



Twenty Years of Women Living with HIV:



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**Past, Present and
Future**

By Terri L. Wilder,
L.M.S.W.

[20 Years at a Glance](#)

1981	1982	1983	1984	1985	1986	1987	1988	1989	1990	1991
1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002

Since the beginning of time, women have had to fight for recognition. Women had to fight to vote. Women had to fight to work. Women even had to fight to wear the clothes they liked.

Twenty years ago women were fighting off unusual symptoms. Twenty years ago women were fighting to be diagnosed. Twenty years ago women were fighting to stay alive.

The last twenty years have taught me that when I gasp in repulsion over the lack of sensitivity or research on women living with HIV, my breath may be taken in prematurely. I know that I should not be surprised, but I am. I keep thinking that twenty years of this illness should have taught a lesson in inclusiveness and pro-activity. Today, women are fighting to be recognized in the AIDS epidemic as if it were 1981.

Despite the gray overcast, I do have hope for my sisters who are living with and affected by HIV. However, the fight is not over and is perhaps just beginning. We (infected and affected) must gather our strength and remember those who have gone before us. We must never go back to [1981](#). We must run our lives as if we are the female CEO of our own company. We must meet with our "Board of Directors" for input. We must set a twenty-year strategic plan for "Women AIDS, Inc." We must be the most important person in our life!

I invite you to read this humble history of women and HIV and decide what you can do to add to the history of HIV and women. As you process

your vision of the future, keep in mind that the final paragraph of this story should include the following words: *cure, women, AIDS, and forever.*

Terri L. Wilder, L.M.S.W. is a licensed social worker who has provided social services for persons living with HIV/AIDS for the past twelve years. She can be reached at twilder@mindspring.com. Terri invites women who are interested in adding information to this history to contact her. Terri apologizes for any oversights in our history.

The history is dedicated to the countless powerful women who are living with and affected by HIV including: Kellie, Ilyse (who is the CEO of her own company), Jane P. Fowler, River, Marguerite G. Wilder, Regina Ann Goldsworthy Stott, Susan, Eva, Valerie Reeder-Bey, Annisha Monic Wilburn, Lois C. and yes, Cara.

1981.

The first case of GRID, which will later be referred to

as AIDS, is reported. Five women are among those diagnosed. Sandra Ford, a drug technician for the Centers for Disease Control (CDC), officially notes an increase in requests for pentamidine for the treatment of *pneumocystis carinii* pneumonia (PCP). A paper napkin will later be taped to Sandra's door stating: "In this office in April 1981, Sandra Ford discovered the epidemic that would later be know as Acquired Immune Deficiency Syndrome."

1982.

Women are sick and dying, falling through the

cracks. Those women diagnosed with this illness are classified under the risk category of "prostitutes." An article in *The Wall Street Journal* states that male and female drug users are being affected by GRID. Mary Richards Johnstone, a wealthy woman from the affluent suburb of Belvedere, receives twenty units of blood from Irwin Memorial Blood Bank in San Francisco during heart surgery. She is later diagnosed with AIDS.

1983. Liz Smith, the nationally syndicated gossip

columnist, is the first popular columnist to write about AIDS. Barbara Fabian Baird, of the National Institutes of Health (NIH), becomes one of the first nurses to conduct AIDS research. The Women's AIDS Network is established. The CDC adds female sexual partners of men with AIDS as a "risk group." The *New York Post* headline reads "L.I. Grandma Dead of AIDS." The story goes on to describe how Lorraine DeSantis died from AIDS after receiving a blood transfusion in 1980.

1984. Margaret Heckler, Secretary, Department of Health

and Human Services, announces that Dr. Robert Gallo has found the cause of AIDS. She also announces the development of a diagnostic blood test to identify the virus and suggests that a vaccine against AIDS could be produced in two years. Caitlin Ryan, a social worker, becomes the first executive director of AID Atlanta. AID Atlanta is the oldest AIDS Service Organization (ASO) in the Southeast.

"There will be a vaccine in a few years and a cure for AIDS before 1990."

-- Margaret Heckler

1985. Actress Elizabeth Taylor and Dr. Mathilde Krim

co-found amfAR (the American Foundation for AIDS Research). Elizabeth Taylor hosts the first Hollywood AIDS fundraiser. San Francisco AIDS Foundation produces their first brochure about women and AIDS. Singers Bette Midler and Barbara Streisand appear in a sold out fundraiser for the San Francisco AIDS Foundation. Mother Teresa visits AIDS patients at George Washington University after receiving the

Medal of Freedom from President Reagan. A reporter from the *San Francisco Chronicle* publishes a front-page story about Silvana Strangis, a prostitute living with AIDS.

For the first time, a woman is admitted to the AIDS ward at San Francisco General (Ward 5B). Frances Borchelt, an older adult from San Francisco, dies from AIDS after she received three pints of infected blood during surgery in 1983. Her family files a negligence lawsuit against Irwin Memorial Blood Bank.

1986. Women represent seven percent of U.S. AIDS cases.

Marie St. Cyr, a Haitian-born social worker, becomes the first director of the New York-based Women and AIDS Resource Network (WARN) after it is formed by several women living with and affected by HIV. Silvana Strangis dies after battling cryptococcosis.

Caitlin Ryan is hired to co-author the first book on AIDS policy, *AIDS: A Public Health Challenge*. This book is distributed to all members of Congress, governors, mayors, and key public officials and served as the basis for many of the recommendations of the first Presidential Commission on AIDS.

1987. Thirteen point five percent of NIH money is

dedicated to women's health issues. ACT-UP is founded. Women are excluded from HIV trials unless they are on the birth control pill or IUD; no childcare, transportation or GYN care is available. Trial inclusion/exclusion criteria read: "No pregnant women and no non-pregnant women" allowed. Surgeon General C. Everett Koop urges any woman considering pregnancy to be tested for HIV.

Princess Diana opens the first specialist AIDS hospital ward in England. The fact that she did not wear gloves when shaking hands with people

with AIDS was widely reported in the press and helped change attitudes towards people with AIDS. Singer Madonna throws her first AIDS benefit concert and later records a song, "In This Life," about friends who had died from the disease. St. Louis University School of Medicine produces *Strong Women, Positive Choices*, an award-winning documentary on the lives of HIV-positive women.

1988.

The New Jersey Women and AIDS Network is

founded. Revised NIH guidelines suggest "by gender" analysis of data being collected in clinical trials but does not establish clear standards for women's inclusion. A *Cosmopolitan* magazine article written by a psychiatrist tells women that they can have unprotected vaginal intercourse with an HIV-positive man if they have healthy vaginas. The article also reports that "most heterosexuals are not at risk" and further states that it is impossible to transmit HIV using the "missionary position." **Women named fastest growing population with HIV.** San Francisco AIDS Foundation develops a women's services program.

A 22-year-old New Yorker, Alison Gertz, is diagnosed with AIDS. Alison's mother Carol comments, "Alison had gotten sick that summer, and they tested her for everything: lymphoma, Hodgkin's, you name it. But they never tested her for AIDS because nobody thought a heterosexual woman who's not a drug user would get it. We subsequently learned that she'd gotten it from a good friend, who she'd only slept with once." Dawn Averitt is diagnosed with HIV. She later becomes a national AIDS treatment advocate and the founder of WISE (now Project WISE at Project Inform). Elizabeth Glaser, Susan DeLaurentis and Susan Zeeger co-found the Pediatric AIDS Foundation after learning that Elizabeth, her daughter Ariel and son Jake are living with HIV.

1989.

Rebekka Armstrong, former Playboy Playmate, tests

HIV positive. The NIH publishes further guidelines on women's inclusion. Bruce Lambert writes an article on Alison L. Gertz for *The New York Times*. In later years, a movie is made about Alison's life.

Amanda Blake, T.V. star ("Miss Kitty") on "Gunsmoke" dies from AIDS. Sisterlove, Inc. is founded by Dazon Dixon as the first and oldest organization in Georgia to focus on the needs of women living with and at risk for HIV. BABES is founded by HIV-positive women in Seattle under the philosophy that HIV-positive women are uniquely qualified to understand and encourage one another.

1990. The First National Women and HIV Conference is held. ACT-UP spearheads a massive protest at the Centers for Disease Control in Atlanta to expand AIDS definitions to include women specific diseases. Women with AIDS lead the demonstration; 94 are arrested. An estimate of women worldwide with HIV is at three million. Cook County Hospital (the only hospital with an AIDS ward in Chicago) refuses to admit women stating they have no women's AIDS ward. Gay and lesbian activists set up a ward in the street in front of the hospital; 35 are arrested. Two days later, the hospital admits women with AIDS for the first time.

National "Speak Out" by women with AIDS is held in Washington, DC to protest the Social Security definition of disability, which discriminates against women and people of color. On March 7th, the CARE bill was introduced into the Senate and House. During a Budget Committee that same day, Elizabeth Taylor speaks forcefully in support of the bill during her testimony, playing a vocal and visible role in its introduction. Elizabeth Glaser, a woman living with HIV, speaks at a House subcommittee hearing on pediatric AIDS, where she is praised for convincing the formerly unresponsive Ronald Reagan to do a public service announcement on pediatric AIDS.

1991. Kimberly Bergalis says her dentist infected her with HIV and requests that Congress mandate testing of healthcare workers. Kimberly writes the American Medical Association (AMA) requesting mandatory testing of healthcare workers. She dies by year's end. WORLD, an AIDS organization in Oakland, California, supporting

women with HIV (founded by Rebecca Denison), publishes their first newsletter, by and about women living with HIV. Mary Fisher, a prominent woman in Washington circles, is diagnosed with HIV. Women Alive is founded in Los Angeles by and for women living with HIV. Mother's Voices is founded by Suzanne Benzer and four other mothers, each of whom lost a child to AIDS.

1992. Mary Fisher addresses the Republican National

Convention as a person living with AIDS and stated "I don't know what kind of reception my speech received. It was like an out-of-body experience. People told me afterwards that the room got completely silent while I spoke, which is unheard of at a convention. Afterwards, President Bush said I'd done a wonderful thing." Elizabeth Glaser gives a speech to the U.S. Democratic National Convention as a person living with AIDS.

A full page ad in *The New York Times* reads "Women Don't Get AIDS. They Just Die From It." Over 300 grass-roots groups signed the ad. The CDC expands the definition of AIDS to include: bacterial pneumonia, TB and stage III cervical cancer. Recurrent vaginal candidiasis (yeast infections) was also added as a symptom of HIV. This is a victory for women living with HIV. AIDS Survival Project creates the first support group for women living with HIV in Atlanta. Three women attend the first group.

1993. The "female condom" is approved. Kristine Gebbie is

appointed as the first national "AIDS Czar," director of the Office of National AIDS Policy. In response to protest by ACT-UP's Lesbian Caucus, Health and Human Services Secretary Donna Shalala forms a Lesbian AIDS Task Force. Gena Corea's book, *The Story of Women and AIDS: The Invisible Epidemic*, is published.

1994. The ACTG 076 study finds that pregnant women taking AZT reduce the risk of HIV transmission to their unborn child by two-thirds. The U.S. Public Health Service recommends that HIV-positive pregnant women use AZT to reduce mother-to-child transmission. Elizabeth Glaser, co-founder of the Pediatric AIDS Foundation, dies. Former U.S. Surgeon General Jocelyn Elders is fired by President Clinton for saying that masturbation should "perhaps be taught" as part of sex education. Rae Lewis-Thornton, an African-American woman living with HIV, is featured on the cover of *Essence* magazine.

1995. Actress Sharon Stone becomes amfAR's celebrity spokeswoman. Elizabeth Dole, president of the American Red Cross and wife of Bob Dole (then the front-runner for the 1996 Republican presidential nomination), halts publication of a highly anticipated HIV/AIDS training manual for 1600 Red Cross chapters nationwide when her "special team" of advisors from outside the organization convinces her its contents are too explicit and controversial. President Clinton appoints Dr. Alexandra M. Levin to the Presidential HIV/AIDS Advisory Council. Dr. Levin's research includes HIV-associated lymphoma, women and HIV, and the development and testing of a therapeutic AIDS vaccine.

1996. The annual incidence of women diagnosed with AIDS begins to decline because of the success of antiretroviral therapies in the U.S. Rebecca Denison (founder and editor of *WORLD*) delivers twin girls, becoming one of the first HIV-positive women to talk publicly about her decision to become pregnant.

1997. Women account for more than half of HIV cases

worldwide. In March, The NAMES Project Foundation presents a month-long online quilt display on its World Wide Web site featuring panels made for women who have died from AIDS, in honor of National Women's History Month. Seventy-five percent of the cases among women are in women of color. Sandra Thurman, former Executive Director of AID Atlanta, is named AIDS Czar. Therapist Penny Chernow starts the first support group in San Francisco for older women with HIV. The National Conference on Women and HIV takes place in Pasadena, CA and chants of "Do Research to Save Women's Lives" echo the conference halls. The *Los Angeles Times* publishes an article on the conference.

Princess Diana, one of the first public figures to urge compassion for people living with AIDS, dies in an automobile crash. Poet River Huston's book, *Portraits of Women Living with HIV*, is released. The book's idea was stimulated by River's own HIV diagnosis and the lack of images of women living with HIV in society. *Catholic World News* reports that Mother Teresa plans to start a new AIDS Ministry in the United States. Her religious order, The Missionaries of Charity, currently run five hospices for persons living with AIDS.

1998. In South Africa, Gugu Diamini, an AIDS activist,

was beaten to death by her neighbors after revealing her HIV status on Zulu television. Forty-five percent of the cumulative HIV cases reported among Asian and Pacific Islander adult/adolescent females were acquired through heterosexual transmission. A cumulative total of 109,311 adolescent/adult females have been diagnosed with AIDS in the U.S. Sixty-three percent of newly reported female AIDS cases are African-American women. African-American women are three times more likely to die from AIDS than Caucasian or Hispanic women.

Of the 6,051 new HIV cases reported in women, eight percent (461) were among Latinas. The Global Campaign for Microbicides is founded at the XII International AIDS Conference in Geneva. The creation of the Microbicide campaign came about from key members of the women's

health and HIV community deciding to work together to focus world attention on the critical need for new HIV prevention options, especially for women. AIDS researcher Dr. Mary-Lou Clements-Mann is killed in the crash of Swissair flight 111.

Kate Shindle wins the Miss America title. AIDS is her platform. She travels all over the country on a national speaking tour titled "On the Way to a Cure: Preventing HIV Transmission in America." She moderates a panel discussion on women and AIDS at the 12th annual World AIDS Conference in Geneva, Switzerland at the invitation of U.S. Health and Human Services Secretary Donna Shalala.

1999. Mary Fisher makes primetime news announcing that she is stopping combination therapy due to the side effects. Of new cases of AIDS reported in women, 68 percent were in ages 30-49, 18 percent were in ages 20-29 and 12 percent were in ages 50 and over. Overall, heterosexual transmission accounts for an estimated 62 percent of AIDS cases diagnosed among women between July 1999 and June 2000. The National Conference on Women and HIV is held in Los Angeles, CA. Over 1,000 women attend. This event is documented as the largest gathering of HIV-positive women in history. Worldwide, over one million women die of AIDS, the highest number so far in a single year.

2000. In the South of the United States, more women with AIDS report their exposure as heterosexual contact than injecting drug use and approximately three to four times more cases are reported from the South than from the Midwest and West. Forty-five thousand 15 to 44-year-old women are reported to be living with AIDS in the United States. Sixty-three percent of women reported with AIDS are African-American. Ofra Haza, internationally known Israeli singer, dies of AIDS in Tel Aviv. Coretta Scott King launches the AIDS Memorial Quilt to black colleges and Universities. One of four pregnant women in South Africa are reported to be living with HIV.

The Food and Drug Administration (FDA) passes the Clinical Hold Rule. This allows the FDA to delay or suspend any clinical trial that's found to exclude women (or men) because of their "reproductive potential." This dramatically increases the opportunity for women with HIV to take advantage of drug trials and other treatment research. Valerie Reeder-Bey along with her granddaughter Annisha Monic Wilburn publish "My Grandma Has AIDS: Annisha's Story." Valerie has been living with HIV since the late 1980s and is the co-founder of Heaven In View, Inc. "A Positive Force."

2001. UNAIDS found that in India women are often blamed

by their parents and in-laws for infecting their husbands or for not controlling their partners urges to have sex with other women. At a conference in Chicago, conference attendee Judy Delmar stated, "This disease does not necessarily behave the same way in both genders. It's just a different disease in women." (The statement was made in response to the need for women to be included in clinical drug trials and other AIDS-related research.) An article written by Jane P. Fowler, on persons living with HIV over 50, is published in *Positive Living*. Jane is a woman living with HIV who was diagnosed at the age of 55 and is the co-chair of the National Association on HIV over Fifty. Dr. Mathilde Krim, Founding Chairman and Chairman of the Board of the American Foundation for AIDS Research (amfAR), receives the African-America Institute's Award for Individual Vision and Achievement.

The Natural Family Living magazine, *Mothering*, cover page article is "HIV-Positive Moms Say No to AIDS Drug; Special Report: HIV, Families & Medical Justice." Many of the articles describe the stories of several HIV-positive women who chose not to use anti-HIV medications during pregnancy in order to avoid the possibility of side effects and toxins that could affect their unborn child. Another article describes one HIV-positive woman's fight to breast feed her child despite her doctor's protest. *Blood Ties: The Stories of Five Positive Women*, edited by Salli Trathen, is available in print. This book describes the lives of five Australian women who are living with HIV/AIDS.

After six years as the Director of the National Center for HIV, STD, and TB Prevention with the Centers for Disease Control in Atlanta, Dr. Helen

Gayle resigns to become the Bill and Melinda Gates Foundation's senior advisor on HIV. Korrin Krause, a sixteen year old girl living with HIV, is fired from her job at the Quality Foods IGA in Wisconsin. A store representative stated that he did not want other store workers "to take this (HIV) home to our families." The Equal Employment Opportunity Commission has sided with Krause in May, however, a settlement has not been reached.

2002. *Women, cure, HIV/AIDS, forever.*

