

History of CABs and HIV Activism

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IMPAACT

International Maternal Pediatric Adolescent
AIDS Clinical Trials Network

ANNUAL MEETING

2024

Key Messages & Agenda

- Key Messages
 - Community engagement is central to solid research
 - CABs are a valuable means of community engagement
- Agenda
 - Discuss the history of CABs
 - Discuss the role/impact of activism in HIV
 - Future vision for CABs and activism

Exercise #1

Who is the person or what is the key event that led to your involvement with HIV research?



HANC

Founded in 2004, the mission of the Office of HIV/AIDS Network Coordination is to support the science and operations of the NIAID HIV/AIDS Clinical Trials Networks by increasing efficiency and resource-sharing through coordination of critical activities across networks and with other research and advocacy partners.



Advancing Clinical
Therapeutics Globally
for HIV/AIDS and
Other Infections



HPTN
HIV Prevention
Trials Network

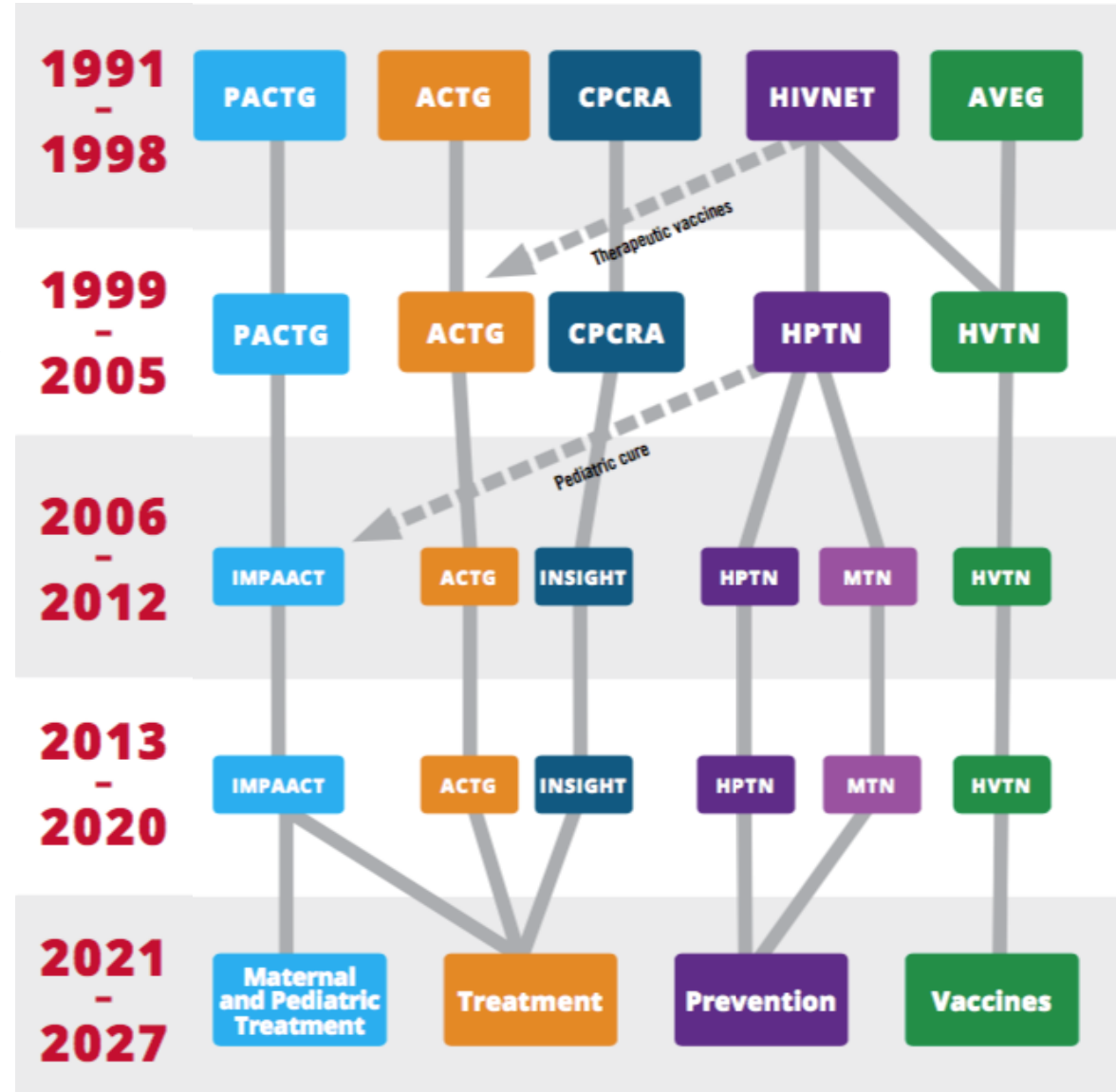


IMPAACT
International Maternal Pediatric Adolescent
AIDS Clinical Trials Network




HIV VACCINE
T R I A L S N E T W O R K

HANC & the NIH-funded HIV Research Networks



Original image from AVAC



Community is the backbone of
biomedical research and must
always be centered.

**"Nothing about us without
us"**

Slido Word Cloud

- What comes to mind when you hear the word “community”?

slido

Please download and install the Slido app on all computers you use



What comes to mind when you hear the word community?

① Start presenting to display the poll results on this slide.



Community

Slido Word Cloud

- What comes to mind when you hear the word “activist”?

slido

Please download and install the Slido app on all computers you use



What comes to mind when you hear the word activist?

① Start presenting to display the poll results on this slide.

Understanding AIDS

A Message From The Surgeon General

This brochure has been sent to you by the Government of the United States. In preparing it, we have consulted with the top health experts in the country.

I feel it is important that you have the best information now available for fighting the AIDS virus, a health problem that the President has called "Public Enemy Number One."

Stopping AIDS is up to you, your family and your loved ones.

Some of the issues involved in this brochure may not be things you are used to discussing openly. I can easily understand that. But now you must discuss them. We all must know about AIDS. Read this brochure and talk about it with those you love. Get involved. Many schools, churches, synagogues, and community groups offer AIDS education activities.

I encourage you to practice responsible behavior based on understanding and strong personal values. This is what you can do to stop AIDS.



C. Everett Koop
C. Everett Koop, M.D., Sc.D.
Surgeon General

Este folleto sobre el SIDA se publica en Español.
Para solicitar una copia, llame al 1-800-344-SIDA.



Understanding AIDS

What Do You Really Know About AIDS?

Are You At Risk?

AIDS And Sex

Why No One Has Gotten AIDS From Mosquitoes



OTIS R. BOWEN, M.D.,
Secretary
U.S. Department of Health and Human Services



ROBERT E. WINDOM, M.D.,
Assistant Secretary for Health
U.S. Department of Health and Human Services

This brochure has been prepared by the Surgeon General and the Centers for Disease Control, U.S. Public Health Service. The Centers for Disease Control is the government agency responsible for the prevention and control of diseases, including AIDS, in the United States.

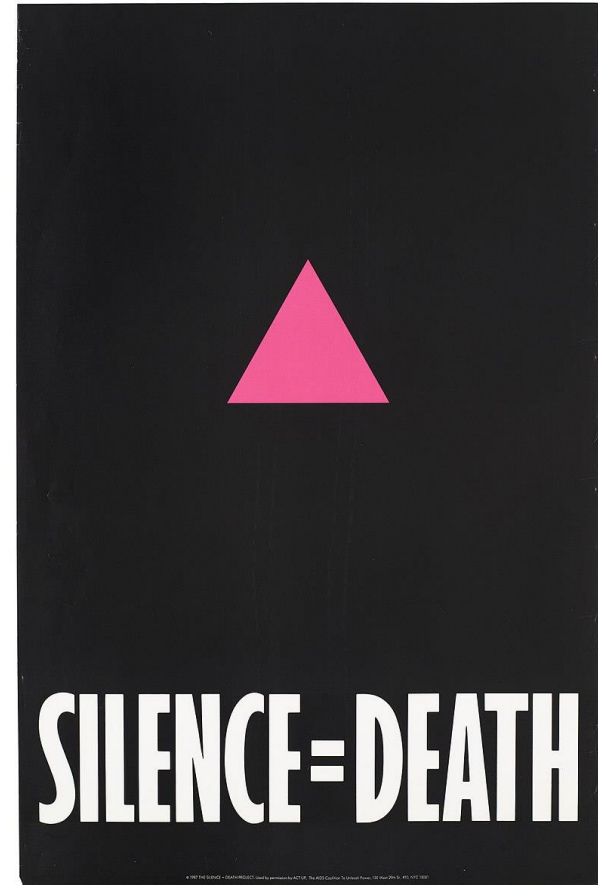
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History of ACT-UP

- ACT-UP was formed on March 12, 1987 at the Lesbian and Gay Community Services Center in New York City
- Larry Kramer spoke, felt the Gay Men's Health Crisis (GMHC) wasn't doing enough politically and was joined by others who wanted a new organization devoted to political action

Selected Highlights:

- 1988 – shut down the Food & Drug Administration (FDA)
- 1989 – infiltrated the New York Stock Exchange protesting the high price of AZT (\$10,000 per person/year). Afterwards, days later Burroughs Wellcome lowered the price to \$6,400 per person/year.
- 1990 – stormed the NIH; demonstration was directed at Dr. Fauci for the slow pace of research and treatment options.



Other HIV Advocacy Groups

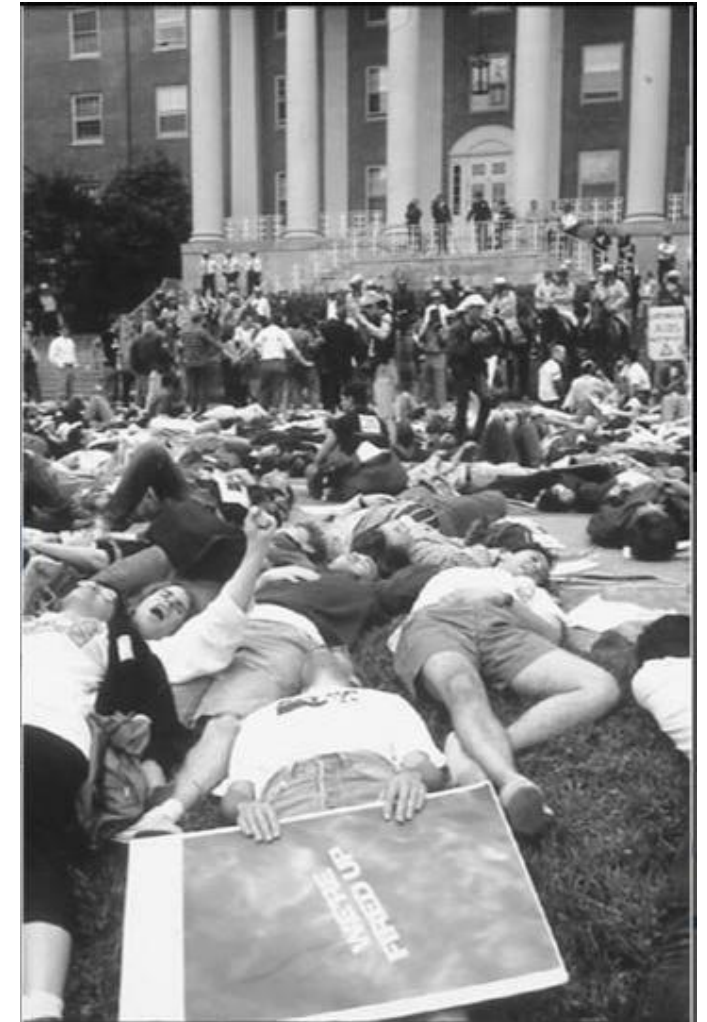
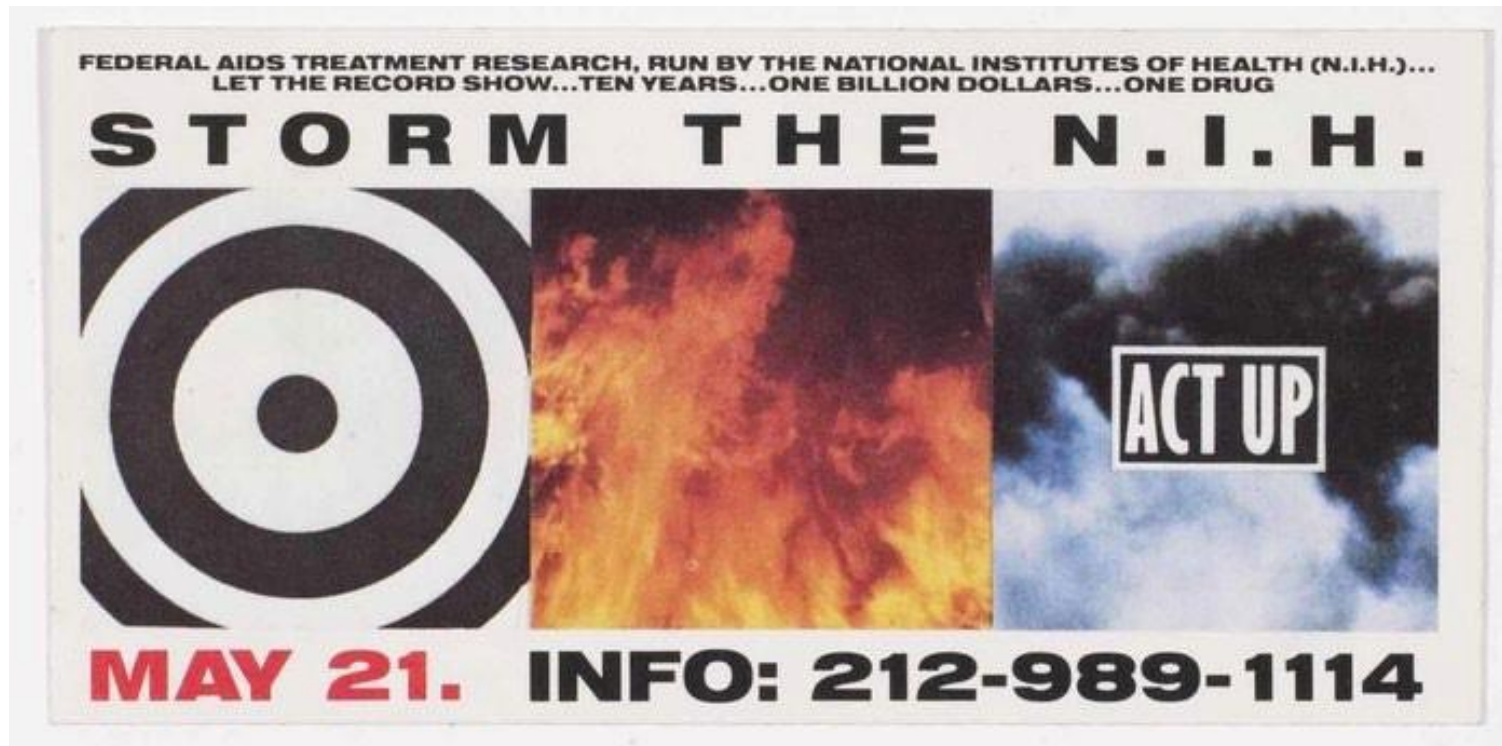
U.S. organizations formed to address the needs of specific communities and areas of research, including Positive Women's Network, SisterLove, Black AIDS Institute, Latino Commission on AIDS and many others.

- **NMAC (originally National Minority AIDS Council)**
 - Started in 1989 by leaders of HIV organizations serving communities of color to build awareness of the impact of HIV in these communities; later expanded mission to build leadership within communities of color to address the challenges of HIV/AIDS
- **AVAC (originally AIDS Vaccine Advocacy Coalition)**
 - Established in 1995 by 9 HIV treatment activists. Original focus on expediting research and development of preventive HIV vaccines, then expanded its focus to include other HIV prevention modalities.
- **TAG (Treatment Action Group)**
 - Founded to address the need for increased funding for HIV treatment research and ensure PLHIV and others with greater chances of acquiring it had access to and information about treatments that could save their lives

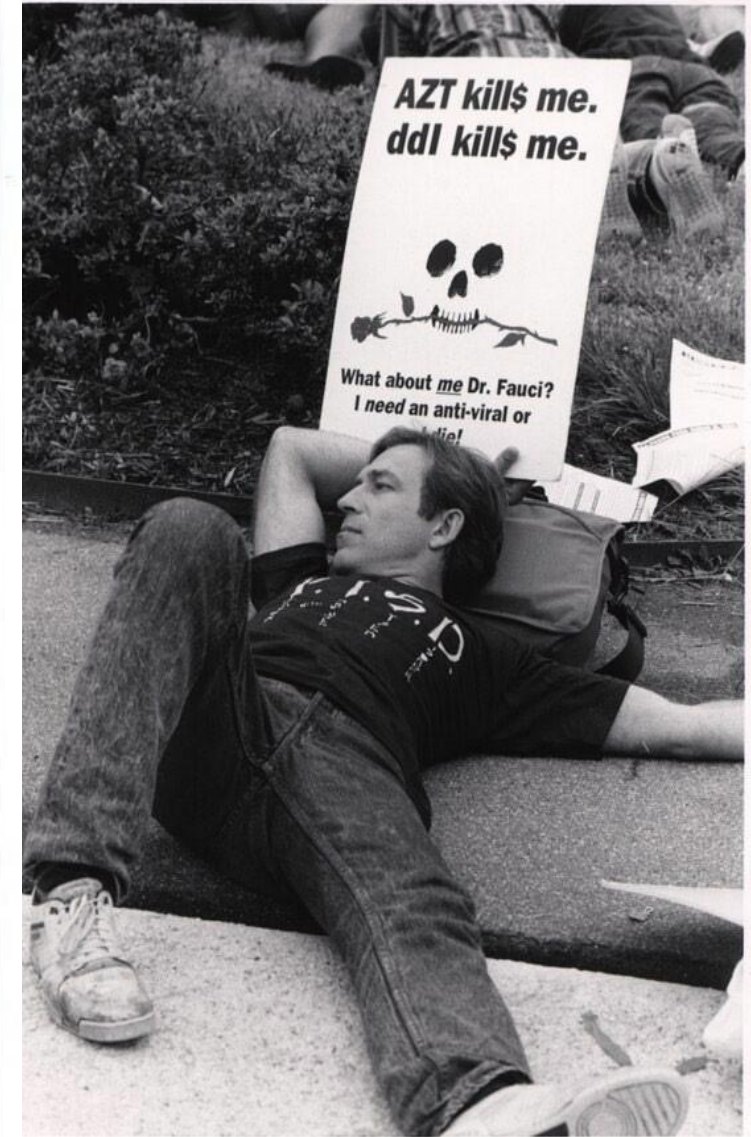


The Early Days

- Activists were concerned about the slow response of the US government and private pharmaceutical companies to respond to the AIDS epidemic.







Dr. Fauci Opens the Door to Community

- “I grew to respect and like these brave young people very much even though we sometimes disagreed, and they did not hesitate to publicly criticize me over these disagreements. But we learned from each other...I valued more and more their unique insight into issues that affected them and their community.”
- “My decision to open the doors to the activist community was one of the best administrative decisions I ever made. Over the years their input proved to be invaluable to our developing the optimal design of clinical trials that were user-friendly to the participants and still yielded the most valuable scientific and clinical information.”

Quotes from Anthony Fauci in “On Call: A Doctor’s Journey in Public Service”

AIDS Clinical Trials Group (ACTG)

History

1985 NIAID issued a Request for Proposals (RPF) to establish AIDS Treatment Evaluation Units (ATEUs) for Phase I and II trials

1986 14 institutions funded as ATEUs

AZT shown to be effective resulting in changes in research direction and a Congressional budget amendment to increase funding:

- 5 additional ATEUs funded
- focused on pediatric and hemophilic populations
- established a clinical trials coordinating center
- established Clinical Study Groups (CSGs)

AIDS Clinical Trials Group (ACTG)

History

1987 Ad hoc review of clinical trials effort

ACTG formed from ATEUs and CSGs

Statistical Center and Operations Office established
NIAID holds first ACTG group meeting (12/87)

1988 NIH Office of AIDS Research (OAR) established

1989 ACT-UP New York attends the 7th ACTG group meeting (11/89) uninvited

15 Pediatric ACTUs funded

CPCRA established

AIDS Clinical Trials Group (ACTG)

History

- 1990** Community reps invited to 8th ACTG group meeting (3/90)
Community Constituency Group (CCG) formed with 22 members
CCG members attend Executive Committee and Scientific Cores sessions the 9th ACTG group meeting as observers
CCG attend the 10th ACTG group meeting as a formal part of the ACTG system (7/90)
- 1991** 9 additional Pediatric ACTUs funded in response to Congressional mandate
Competitive renewal of Adult ACTUs: 35 sites funded

AIDS Clinical Trials Group (ACTG)

History

1993 Competitive renewal of 15 original Pediatric ACTUs
CCG expanded pediatric representation from 1 to 6
- total membership now = 30

NHF funded to enroll persons with hemophilia in ACTG

Ad hoc review of ACTG

Separation of adult and pediatric research efforts

OAR authorities expanded

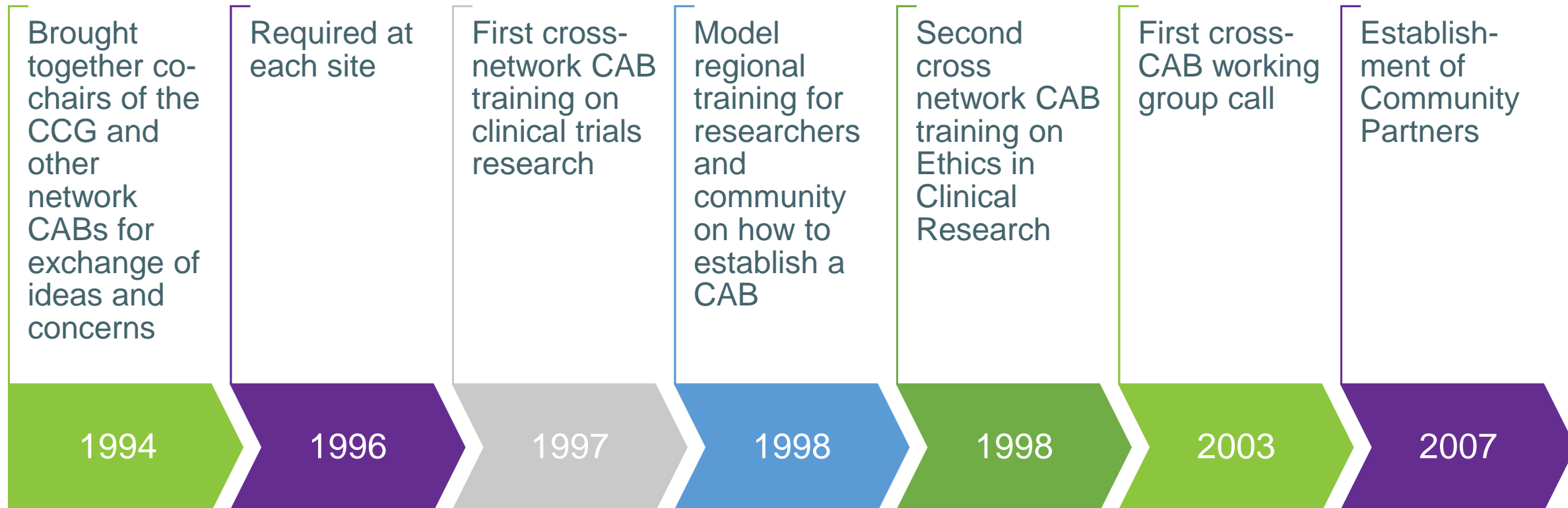
1995 OAR task force to review NIH AIDS research

AIDS Clinical Trials Group (ACTG)

History

- 1996** Competitive renewal and restructuring of Adult ACTG
- 30 sites funded
OAR task force's report is released
CCG increased pediatric reps to 10 (total = 34)
CCG surveyed ACTU PIs and CABs
- 1997** Competitive renewal and restructuring of Pediatric ACTG
- 21 sites funded
HRSA provided childcare services to CCG & CAB representatives at the 24th ACTG group meeting (12/97)
- 1998** Pediatric CCG ceased being a subcommittee of the Adult CCG as it became a committee within the PACTG structure

Evolution of Cross-CAB Activities



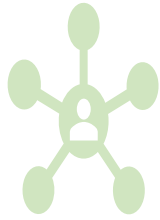
What is a CAB?

- A formal advisory group that is coordinated by the research study, site, or network.
- Made up of diverse community members varying in age, race, gender, education, religion and sexual orientation.
- Meets regularly to provide feedback to the site on research and its relevance to the local community.
- Provides 2-way communication channel for information between the research site and the broader community.

Exercise #2

- When did you first become active in HIV advocacy?
 - When did you join a CAB?

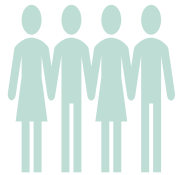
Role of the CAB



EXCHANGE OF INFORMATION BETWEEN RESEARCHERS AND THE COMMUNITY



REPRESENT INTERESTS OF THOSE ENROLLING IN THE CLINICAL STUDIES



SHARE INFORMATION TO HELP RESEARCHERS BETTER UNDERSTAND THE COMMUNITY



ENSURE RESEARCH IS CONDUCTED ETHICALLY, AND CONSISTENT WITH COMMUNITY NEEDS AND CONCERNS



PROVIDE FEEDBACK ON HOW/WHERE TO REACH POTENTIAL PARTICIPANTS



PROVIDE FEEDBACK ABOUT PROTOCOLS, INFORMED CONSENT DOCUMENTS, AND EDUCATIONAL MATERIAL, AND OVERALL RESEARCH PRIORITIES AND PROCESS

Exercise #3

What are your proudest accomplishments and biggest frustrations as a CAB member?

Reflections

Group report back

Break



Exercise #4

How has the community's role in HIV research changed overtime?

Reflections

Group report back

Community Partners



A cross-network body that promotes effective representation of the many communities within which the NIH HIV/AIDS Clinical Trials Networks conduct research.



Is comprised of four representatives from each of the four Networks and the community coordinator from each Network.



Members represent the global research sites.



Identifies cross-Network community research needs and priorities for network and DAIDS leadership and is a venue for sharing resources and experiences, avoiding duplicative efforts, identifying and addressing challenges to trial participation.



Tasked with ensuring network accountability re: scientific research priorities; ethical conduct of clinical trials; community training; communication and information dissemination; and continued community engagement.



Recommendations for Community Engagement in HIV/AIDS Research

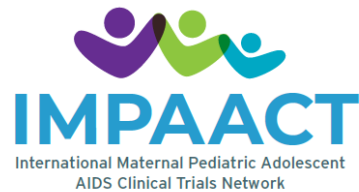


A guide for communities and researchers

November 2020



Division of AIDS, National Institute of
Allergy and Infectious Diseases,
National Institutes of Health



Mentorship Program

To support site staff and CABs in an effort to rebuild and reenergize CABs.

In addition to the Recommendations for Community Engagement document, CP can offer more specific and/or hands-on orientation, consultation, or training.

Pool of experienced CAB liaisons that sites across the networks can reach out to for mentorship (ex. how to run a CAB meeting, develop your program, schedule trainings, identify critical training needs, prepare bylaws, organize a CAB).

These individuals who agree to volunteer as mentors would be valuable resource.

Exercise #5

How do you want to see community engagement change in the future, including during the next network recompetition?

Reflections

Group report back

Resources for Inclusive Community Involvement

[Bill of Rights and Responsibilities for HIV Research](#)

[Community Engagement Resource Highlights](#)

[!\[\]\(cbe80b694ebd74fcfe136a095b608235_img.jpg\) DAIDS CAB and CWG Directory](#)

[Guidance for Gender-Inclusive HIV Research Practices](#)

[H=H, the H is for Human Podcast](#)

[HIV & AIDS Awareness Days](#)

[How to Critically \(and Quickly\) Read a Protocol](#)

[Long-Acting Antiretroviral Injectables Info Sheet](#)

[NIAID HIV Language Guide](#)

[Recommendations for Community Engagement](#)

[Representative Studies Rubric](#)

[TB Resources for Communities](#)



Acknowledgements

- Dr. Anthony Fauci
- The many HIV activists and CAB members who paved the way
- Sarah Alger, DAIDS
- Brian Minalga, HANC Deputy Director

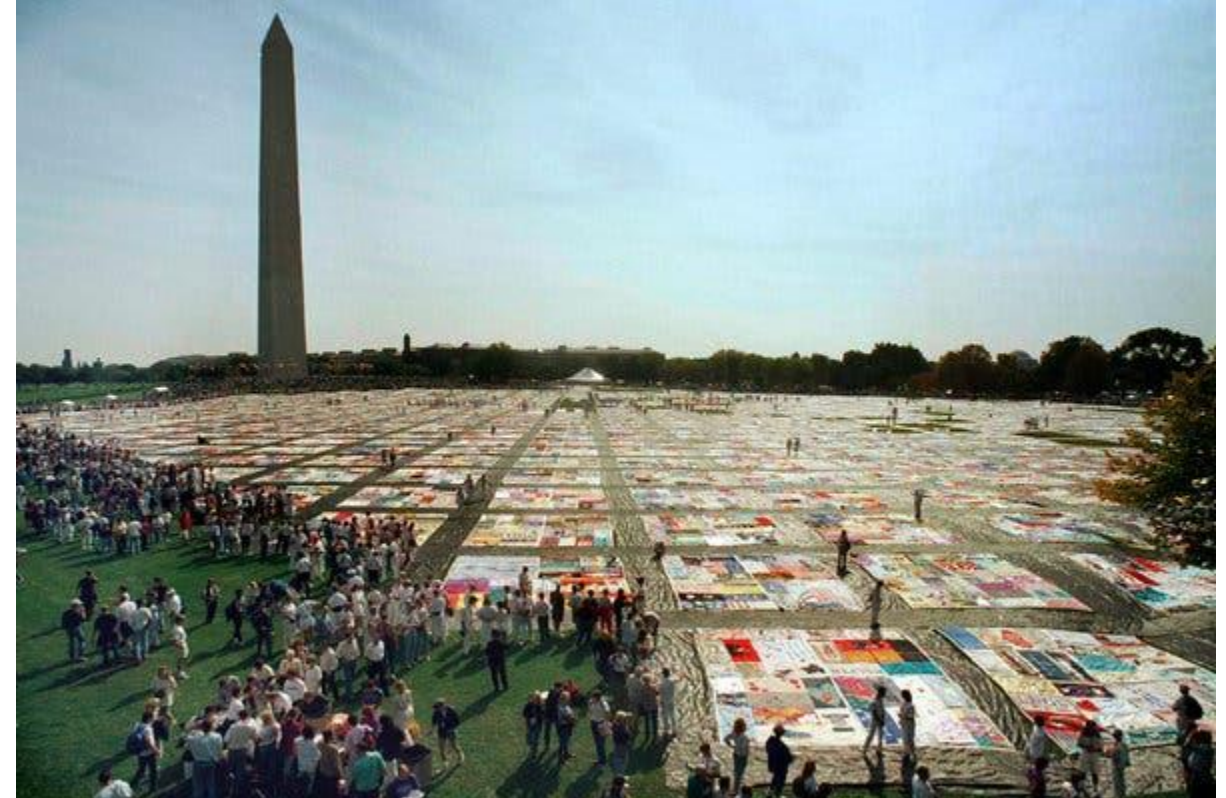


Photo Credit: Shayna Brennan/Associated Press

Thank You

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