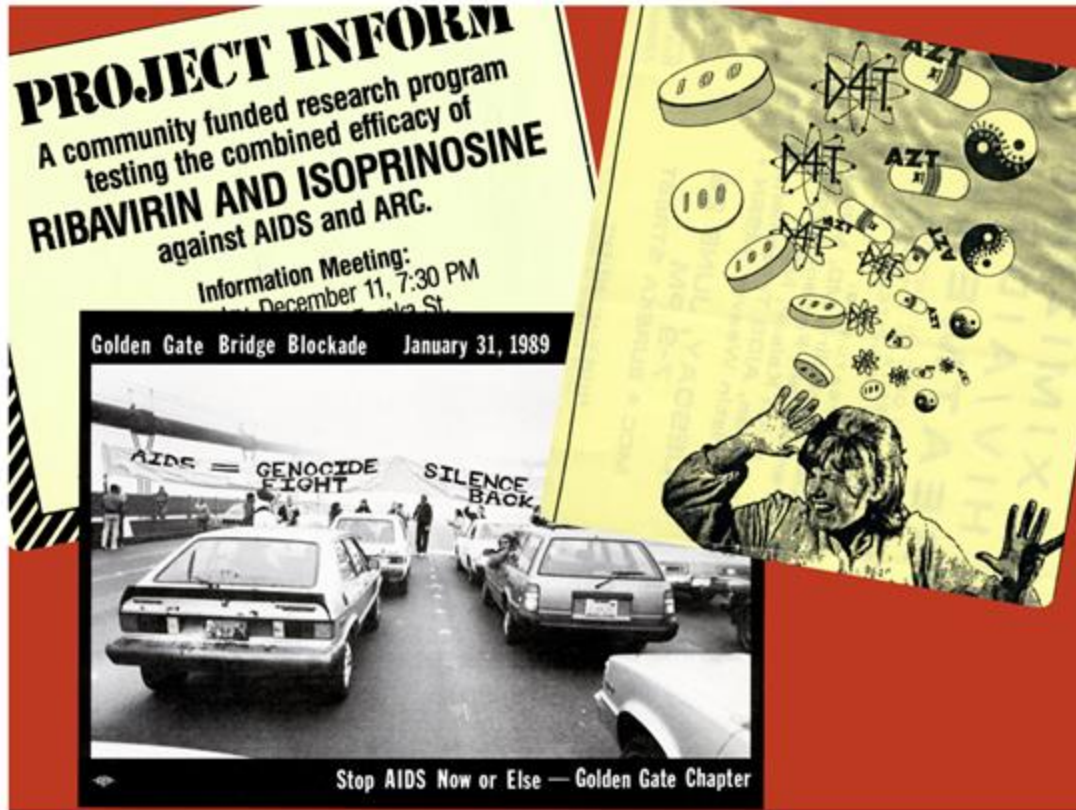
“We condemn attempts to label us as ‘victims,’ a term which implies defeat, and we are only occasionally ‘patients,’ a term which implies passivity, helplessness, and dependence upon the care of others. We are “People With AIDS.”

GIPA: Greater Involvement
of People Living with AIDS

MIPA: Meaningful Involvement
of People Living with AIDS

“Nothing about us without us!”

AIDS Treatment Activism: A Bay Area Story



Top left: Project Inform town meeting flyer, ca. 1990; San Francisco LGBT Groups Ephemera Collection (SUB EPH), folder "Project Inform," GLBT Historical Society.
 Top right: ACT UP flyer, ca. 1990; San Francisco LGBT Groups Ephemera Collection (SUB EPH), folder "ACT UP San Francisco," GLBT Historical Society.
 Bottom: Stop AIDS Now or Else postcard with photograph of the 1989 Golden Gate Bridge blockade, ca. 1989; photograph by Rick Gerharter, San Francisco LGBT Groups Ephemera Collection (SUB EPH), folder "Stop AIDS Now or Else," GLBT Historical Society.

AIDS Treatment Activism: A Bay Area Story

By Brenda Lein

In the face of daily tragedy, the Bay Area's AIDS treatment activists of the 1980s and 1990s undertook their advocacy with

ACT UP

**ACT UP
Golden Gate
Research**

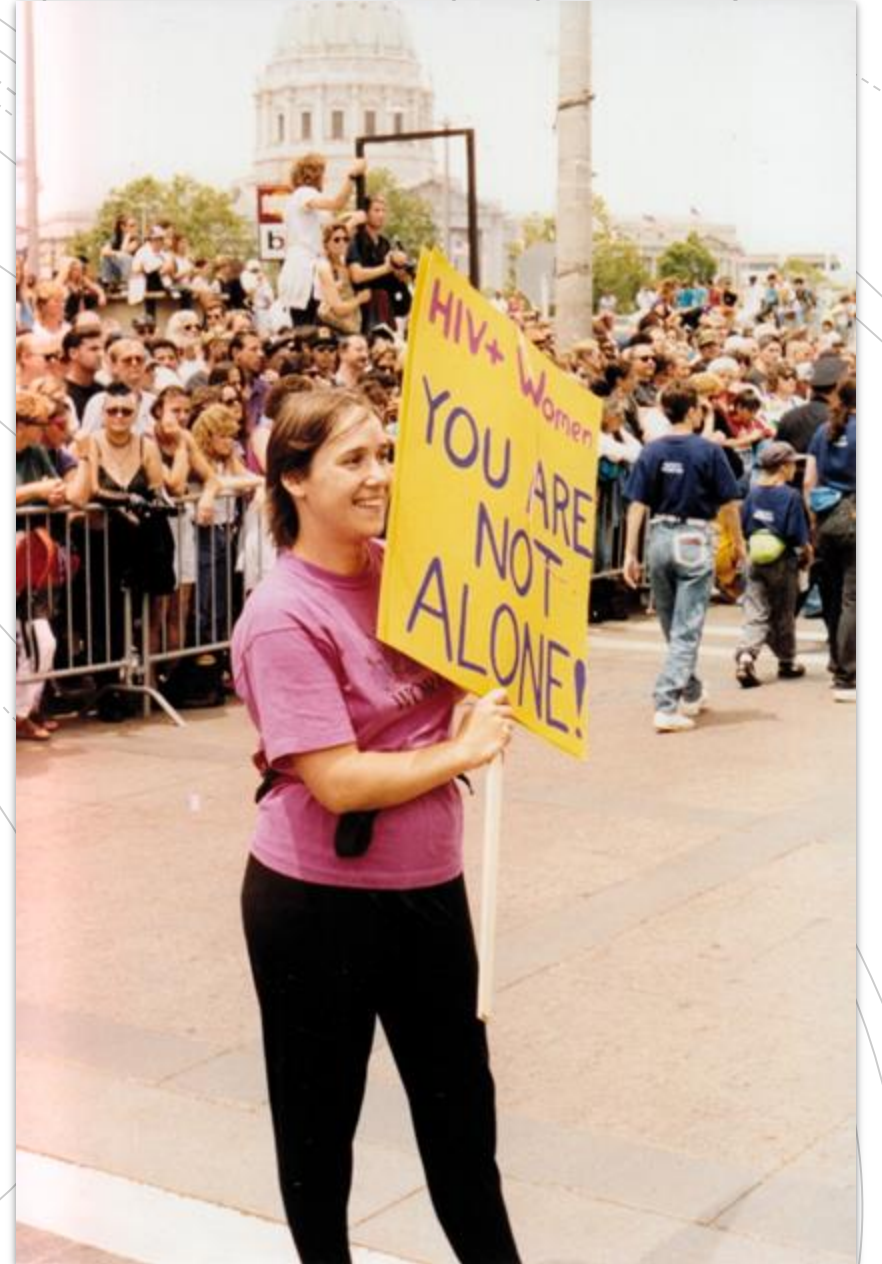
**ACT UP
San Francisco
Social Justice**

We needed both.



Our motto was:

“You are not alone”



Number 1

WORLD*

May 1, 1991

*Women Organized to Respond to Life-threatening Diseases

A Bay Area newsletter by, for and about women facing HIV disease

Welcome to WORLD, a Bay Area newsletter by, for and about women living with HIV. This is our first issue.

If you are a woman living with HIV or AIDS, then this newsletter is for you. Women living with HIV and AIDS represent every race, class, age, and sexual orientation. Regardless of how we were infected, we deserve access to services, and access to the information we need to make decisions in our lives. Yet, it is difficult for us to find each other, and many of us feel isolated, scared and alone.

We hope WORLD can help us to communicate with each other, to share information and to provide support to all women facing this disease.

Please get involved! Let us know how WORLD can help you get the information you need to live better and longer.

Testimonial

My name is Alba. I am a woman, a Latina, a mother and a grandmother. I had to leave my home country in Latin America to escape the political turmoil there. Now I have lived in this country for many years.

would kill himself. In the end, he abandoned me. Who knows how many women he has infected since then.

When I first found out, I felt so terribly sad. It was like I became another person. First I had to

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Si desea recibir esta revista en español, llámenos por favor.
If you want to receive WORLD in Spanish, please call.

ICW Global



**International Community of
Women Living With HIV/AIDS**

Founded in Amsterdam in 1992

***Women Organized to Respond to Life-threatening Diseases**

A newsletter by, for and about women facing HIV disease

Women graduate from WORLD's HIV University

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March 16, 1996, 27 women, HIV/AIDS, graduates of loving family and WORLD's HIV University in San Francisco in a beautiful chapel in the Chapel of St. Ignace and volunteered to share a celebration with the graduating students together to learn about HIV, to learn about health care for them-

selves and their loved ones. It was HIVU's second graduation. (The first group of women to organize HIVU graduated last year, in April 1995.)

The graduation was the culmination of many months of hard work (and play) together. Students and volunteers met in November 1995 to organize the two classes: one Monday evenings and one Friday mornings. Two volunteer interns, Kate Wadsworth and Sarah Moulding, social-work students from Smith College, each agreed to coordi-

nate a class. Both classes chose their own curriculum, meeting times and instructors. Each class also chose a Dean of Instructors, a Dean of Students and a Dean of Nutrition. Students included HIV positive women, women with AIDS, ser-

Students from the Spring 1996 graduating class of HIVU, March 16, 1996 (Note: not all graduates were present or photographed.)

Photo by Scott Braley

Antiviral immunity in HIV-1 infected long-term non-progressors (LTNPs)

Giuseppe Pantaleo, Mauro Vaccarezza, Cecilia Graziosi, Oren J. Cohen and Anthony S. Fauci



Now that the acquired immunodeficiency syndrome (AIDS) epidemic is well into its second decade, it has become evident that a small percentage (approximately 5%) of HIV-infected individuals do not experience progression of HIV disease even after several years of being infected with HIV. These individuals have been designated as long-term non-progressors (LTNPs). From a virologic standpoint, these LTNPs have low viral burden in mononuclear cells, but persistent virus replication as manifested by chronic and generally low levels of plasma viremia. From an immunologic standpoint, immune functions including CD8⁺ T-cell and CD4⁺ T-cell-mediated functions are preserved. In addition, they show a vigorous humoral immune response. More importantly, lymphoid tissue structure and function are preserved in LTNPs. Despite persistent low-level virus replication and chronic stimulation of the immune system, immune activation is qualitatively and quantitatively different in LTNPs compared to that observed in HIV-infected individuals whose HIV disease has progressed.

Key words: immune response / immune activation / viral load / lymphoid tissue / long-term non-progressors

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THE TYPICAL CLINICAL COURSE of human immunodeficiency virus (HIV) infection in the majority (80% to 90%) of HIV-infected individuals can be divided into three major phases¹: (1) primary infection; (2) clinical latency; and (3) clinically apparent disease. The phase of primary infection is characterized by a mononucleosis-like clinical syndrome of variable severity in 50% to 70% of individuals^{2,3}; symptoms may include fever, lethargy, sore-throat, malaise, maculopapular rash, lymphadenopathy, arthralgias, myalgias, headaches, retro-orbital pain, photophobia,

and rarely meningitis. The phase of primary infection is followed generally by a long period of clinical latency that usually lasts for several years (median 8 to 10 years)^{4,5}. HIV disease is, however, active and progressive even during the clinically latent period as indicated by the recent observations of high and persistent levels of virus replication in lymphoid tissue throughout the entire course of infection.⁶ Persistent virus replication in lymphoid tissue and the inexorable deterioration of immune function results in progression to the phase of clinically apparent disease or AIDS. This phase is characterized by severe constitutional symptoms, and by opportunistic infections and neoplasms. HIV-infected individuals who experience this clinical course are designated as 'typical progressors'.

A minor percentage (5% to 10%) of HIV-infected individuals experience an unusually rapid course of infection with progression to AIDS occurring within 2 to 3 years from seroconversion.^{8,9} These HIV-infected individuals have been designated as 'rapid progressors'. Resolution of the symptoms associated with primary infection may be incomplete in rapid progressors, and constitutional symptoms of variable severity may persist even after the initial down-regulation of viremia that characteristically follows acute primary HIV infection. The period of clinical latency may be very short or even absent in these rapid progressors.

In addition to typical progressors and rapid progressors, it has now become clear, well into the second decade of the AIDS epidemic, that a small fraction of HIV-infected individuals do not experience progression of HIV disease; these individuals have been designated as long-term non-progressors (LTNPs).^{8,6,11-17} On the basis of retrospective analyses of the clinical course in HIV-infected individuals who had been enrolled in large cohorts and who have been prospectively studied for at least 7 years, LTNPs represent approximately 5% of HIV-infected individuals.

From the Laboratory of Immunoregulation, National Institute of Allergy and Infectious Diseases, National Institutes of Health, Bethesda, MD 20892, USA.
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1044-5773/96/020131 + 08 \$18.00/0

I begged Dr. Fauci to cut me open





March 1996: My daughters, participants in a phase 1 NVP study, born at San Francisco General Hospital and remain HIV-negative thanks to many of you.



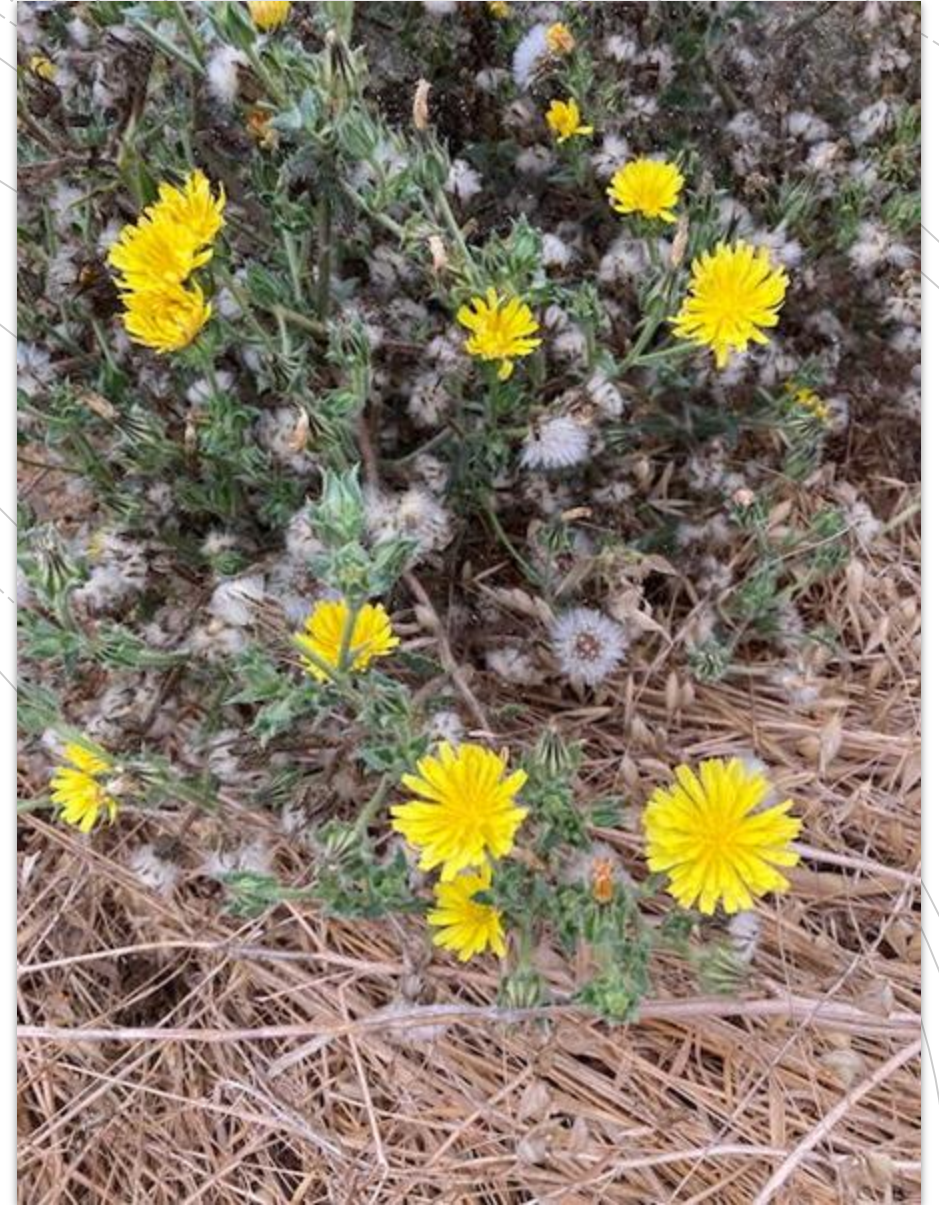
2001: An article in posted on the wall of a rural clinic in Uganda. Photo courtesy of Art Atman.

Some would
survive, but not
without scars



Lifetime Survivors

Those who acquired HIV at or shortly after birth.

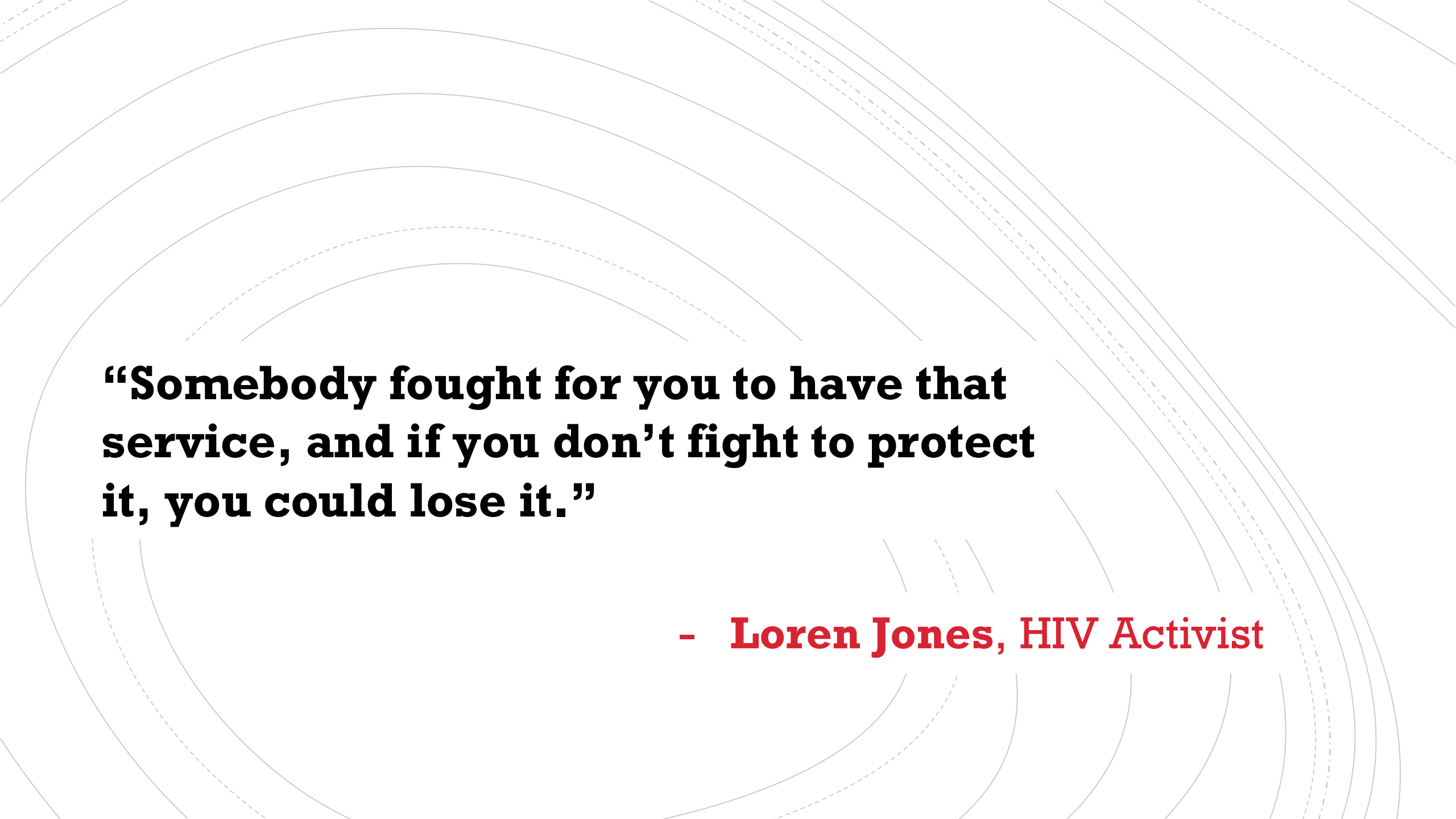


Then and Now — What's Changed

1990	2025
“We’re all going to die.”	Long-term survivors & Lifetime survivors
High dose AZT monotherapy every 4 hours	ART
Surrogate markers: illness or death	Surrogate markers: care & treatment cascade
25% risk of vertical transmission to infants	<1% risk with access to treatment and care
Breast/chest feeding not recommended	Breast/chest feeding recommended for many
Prevention = condoms	Prevention = PrEP, PEP, condoms, U=U, long-acting injectables
No PEPFAR	Since 2003, 23 million lives saved
Pre-existing conditions = Uninsurable	Affordable Care Act
Limited Health Access for PLHIV	USA: Ryan White Care Act, Medicare, Medicaid
>10 years lag for women to be involved in clinical research	LEN started with women, and pregnant women, with a focus on informed consent.
Abortion legal	Abortion illegal in many states.
“AIDS victims”	person-centered language

What Hasn't Changed

- Stigma, Misinformation, Disinformation
- Social determinants of health fuel inequities - disproportionate impact of HIV on communities of color
- Lack of political will to accelerate access to adequate care and treatment
- Women and other key populations still underrepresented in research
- Key populations under attack
- Community / research partnerships save lives

The background of the slide features a series of concentric, curved lines in shades of gray, creating a sense of depth and movement. The lines are solid and dashed, and they curve from the top left towards the bottom right.

“Somebody fought for you to have that service, and if you don’t fight to protect it, you could lose it.”

- Loren Jones, HIV Activist

What Shouldn't Change

- The US global commitment to ending the HIV epidemic by 2030
- Existing protections for discrimination in employment, housing, and access to medical care
- Programs that promote a healthy society (US examples: ADA, Ryan White Care Act, medicare, medicaid)
- Our existing civil rights (such as the right to same-sex marriage)

What Must Change

- **Stigma**
- **The demonization and criminalization of people most impacted by HIV**
- **All governments and levels of civil society holding themselves and one another accountable to ending the HIV epidemic**

Have you seen the news?

GLOBAL HEALTH

Abandoned in the Middle of Clinical Trials, Because of a Trump Order

The stop-work order on U.S.A.I.D.-funded research has left thousands of people with experimental drugs and devices in their bodies, with no access to monitoring or care.

New York Times, February 6, 2025

Science Magazine, February 5, 2025

'It's tectonic': U.S. foreign aid freeze deals a blow to research around the globe

Dismantling of USAID could disrupt clinical trials and wipe away U.S. "soft power" in developing countries, scientists warn

Emergency Food, TB Tests and H.I.V. Drugs: Vital Health Aid Remains Frozen Despite Court Ruling

GLOBAL HEALTH

As Ebola Spreads in Uganda, Trump Aid Freeze Hinders Effort to Contain It, U.S. Officials Fear

U.S. Terminates Funding for Polio, H.I.V., Malaria and Nutrition Programs Around the World

Exclusive: NIH to terminate hundreds of active research grants

NIH will eliminate many peer review panels and lay off some scientists overseeing them

Studies that touch on LGBT+ health, gender identity and DEI in the biomedical workforce could be terminated, according to documents obtained by *Nature*.



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How Hitler Dismantled a Democracy in 53 Days

He used the constitution to shatter the constitution.

By Timothy W. Ryback

We are on
day 48



Adolf Hitler and his cabinet, January 30, 1933, the day he became Chancellor of Germany. (Everett Collection / Alamy)

Chaos, Confusion, and Cruelty

A Timeline of Cuts, Legal Orders and Chaos at U.S.A.I.D. — NY Times, March 5, 2025

Jan. 20 — President Trump issues an executive order halting foreign aid programs pending a 90-day review.

Jan. 27 — Dozens of U.S.A.I.D. officials are placed on leave.

Jan. 28 — Secretary of State Marco Rubio issues a temporary waiver to allow for lifesaving aid activities to continue.

Feb. 4 — More than a thousand more employees are put on leave, and the agency announces nearly all workers will be on leave soon. Staffers are not allowed to report to the agency's headquarters.

Feb. 6 — The administration notifies agency officials that it will reduce the agency's global work force to just a few hundred from more than 10,000.

Feb. 8 — A federal judge temporarily halts the layoffs, ruling that some of the agency employees on leave must be reinstated.

Feb. 10-11 — Aid recipients and other nonprofits file two lawsuits to challenge the aid freeze.

Feb. 12 — Agency employees say that lifesaving aid remains halted despite the waiver, because of obstacles such as the shutdown of the agency's payment system.

Feb. 13 — A second federal judge issues a temporary order prohibiting Trump officials from ending or pausing payments for contracts in place before Jan. 20.

Feb. 19 — Aid groups report that the administration is not abiding by the order and file an emergency motion to enforce it.

Feb. 21 — The federal judge in the lawsuit to halt firings says that the Trump administration can proceed with plans for massive layoffs.

Feb. 23 — An additional 2,000 agency employees are fired, and thousands more are put on leave.

Feb. 25 — The federal judge in the lawsuit to reinstate foreign aid orders the administration to pay nearly \$2 billion in already completed aid work, setting a deadline for midnight the next day.

Feb. 26 — The administration asks the Supreme Court to intervene, and Chief Justice John Roberts cancels the lower court's deadline. Separately, officials reveal in court documents that they have completed their review of all foreign aid and will terminate 6,000 U.S.A.I.D. awards, about 90 percent of the agency's work.

March 2 — Internal agency memos leak detailing the human costs of cuts to foreign aid, and blaming the administration and agency leadership for blocking lifesaving aid programs. The whistleblower, an acting assistant administrator, is put on leave.

March 5 — The Supreme Court rejects Trump's request to freeze nearly \$2 billion in foreign aid payments for already completed work through U.S.A.I.D. and the State Department.

The Cruelty is Intentional

Russell Vought: Trump appointee who wants federal workers to be 'in trauma'

The Christian nationalist head of the office of management and budget was central to the Project 2025 blueprint



📹 Russell Vought testifies before the US Senate committee on the budget on his nomination on Capitol Hill in Washington DC on 22 January. Photograph: Rex/Shutterstock

If federal employees are feeling traumatized right now, Russell Vought, the **new head of the office of management and budget (OMB)**, probably has something to do with it.

"We want the bureaucrats to be traumatically affected," Vought said in a video revealed by ProPublica and the research group Documented in October. "When they wake up in the morning, we want them to not want to go to work, because they are increasingly viewed as the villains. We want their funding to be shut down ... We want to put them in trauma."

"We want the bureaucrats to be **traumatically affected**... When they wake up in the morning, we want them to not want to go to work, because they are increasingly viewed as the villains. We want their funding to be shut down... We want to put them in trauma."

— Russell Vought, Project 2025 author and OMB director

These are people's lives they're playing with...

“Majorly, I can say all the adolescents right now are in a panic. Same to me as well, I’m in a panic, cause we are about to have some shortages of drugs, and unfortunately maybe the youth friendly center will be closed because it was also being supported by USAID.

So I don’t know what we are going to do because our major challenge will be going to take our drugs from the main pharmacy where everybody takes their drugs and there’s a lot of discrimination there, accidental disclosures can occur. So it is a big challenge.

I’m also a bit scared going to take my medications from the main pharmacy and we are not even guaranteed that the drugs will be there. I just heard that the drugs that are remaining can last for 6 months so we don’t know after that 6 months what’s going to happen.

So people are really in a great panic, and then there’s a lot of discrimination in social media. There’s comments that can even make you cry. So many people are in a panic, many people they think are just waiting for death. But I keep telling them that god will open another way.”

- Young Person Living with HIV in East Africa

The Impact of Dismantling USAID

Due to the dismantling of USAID, Nicholas Enrich, now former USAID Acting Administrator for Global Health, estimated in an internal memo that globally each year we will see:

18 million

more cases of malaria

166,000

more malaria deaths

200,000

Children paralyzed by
polio

1 million

Children untreated for
acute malnutrition

28,000

New cases of infectious
diseases like Ebola and
Marburg






















28-32%

Increase in global TB (&
MDR TB) incidence

All of these things kill people living with HIV faster and on greater scale.

And while we might not see people dying of HIV-related illness immediately, but they will.

Trials & Projects Halted by USAID Funding Suspension

Project	Product(s)	Type	Country(ries)	# of participants
	 TAF/EVG Fast-dissolving insert	MATRIX-001 Phase 1 safety and acceptability	Kenya, South Africa, USA	60
	 One month dapivirine vaginal film	MATRIX-002 Safety, acceptability, usability of placebo	Kenya, South Africa, USA, Zimbabwe	100
	 Non-ARV nonhormonal contraceptive multipurpose vaginal ring	MATRIX-003 Safety, acceptability, usability of placebo	South Africa, USA, Zimbabwe	100
	 Injectable CAB, Dapivirine Vaginal Ring, Oral TDF/FTC	Cohort study of safety in mothers and babies exposed to ARV-based prevention	Kenya, Lesotho, Zimbabwe	500-800
	 One-month dapivirine vaginal film plus levonorgestrel (LNG)	Preclinical study	USA	Preclinical
	 BG505 GT1.1 and 426c.Mod. Core-C4b	B-001 Phase 1 clinical trial	Kenya, South Africa, Uganda	48
	 Polyvalent HIV-SET saMRNA vaccine clinical program	Pre-clinical and clinical trials	Multiple African countries	Exploratory
	 CAP 256 based mRNA vaccine candidates incl Africa-based mRNA manufacturing	Development program	Multiple African countries	Exploratory
	 Multiple founder virus-based vaccines	Exploratory program	Multiple African countries	Exploratory
	 Tech-transfer activities in Uganda with SOSIP trimers	Technology transfer	Uganda	Exploratory
	 Mosaic Trimers: MOS1SIP, MOS2SIP, M3SIP8 and MPLA	Vaccine	Rwanda, Zambia	40
	 Multisite Adolescent Girls and Young Women study	MAGY Epidemiological study	Uganda, Zambia, Kenya, South Africa	1,210
	 Injectable CAB, Dapivirine Vaginal Ring, Oral TDF/FTC	CATALYST Implementation Science Study	Kenya, Lesotho, South Africa, Uganda, Zimbabwe	7,500
	 Injectable CAB, Dapivirine Vaginal Ring	Policy and programmatic support, including user-centered research and technical assistance	Botswana, Eswatini, Kenya, Lesotho, Namibia, South Africa, Uganda, Zambia, Zimbabwe	Community-based
	 Dapivirine Vaginal Ring, Oral TDF/FTC	Increasing PrEP Options for Women in Eswatini	Eswatini	400
	 PrEP, vaccines and multipurpose technologies	Research translation and preparedness, policy support and advocacy to support prevention research	Kenya, Lesotho, Malawi, Nigeria, South Africa, Uganda, Zambia, Zimbabwe	Community-based

Estimated deaths associated with the freezes and terminations of PEPFAR programs as of 1pm PCT, March 9th, 2025:

19,257 Adult Deaths
Incrementing every 3.3 minutes

2,049 Infant Deaths
Incrementing every 31 minutes

They're coming for the rest of us next.

Kaiser Permanente Mail Order Pharmacy

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9am - 6pm Sunday (closed holidays)

ORDER: [REDACTED] 2/12/25 10:48 AM

Name: Rebecca S Denison

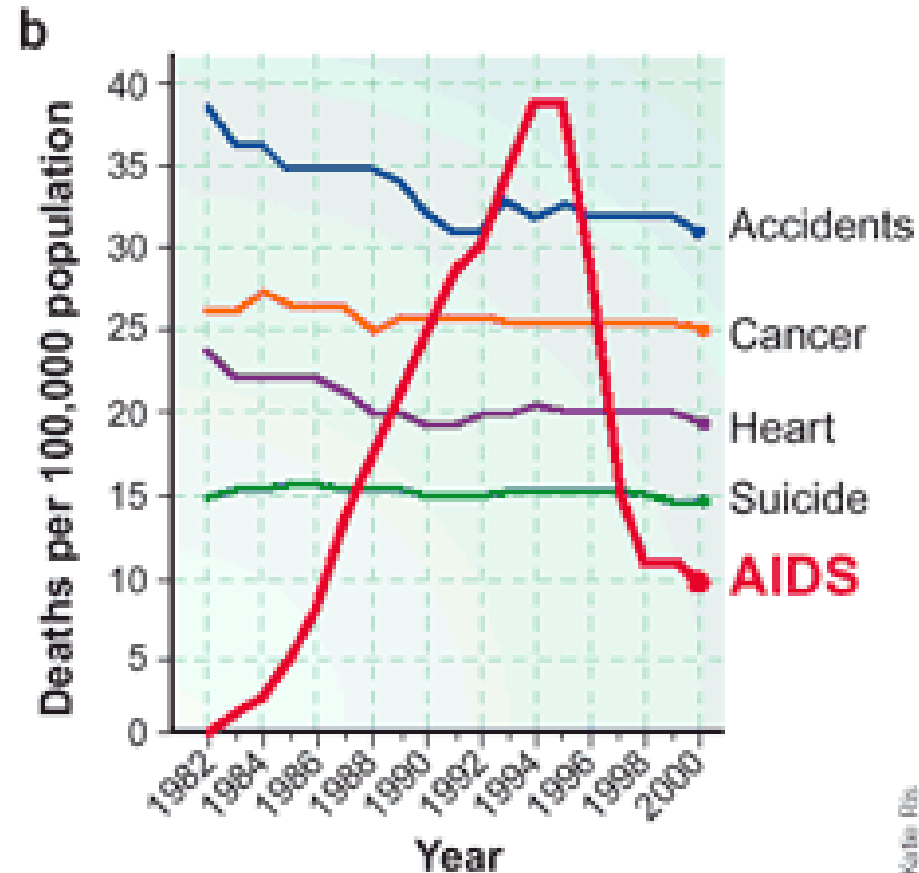
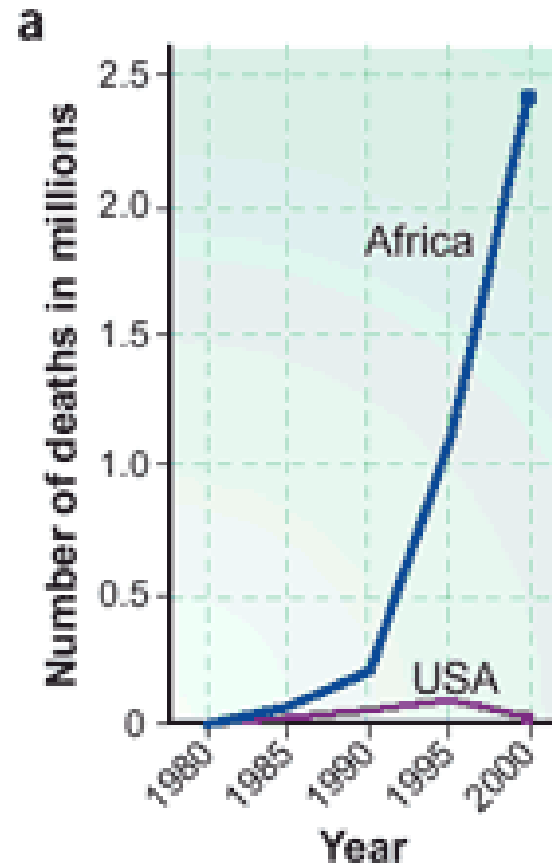
Medical Record Number: ***** [REDACTED] 1038

RX Number	Med Qty	Medication Name	NDC Number	KP Retail		Your Price
[REDACTED]	100	DILTIAZEM CD 120 MG CAPSULE,	[REDACTED]	\$24.43	F	\$0.00
[REDACTED]	90	BIKTARVY 50 MG-200 MG-25 MG	[REDACTED]	\$12,285.2	F	\$0.00
				2 [REDACTED]		

Look where we were 30 years ago.
We can't go back.

Medscape®

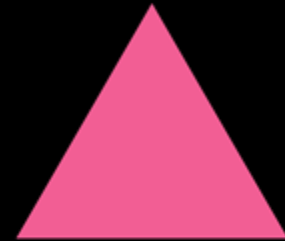
www.medscape.com



Kate Fitz

Source: Nat Med © 2003 Nature Publishing Group

**Your silence will
not protect you.**
— Audre Lorde



SILENCE=DEATH

NATIONAL

US foreign aid cuts leave a funding gap that private donors are unlikely to fill

by: THALIA BEATY, Associated Press
Posted: Mar 7, 2025 / 07:32 AM CST
Updated: Mar 7, 2025 / 07:32 AM CST



FILE - Demonstrators protest against cuts to American foreign aid spending, including USAID and the PEPFAR program to combat HIV/AIDS, at the Cannon House Office Building on Capitol Hill, Feb. 26, 2025, in Washington. (AP Photo/Mark Schiefelbein, file)

[Read Less](#)

We need each other.



On Thursday, February 6th, Housing Works held a demonstration outside the State Department and blocked an intersection. Photo by [SWinksy](#)



March 7 2025, Krista Heitzman and Olivia Ford, members of The Well Project, join a protest in defense of science, diversity, equity, inclusion, and accessibility. Photo courtesy of Olivia Ford.

What You Can Do

Time



- **Come to our Save Science protest tomorrow**
 - 6 PM in Yerba Buena Gardens
- **Join other protests**
- **Volunteer with mutual aid groups or community service efforts**
- **Call your congressional representatives**
(The “5 Calls” app makes this easy)

What you can do

Resources

- Donate money
- Use your sphere(s) of influence (Inside/Outside strategy)
- Share your professional connections with those trying to organize
- Offer your home as an organizing space
- Bring food / water / signs to protests to share
- If in a position of power, privilege, and influence, share it with others



**What you
can do**
Expertise

- **Share your story**
- **Mentor others**
- **Educate the public about why your work matters**
- **Sign our sign-on letter**
- **Write an OpEd, or be a source**
- **Join Indivisible or other groups that let you share your expertise beyond your bubble**
- **Engage with your local school boards and advocate that they teach the science foundational to health literacy and protect all students (including trans kids).**



**What you
can do**
Life

- **Promote diversity, equity, and inclusion in your own work and life (it doesn't have to be your job title)**
- **Center community voices in your work**
- **Tell your patients that they matter, they are loved, and that they can have a long and healthy life**
- **Challenge your own stereotypes, and engage with compassion, dignity, and respect.**
- **Defend human rights of all people, not just subsets**
- **Embrace joy wherever you find it**

**Fear
is a reaction.**

**Courage
is a decision.**

