



AIDS Treatment Activist Milestones/Accomplishments

Milestones in community involvement with HIV research

1985

- Activists co-found first community-based HIV drug trial in the United States.
- (To the present) Activists were involved in refinements to the Multicenter AIDS Cohort Study (MACS), one of the most influential natural history studies in HIV. Their participation continues to this day on studies using MACS data and MACS participants.
- Activist participation in Institutional Review Boards (IRBs) and Data Safety and Monitoring Boards (DSMB), both of which are designed to protect participants in research, began and continue to this day.

1987

- Activists protest high price of Retrovir (AZT) and ultimately win a price reduction.

1988

- Activists publish first of several opportunistic infection research recommendations.

1989

- Activists begin working with the National Institutes of Health on the development of grants for AIDS research.
- Late 1980s - Activist concerns strongly influence adoption of first of regulations to hasten Food and Drug Administration (FDA) approval of medicines for life-threatening conditions, including HIV.
- Activists collaborate with researchers to establish the Terry Bein Community Program for Clinical Research on AIDS (CPCRA). The CPCRA included community-based clinics with the aim of involving a more representative and diverse population of people with HIV than were being enrolled in trials based solely at academic centers.

1990

- Activists advocate for expanded access program for Videx (ddI) that ultimately results in early access to the drug for thousands who were very ill.

- Formation of first community advisory boards at all government-sponsored AIDS clinical trials sites - network called the Community Constituency Group (CCG).

1992

- Activists' urging to form a natural history study of women and HIV was finally heeded and various activists worked on the design of the Women's Interagency HIV Study (WIHS). Activists continue to be involved in the development and conduct of new studies based on WIHS data.

1994/1995

- Activists heavily influential in the development and pricing of protease inhibitors.

1995

- Activists intimately involved in the development of the first HIV treatment guidelines, published by the Department of Health and Human Services (DHHS)

1999

- Early studies suggested Viread might be highly toxic to the liver and its development was nearly derailed. Activists played a leading roll in encouraging Gilead to continue developing the drug.
- Activists advocate against the approval of adefovir (then branded Preveon) for treatment of HIV. This was due to problems with kidney toxicity at the high doses used in HIV. The drug was later approved at lower doses to treat hepatitis B.

2002

- Partly as a result of activist pressure for a comprehensive evaluation of intermittent instead of continuous antiretroviral therapy, the Strategies for the Management of Antiretroviral Therapy (SMART) trial begins. ATAC member and respected AIDS activist Carlton Hogan is closely involved in the study design. The SMART results reveal critical and heretofore unappreciated aspects of HIV pathogenesis that would have been missed by a smaller trial. SMART is conducted by the INSIGHT network, which grew out of the CPCRA.
- Activists work with key researchers to encourage Trimeris to continue development of Fuzeon, the future of which was uncertain. Though the drug did not—and was never expected to—become a heavily used drug, it did protect thousands of people with HIV from death and serious illness until better drugs came along.

2006

- Activists achieve success with the FDA after encouraging them for years to insist that pharmaceutical companies involved in HIV research study their drugs in more women and people of color.