# KEEPING TIME

social and governmental developments in HIV

The Centers for Disease Control and Prevention (CDC) publishes the first

## 1980

■ The first cases of two rare illnesses – *Pneumocystis carini* pneumonia and Kaposi's sarcoma (KS, a rare cancer) – are reported in New York and California. These are the first reported cases of what will later be known as AIDS.

- The New York Times, with a circulation of 912,649, publishes its first story on 41 cases of a "rare and often fatal cancer" in gay men in New York and
- The first weekly support group meeting for people living with KS begins in San Francisco through the Shanti Project, a volunteer-based organization whose mission is to provide support, both physical and emotional, for people living with life-threatening illnesses.iv

## 1982

- After being known as "gay cancer," "new pneumonia," and Gay-Related Immune Deficiency (GRID), the syndrome is renamed Acquired Immune Deficiency Syndrome (AIDS).v
- The Bay Area Reporter, a San Francisco weekly newspaper targeted to the gay community, publishes its first cover story on Acquired Immune Deficiency, an article prepared by New York City's Gay Men's Health Crisis Committee, which advises that, "It is the number of different sexual encounters that may increase risk, not sex itself."vi
- The city of San Francisco agrees to spend \$450,000 to fund the world's first AIDS clinic that includes grief counseling and personal support programs for people with AIDS (through the Shanti Project), and the first locally funded outreach and education efforts through the Kaposi's Sarcoma
- Foundation (later renamed the San Francisco AIDS Foundation).vii ■ The first AIDS hotline is established by Gay Men's Health Crisis (GMHC). a New York non-governmental organization, to answer questions and pro-
- vides support and crisis response to callers.viii ■ The "Buddy" program is established by GMHC as a peer support service for people who are sick or dying from AIDS to help with their day-to-day needs as part of a newly established Patient Services division. Meanwhile, Shanti
- has established a similar program in San Francisco.io ■ The first safe sex pamphlet for gay men, entitled "Can We Talk...," is published in San Francisco by the Sisters of Perpetual Indulgence.x

1983 ■ Terms such as "sexually active" and "bodily fluids" become part of the first

### official public health language of AIDS.xi People living with AIDS, attending a conference in Denver, develop the "Denver Principles," a set of recommendations for a more humane response to the AIDS epidemic and form the National Association of

■ The first inter-faith religious meeting on the spiritual needs of people living with AIDS is sponsored by the Shanti Project; the meeting results in the call for an inter-faith AIDS network.xii

People with AIDS (NAPWA), the first national AIDS advocacy group.xii

- AIDS cover story in *Time* magazine, which has a circulation of 4,615,594, uses the term "groups at risk" and identifies the four "groups" as "homosexual men," "intravenous drug users," "immigrants from Haiti," and "hemophiliacs."xiv
- The first governmental AIDS hotline is established by the federal Department of Health and Human Services.xv
- The first woman is diagnosed with AIDS (in San Francisco).xvi
- A service to find emergency housing for people with AIDS who are evicted from their homes or discharged from hospitals with no place to go is formed in New York City by the AIDS Resource Center (later called Bailey House).xvii
- The first meeting of the AIDS/KS Social Work Discussion Group is held in New York City with the objective of setting standards to address the psycho-social needs of people living with AIDS and their loved ones.xviii ■ The first AIDS discrimination lawsuit is filed by GMHC and the Lambda

Legal Defense Fund in the case of a New York doctor who is evicted from

1984 The virus that causes AIDS is identified by American and French scientists.

his building for treating AIDS patients.xix

- The virus is initially called Human T-Cell Leukemia Virus (HTLV-III) by the mericans and Lymphadenopathy-Associated Virus (LAV) by the French. Later it is renamed HIV - Human Immunodeficiency Virus.xx ■ Community-based AIDS service organizations join together to form AIDS
- Action, a national organization in Washington, DC, to advocate on behalf of people and communities affected by the epidemic, to educate the federal government, and to help shape policy and legislation relating to AIDS.

## 1985

- The enzyme-linked immunosorbent assay (known as ELISA) test kit is licensed for clinical use, allowing for the first testing of blood for the presence of HIV antibodies.xxi
- The first anonymous HTLV/LAV test sites open in New York and San Francisco.xxii ■ The first International AIDS Conference is held in Atlanta, Georgia. The
- opening address, by Dr. James Curran, director of the CDC's AIDS Program, on "The HTLV/LAV Update," reflects early assumptions about infection and the progression from infection to AIDS.xxiii

### 1986

- The Texas State Health Commissioner proposes, then drops, a statewide plan to add AIDS to the list of diseases for which people could be quarantined.xxiv
- California voters defeat Proposition 64, which would have allowed for the quarantine of people living with AIDS.xxv The Surgeon General issues a landmark federal report to the Reagan
- Administration and to the public that calls for AIDS education and condom use to prevent the transmission of HIV.xxvi Activists in New Haven and Boston begin the first street outreach
- needle exchange programs specifically targeted toward HIV prevention.xxvii Women living with HIV/AIDS in New York City come together to form
- Women and AIDS Resource Network (WARN). xxviii

## 1987

- The AIDS activist group ACT UP (the AIDS Coalition to Unleash Power) is founded by Larry Kramer in New York City. On March 24th, the coalition holds their first demonstration on Wall Street to protest against the high profit margins enjoyed by the pharmaceutical companies.xxix
- In Florida, Ricky, Randy, and Robert Ray, three brothers who are all HIV positive and hemophiliacs, return to school after a judge orders the school system that barred the boys from attending class for a year to readmit them. On August 28th, the Ray family's home is set on fire, and the Rays decide to leave town. The case is never solved.xxx
- specific needs of nurses working with people living with AIDS.xxxi AZT (zidovudine), the first drug for the treatment of AIDS, is approved by the federal Food and Drug Administration (FDA).xxxii
- The Association of Nurses in AIDS Care is founded to address the
- National Minority AIDS Council establishes offices in Washington, DC to address disparities and the needs of people and communities of color living with and affected by HIV/AIDS.

# 1988

- Ryan White, an HIV positive teenager, who has become a national spokesperson for AIDS education, treatment, and funding, testifies before the President's Commission on AIDS during the Reagan Administration. Ivii ■ Elizabeth Glaser, an HIV positive mother of two HIV positive children, and two
- of her friends form the Pediatric AIDS Foundation (later renamed the Elizabeth Glaser Pediatric AIDS Foundation) to advocate for research into the care and treatment needs of children living with HIV. Ivii ■ The U.S. Department of Health and Human Services mails "Understanding AIDS," an eight-page booklet that includes information on transmission
- testing, risk behaviors and prevention, to all 107 million U.S. households.  $^{\rm lix}$ ■ An article published in Cosmopolitan magazine (current readership: 2,963,351) authored by a psychiatrist informs women that "most
- using the missionary position." ■ The first HIV specific needle exchange program to operate with community support begins in Tacoma, WA. Later called the Point Defiance AIDS Project, this program receives a contract to operate under the city health

heterosexuals are not at risk" and that it is impossible to transmit HIV

- ACT UP closes down the offices of the FDA to protest the lengthy testing and approval process that is preventing access to experimental HIV
- medications. Ixii 1990 Ryan White dies at the age of 18. Later that year, the Ryan White CARE Act is

- treatments and the expansion of clinical trials to include more women and people of color. Ixiv
- ACT UP organizes a protest to "Storm the NIH" demanding more HIV

### 1991 ddl (didanosine), a nucleoside reverse transcriptase inhibitor, is the second drug for treatment of AIDS approved by the FDA. Ixv

■ The female condom is approved by the FDA. Ixvi

Researchers in France and Britain conclude that AIDS treatment AZT ha little or no benefit when taken early in the progression of the disease. Ixvii 1994

■ The CDC announces that AIDS is the leading cause of death among 25-44

- The FDA approves the first HIV saliva test (OraSure) for use in clinical settings.lxix
- 1995 Saquinavir, the first protease inhibitor (a new class of antiretroviral treatment)
- of viral replication that takes place in the body, and the fact that the virus is easily susceptible to mutation, it is inevitable that such replication and mutation will lead to drug resistance in individuals on antiviral therapy. Ixxi

■ Researchers studying the life cycle of HIV show that because of the high level

### 1996 ■ The viral load test, which determines the amount of HIV present in a person's

the best course of treatment for an individual is and to measure a treatment's effectiveness.lxxi ■ "Triple combination therapy," using three antiretroviral medications in

blood, is approved by the FDA. Test results can be used to determine what

combination, is introduced and becomes the new standard of HIV care. IXXIII Dr. David Ho advocates for a new strategy for treating HIV — "hit early, hit hard," in which patients are placed on new, more aggressive treatment

regimes earlier in the course of their infection in hopes of keeping them

healthier longer. Ixxiv ■ Time magazine names Dr. Ho "Man of the Year" for his ground-breaking work on protease inhibitors, a new class of antiretroviral drugs. Ixxv

# 1997

- The effect of new treatments is clearly seen as the number of Americans newly diagnosed with AIDS drops for the first time since the epidemic began. Ixxvi ■ Highly active antiretroviral therapy (HAART), consisting of three or more
- antiretrovirals, replaces the expression "triple combination therapy" and becomes the new standard of HIV care in response to the call to "hit early, hit hard.'

- As a greater number of people begin taking protease inhibitors, resistance to the drugs becomes more common and emerges as an area of grave
- concern within the AIDS community. Ixxvii 1998 ■ The CDC announces that the number of American AIDS deaths dropped 47%
- in the previous year. The drop is credited to the effectiveness of HAART. Ixxviii ■ The unpleasant side effects of HAART, including nausea, kidney failure, changes in body shape, and hallucinations, are seen in many
- patients taking the medications. Ixxix

- "Adherence" to the complicated treatment regimes that characterize HAART becomes a major concern within the HIV/AIDS community and health care professionals.lxxx
- The Alliance for Microbicide Development, a global, non-governmental organization, is founded to encourage the development of safe, affordable, and effective microbicides to prevent HIV/AIDS and other STDs. IXXXI

# 2000

1999 ■ The first Minority HIV/AIDS Initiative (MHAI) funding is made available to organizations and institutions responding to HIV in minority communities. Ixxxii

### ■ Nonoxynol-9 (N-9), a common spermicide believed to be a potentially effective barrier against HIV, is shown to significantly increase the risk of HIV transmission. Prior to this discovery, prevention efforts encouraged

- individuals to use products containing N-9, whose possible microbicidal effect against HIV was being actively studied. IXXXIII 2001
- protection against the transmission of HIV and other STDs. The report renews the controversy around the CDC's policy regarding the promotion of condoms as an effective HIV prevention tool. IXXXII AIDS service organizations participate in an historic session of the United Nations General Assembly on the AIDS epidemic in which a unanimous resolution declaring the disease a global catastrophe and

■ The NIH releases a report showing mixed effectiveness of condoms in

calling for worldwide commitment to end the epidemic is passed. The meeting also calls for the creation of an international "global fund" to support efforts by countries and organizations to combat the spread of HIV through prevention, care, and treatment - including the purchase of HIV medications. lxxxv

# ■ Side effects and increasing evidence of drug resistance call into question

2004...

- the "hit early, hit hard" strategy and HAART is replaced by ART (antiretroviral therapy) as the new standard of treatment. 2003 A \$60 million grant is awarded to the International Partnership for
- and development of microbicides to prevent the transmission of HIV. This is the largest grant ever awarded to support work on microbicides. IXXXV ■ The CDC announces to the HIV community a new initiative to target people who are living with HIV and their prevention and care needs. IXXXVI

Microbicides by the Bill and Melinda Gates Foundation to support research

report on what will become the AIDS epidemic in its weekly Morbidity and Mortality Weekly Report (MMWR).xxxiii NINETEEN-EIGHTY 1982 1981 ■ San Francisco Representative introduces the first legislation to target funding to the CDC (\$5 million) and the National Institutes of Health (NIH) (\$10 million) for AIDS research.xxxiv California.ii The article suggests that the illness may not be contagious and that there is "no apparent danger to non-homosexuals."ii The CDC releases its first AIDS case definition, which "defines a case of AIDS as a disease, at least moderately predictive of a defect in cell-mediated

NINETEEN-EIGHTY-ONE

NINETEEN-EIGHT

NINETEEN-EIGHTY-FOUR

NINETEEN-EIGHTY-SIX

NINETEEN-EIGHTY-SEVEN

NINETEEN-EIGHTY-EIGH

NINETEEN-EIGHTY-NINE

NINETEEN-NINET

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NINETEEN-NINETY-FOUR

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TWO-THOUS AND-THREE

TWO-THOUSAND-FOUR

NINETEEN

- immunity, occurring in a person with no known cause for diminished resistance to that disease."xxxv
- The CDC publishes a report in the MMWR hypothesizing that "transmission" of the agent [that causes AIDS] would appear most commonly to require
- intimate, direct contact involving mucosal surfaces, such as sexual contact among homosexual males." The article makes no mention of the possibility of transmission to women and/or via heterosexual contact.xxxvi
- The NIH rejects a proposal for a research study to determine whether women get AIDS.xxxvii

# 1983

1981

- Congress passes the first bill that includes funding specifically targeted for AIDS research and treatment. The funding is passed as part of the supplemental federal appropriations bill for fiscal year 1983 and totals \$12 million for agencies within the department of Health and Human Services (HHS),xxxvii Congress, through the Subcommittee on Human Resources and
- Intergovernmental Relations, and the Subcommittee on Science and Technology, conducts the first investigation into the Reagan administration's efforts to address the growing AIDS epidemic and the lack of adequate funding and support.xxxix

## 1985

- The CDC AIDS case definition is revised to include new knowledge that AIDS is caused by a newly identified virus.xl NINETEEN-EIGHTY-THREE
  - The AIDS/HIV Service Demonstration Program, administered by the Health Resources and Services Administration (HRSA), begins. The program provides funding for services for people living with AIDS to four urban areas. This program is the precursor to what will be Title I of the Ryan White CARE Act, the comprehensive federal legislation that provides funding for HIV and
  - 1987
  - AIDS care and treatment programs.xli ■ The CDC expands the AIDS case definition to include infection with HIV, regardless of the appearance of an AIDS-defining opportunistic infection.xlii

# The states are awarded \$30 million for the first federal funding to pay for AZT,

authorized by the Ryan White CARE Act in 1990.xlii Senator Helms of North Carolina introduces the "Helms Amendment" to prohibit the use of federal money for AIDS education materials that "promote or encourage, directly or indirectly, homosexual activities."

a predecessor of what will be the AIDS Drug Assistance Program (ADAP)

- The amendment passes and becomes part of every subsequent bill that provides funding for federal AIDS programs.xliv ■ The federal government announces a new policy barring people living with AIDS from entering the country as visitors or immigrants.x 1988
- providers about HIV/AIDS. They are later incorporated into the Ryan White CARE Act.xlv ■ The Health Omnibus Programs Extension of 1988 (Public Law 100-607) is signed into law by President Reagan. This law contains many provisions relating to federal funding of HIV and AIDS programs; most notably it represents the first time that the CDC is authorized to directly fund community-based organizations for prevention programs. Prior to this legislation the CDC only funded city and state health departments for HIV prevention activities. The law

emphasizes the importance of reaching "populations or communities at risk,"

create a plan for HIV/AIDS systems of care. This lays the groundwork for the

statewide programs that will later be funded under Title II of the CARE Act.xlviii

■ The AIDS Education and Training Centers (AETCs) begin educating medical

- populations [and] geographic areas," and "minority communities [and] populations." ■ HRSA awards HIV Planning Grants to 11 states and ten cities in order to
- This program will eventually become Title IV of the CARE Act.xlix 1989 ■ The funds for the CDC programs, previously authorized by the 1988 Health

HRSA funds Pediatric AIDS Service Demonstration Grants for the first time.

"underserved

Omnibus Programs Extension Act, are now made available for use in the direct funding of organizations for innovations in HIV prevention. The CDC receives ten applications and funds four of the community-based organizations (CBOs) for three years.1 ■ HRSA grants \$20 million for HIV care and treatment through The Home and

Community Based Care State grant program. For many states, this represents

- their first involvement in HIV care and treatment.li Seven community health centers receive a total of \$11 million under a joint CDC/HRSA initiative to provide HIV counseling and testing services. This
- is a precursor of what will be Title II of the CARE Act.lii 1990 ■ Congress passes the Ryan White Comprehensive AIDS Resources

### Emergency (CARE) Act (Public Law 101-381). The CARE Act consolidates the patchwork of existing federal HIV/AIDS care and treatment programs, as well as adding

- to and expanding the scope of these programs. The CARE Act initially consists of three sections, known as Titles, and an auxiliary funding program called Special Projects of National Significance (SPNS). Title II of the CARE Act includes the AIDS Drug Assistance Program (ADAP), which provides HIV related medications to those who would otherwise be unable to afford them. The CARE Act is designed to be the "payer of last resort" - a resource for those who have no others means of accessing HIV specific medical care. It was created because many people living with HIV/AIDS lacked the resources to pay for care and/or the support that is needed in order to cope with the physical debilitation and social stigma of the disease. The CARE Act was originally written to be valid for five years, with the option of reauthorization at the end of that time. However, each year, funding levels for the Act's programs must be set as part of the annual Congressional budget process. This means that the exact amount of funding available through its programs can change yearly.liii
- given to states under Title II. States are instructed to consider the "unmet needs" of areas that do not receive Title I funds when awarding their Title II grants.li ■ The CDC adopts the HIV prevention counseling model, a "client-centered"

■ Within the CARE Act, the term "unmet needs" is used in the instructions

approach that moves away from the medical model that has been predominant in health interventions, which focuses on the disease rather than the patient.lv 1991 ■ The funding authorized in 1990 by the CARE Act is distributed for the first

### time. In the first year, 16 cities receive Title I funding as "Eligible Metropolitan Areas," (EMAs) meaning that they have either a cumulative total of more than 2,000 cases of AIDS or their per capita incidence of cumulative

- cases of AIDS is not less than 0.0025. The first Title II, Title III, and SPNS (special projects of national significance) funds are also awarded. Ivi 1992 ■ The CDC awards a second round of grants to 70 directly-funded CBOs, 52 of which are minority targeted, for a three year period. These grants are for
- prevention case management services for HIV negative people. IXXXVII 1993 Under a new program announcement and increased funding from Congress, the CDC funds 103 CBOs, 85 of which are minority targeted. This funding is for

group-level interventions in the areas of behavior change, skills-building, and

■ The AIDS case definition is revised by the CDC. The new definition is more inclusive of women and injection drug users; therefore, the number of documented AIDS cases goes up in these populations. As a result, seven more areas become eligible for Title I funds, which brings the total number of EMAs to 25.xc The NIH implements new guidelines requiring that women and minorities are NINETEEN-NINETY-THREE included in all clinical trials involving human subjects, unless there are

# 1994

a period of three years. Ixxxii

scientific indications to the contrary.xci

■ The CDC instructs state and city health departments to incorporate an open and inclusive community planning process for the estimation of needs and the allocation of funds for HIV/AIDS programs.xcii 1996

## ■ The Ryan White CARE Act is reauthorized for an additional five years. Three additional programs are added to the CARE Act in 1996: Title IV, a grant

program for women and children; the AIDS Education and Training Centers (AETCs); and the dental reimbursement program. Otherwise, the 1996 amendments largely preserve the language and intent of the original act, including the instructions to States to consider the "unmet needs" of areas that do not receive Title I funds when awarding their Title II grants.xci 1997 ■ Under a new program announcement, 482 CBOs apply for prevention

funding from the CDC. Of these, 93 are funded. In this round of funding, the

# CDC awards 90% of the grants to organizations whose board members and

- clients are at least 50% women and people of color; the remaining 10% of NINETEEN-NINETY-FIVE grants do not have this restriction.xci 998 ■ The Secretary of Health and Human Services declares AIDS to be an ongoing
  - and severe crisis in African American and Hispanic communities in the United States and encourages Congress and the Administration to respond to the growing epidemic in these underserved areas.xcv Under the leadership of the Congressional Black Caucus, Congress funds the Minority HIV/AIDS Initiative (MHAI), designed to directly target increased funding, capacity building services, and technical assistance to respond to the
    - growing needs in minority communities.xcvi ■ Congress passes the Ricky Ray Hemophilia Relief Fund Act of 1998 (Public Law 105-369), which authorizes payments of \$100,000 to individuals with blood-clotting disorders, including hemophilia, who contracted HIV through infected blood products between July 1, 1982 and December 31,

Under a new program announcement the CDC directly funds 47 CBOs for

## work with African-Americans, 37 CBOs to work with gay men of color, and ten faith-based organizations - all for four years. These grants are award-

1999

- ed for health education and risk reduction activities, and prevention case management for HIV negative people.xcvii ■ The CDC releases a new HIV case definition to be used for surveillance purposes so that state health departments may expand their current surveillance efforts to include HIV in order to more accurately track the changing course of the epidemic.xcii
- The CDC begins funding the "Prevention for HIV Infected Persons Project" (PHIPP), asking certain jurisdictions to make prevention for positives a priority. Grants are awarded to five health departments, three in California, one in Maryland, and one in Wisconsin, to develop targeted prevention messages for people living with HIV.c
- Three national AETC centers are funded; the National Resource Center, the National Evaluation Center, and the National Minority AETC to expand training and education in clinical and community services.ci 2000
- and are not receiving regular medical care.cii Congress reauthorizes the Ryan White CARE Act for an additional 5 years. Among the changes implemented in the 2000 amendments are new instructions to those entities allocating and receiving CARE Act funds calling for the targeting of a new priority category: "individuals with HIV disease who know their status and are not receiving HIV related services." Language within the

■ The CDC reports that an estimated 850,000 – 950,000 people are living with HIV

in the United States. Of those, 212,500 - 237,500 people know their HIV status

- amendments instructs grantees to address the "unmet need" for services for this population. In addition, the 2000 reauthorization adds the category of emerging communities to Title II and authorizes ADAP funding for severe ■ Title I and Title II of the CARE Act provide funding for over 4 million HIV-related health care visits, including doctor's appointments, laboratory visits, case management services, and other auxiliary health services, cir ■ At the end of fiscal year 2000 the CDC is directly-funding 233 organizations.cv
- 2001 After evaluating the effectiveness of PHIPP, the CDC announces SAFE (Serostatus Approach to Fighting the Epidemic), which expands on the existing prevention programs targeting HIV positive people funded under PHIPP. All state and city health departments are instructed to prioritize prevention for positives in their community planning process, emphasizing behavioral change

and participation in regular medical care.cvi

people who know their status to 85%; 3) increase the number of people living with HIV who are receiving regular care to 90%; and 4) strengthen the capacity to monitor the epidemic nationwide and implement and evaluate effective prevention programs.cvii HRSA begins the implementation process of the 2000 changes to the Ryan White CARE Act, including the targeting of a new priority category: "individuals with HIV disease who know their status and are not receiving HIV

related services." Language within the amendments instructs grantees to

address the "unmet need" for services for this population.cvii

■ The CDC releases a five year strategic plan for HIV prevention, which includes

goals to 1) reduce new infections by 50%; 2) increase the number of HIV+

services reach 533.000 individuals infected and affected by HIV, who rely on CARE Act funded resources for one, some, or all of their medical service needs.ci> 2003 ■ The CDC estimates that of the 40,000 new infections that occur each year in the

According to HRSA, each year CARE Act-funded medical and support

### United States, 27,000 are the result of transmission from someone who is unaware that they are infected and 13,000 are the result of contact with someone who is aware of their HIV positive status.cx

2004

2002

■ The CDC announces "Advancing HIV Prevention: New Strategies for a Changing Epidemic," a new prevention initiative that "is aimed at reducing barriers to early diagnosis of HIV infection and increasing access to and utilization of quality medical care, treatment, and ongoing prevention services for those living with HIV."cxi

### ■ Through a national cooperative agreement between HRSA and AIDS Action, the "Connecting to Care" workbook is produced, identifying strategies for grantees to address the 2000 CARE Act reauthorization requirements regarding "unmet needs" in HIV.cxii

AIDS **ACTION** 

(until it's over)