

AIDS
ACTIVISTS
SHOWED US
THAT EVEN UNDER
THE MOST

BACK TO **BASICS**

HIV/AIDS ADVOCACY AS A MODEL FOR CATALYZING CHANGE

DIFFICULT
CIRCUMSTANCES
IT IS POSSIBLE TO
ACHIEVE
CHANGE

CHANGE
ACHIEVE

THE MOVEMENT

Change in the medical research paradigm

...to create change, the focused voices of advocates must be heard through the din.

KEY ACCOMPLISHMENTS

Specific medical research successes of the HIV/AIDS movement

“PARALLEL TRACK” PROGRAM

Unsatisfied with waiting for HIV drugs to be released, AIDS activists collaborated in 1992 with the head of NIAID to create a system of their own: a “Parallel Track” program.

Accelerated Approval
implemented

FDA establishes Treatment Investigational New Drugs (IND), which accelerates drug approval by two to three years

1987

NIAID CREATES AIDS CLINICAL TRIALS GROUP (ACTG)

NIH Revitalization Act

Ryan White CARE Act is enacted by Congress

WHAT ARE THE ELEMENTS OF THE MODEL?

- 1 ATTENTION**
- 2 KNOWLEDGE & SOLUTIONS**
- 3 COMMUNITY**
- 4 ACCOUNTABILITY**
- 5 LEADERSHIP**

ATTENTION

Creating the political will to transform policies



“The political theater was important because we needed to use theater to communicate directly with the American people, and that would result in connecting through the American people to Congress and to the Administration.”

MARK HARRINGTON became an activist with ACT UP in 1988. He is also a co-founder and current executive director of the Treatment Action Group.



**“You have to be able to inspire people
at a level of civil disobedience”**

JAMES CURRAN, M.D., is the current dean and a professor of epidemiology at the Rollins School of Public Health at Emory University in Atlanta, Ga. He is also co-director of the Emory Center for AIDS Research. In the 1980s, Curran coordinated the task force on acquired immune deficiency at the CDC and then led the HIV/AIDS Division.

“We were fighting for our lives, for our friends who were there with us who were dying like flies all around us, so we were motivated.”

LARRY KRAMER, FOUNDER OF ACT UP



NYTIMES PHOTO: JOHN SOTOMAYOR/THE NEW YORK TIMES/REDUX

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KNOWLEDGE & SOLUTIONS

Shaping the discussion and getting answers



“It wasn’t that they were simply advocates. It was that they really were contributors and that they really brought a very sophisticated understanding.”

MARGARET A. HAMBURG, M.D., is the current commissioner of the FDA, a position she has held since 2009. From 1986 to 1988, Hamburg served in the U.S. Office of Disease Prevention and Health Promotion, and from 1989 to 1990 she was assistant director of NIAID at NIH.



“[I was] enormously struck and impressed that the activists at the table had as much scientific sophistication as the other members.”

DAVID KESSLER, M.D., was commissioner of the FDA from 1990 to 1998. He is currently a professor of pediatrics, epidemiology, and biostatistics at the School of Medicine, University of California, San Francisco.

“It basically exploded all over the world, and it is less around scientific, technical knowledge than knowing intellectual property frameworks and legal things about how generic drugs are approved.”

GREGG GONSALVES, co-founder of the Treatment Action Group and International Treatment Preparedness Coalition.



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COMMUNITY

Working together for the same cause



“ACT UP started in 1987 when a critical mass of people with AIDS realized their bodies were not just the site of a disease. It had also become the site of a social struggle.”

JIM EIGO is a writer and AIDS activist. He began working with ACT UP shortly after the group was founded in 1987.



“People who are young feel invincible. People who are young feel like they shouldn't be dying. They feel entitled to life and it's easier for them to stand up and say, ‘This is wrong.’ ”

BRENDA LEIN is a board member of the Foundation for AIDS and Immune Research. A member of ACT UP San Francisco, she worked with Martin DeLaney, AIDS activist and founder of Project Inform.

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ACCOUNTABILITY

Implementing an 'inside and outside' strategy



“There were the real nerdy geeks who just salivated over becoming experts on the most obscure minutia of immunology and virology. And then there were a few big picture people like me.”


PETER STALEY joined ACT UP in New York shortly after its founding in 1987, and headed its fundraising committee for three years. In 1988, he left his Wall Street job to become a full-time AIDS activist, joining ACT UP's Treatment & Data Committee.



“What I think was unique about them was that combination of theater to get your attention and their phenomenal analysis of things that actually make logical sense.”

ANTHONY S. FAUCI, M.D., Director, NIAID at NIH

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- 

LEADERSHIP

Inspiring and motivating people to act on a shared vision



“Activist leaders, regular people who had leadership forced upon them, took their skills and passion and built a movement.”

MAUREEN BYRNES was staff director of the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies for Senator Lowell Weicker from 1986 to 1988, and she served as executive director of the National Commission on AIDS from 1989 to 1991.

CHANGE THE SYSTEM

The tens of thousands of Americans who had HIV/AIDS became a movement that put a human face on the epidemic. This movement helped to provide cover, ammunition, and purpose to leaders in critical positions so they could stand up and change the system and be true leaders.

DO THE RIGHT THING

What the HIV/AIDS movement shows us is that you need strong leadership on the outside to stand up and demand that government leaders do the right thing so that leaders on the inside have a greater likelihood of success.

TODAY'S REALITY

Understanding what can and cannot be replicated

What they left behind as a legacy is a model of advocacy that, when taken as a whole and adapted to today's environment, can be as powerful and effective today as it was in the mid-1980s and early 1990s.

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