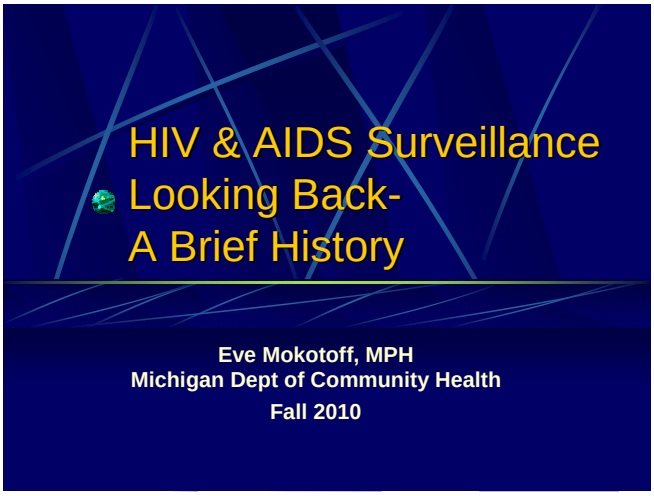
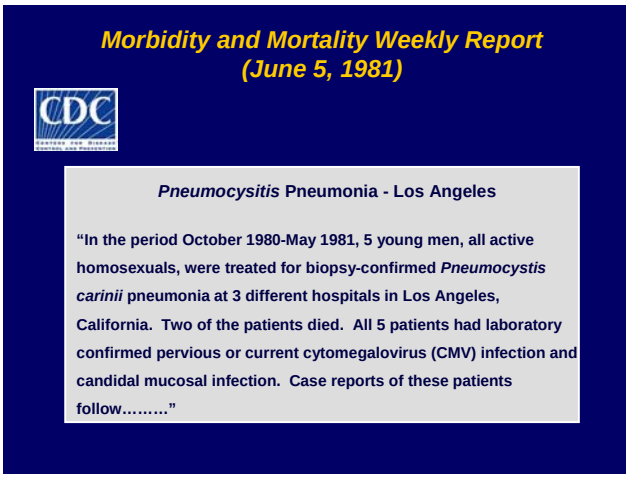
Surveillance for HIV/AIDS
Eve Mokotoff

Looking Back



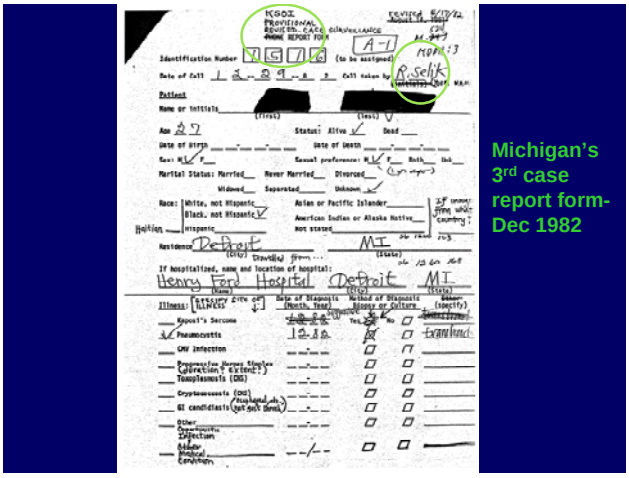
AIDS surveillance in the United States started when it was first described in June 1981 by physicians in Los Angeles and New York City who began reporting previously healthy, severely immune suppressed gay men appearing for care close to death.



The initial case definition was informal and included reported cases of Kaposi's sarcoma (KS) and Pneuomocystis carinii pneumonia (PCP) in young homosexual men.

In 1982 more opportunistic illnesses (OIs) were added. Up until September 1982 CDC officially referred to the syndrome with the neutral, if somewhat cumbersome, term "Kaposi's sarcoma and opportunistic infections in previously healthy persons." By this time there were already

Morbidity and Mortality Weekly Report (MMWR) articles describing similar symptoms among Haitians and persons with Hemophilia A. In the September 24, 1982 MMWR they started using the term Acquired Immune Deficiency Syndrome- AIDS. However, elsewhere the association between AIDS and homosexual men persisted and the term Gay Related Immune Deficiency (GRID) was used in the more general scientific and lay press. (Shilts) Initially case reports were taken verbally over the phone by the Centers for Disease Control and Prevention (CDC). Richard Selik, still a part of HICSB at CDC, took one of the first verbal case reports from Michigan.

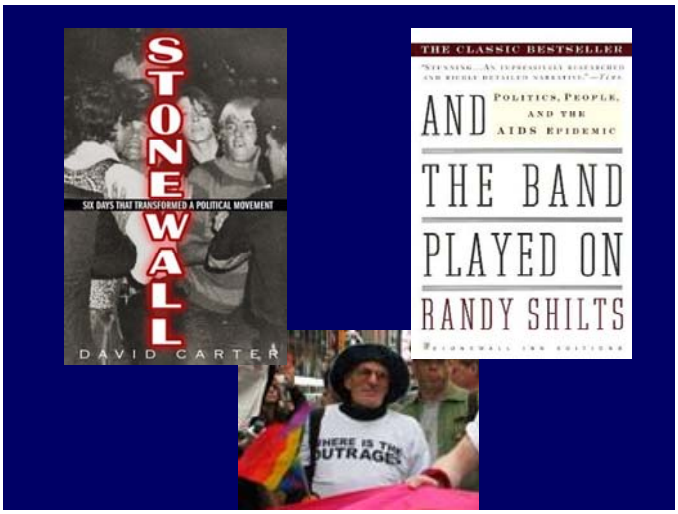


Notice the name of the syndrome in December 1982- KSOI

In 1985 what became known as Human Immunodeficiency Virus (HIV) was identified as the causative agent of AIDS. Later that year, when the first HIV antibody tests were released and laboratories began to offer testing, it became possible, to conduct surveillance for the virus itself. But the political environment and fear of this heretofore unknown and largely unexplored virus made for public health policy that was driven more by prejudice and fear than by sound public health principles that had been used to successfully combat previous communicable disease threats. This environment had a powerful impact on surveillance and, one could argue, impeded its natural evolution.

It would be incomplete to discuss the history of surveillance for AIDS and HIV infection without a discussion of this political context. In the United States, the most vocal initial people presenting with this syndrome were white gay men. In the decade just prior to these first cases in

1981, the rise of the modern gay rights movement began. Its beginning is attributed to the June 1969 Stonewall Riots in New York City 41 years ago this month where gay men and women finally fought back after decades of oppression and harassment.



To Quote Randy Shilts in his 1987 treatise "And The Band Played On" future gay pride events (that usually take place in June) commemorate "the riot in which Greenwich Village drag queens attacked police engaged in the routine harassment of a gay bar called the Stonewall Inn. From the Stonewall Riot, ….the gay liberation movement was born, peopled by angry men and women."

People often ask why this book- the classic history of the early days of HIV and AIDS and which should be required reading for anyone working in HIV-- is called "and the band played on". It represents the way the disease was ignored as long as it only affected "those people". As in, "while we were dying, the band played on, and on and on". We are in a crisis and no one is listening to us. Shilts himself died of AIDS in 1994.

This epidemic appeared on the heels of the active political gay liberation movement. The movement said you are not sick for having same sex desires. Gay people were taking pride in who they were and expressing it through their sexuality. By 1973 even the American Psychological Association had said that homosexuality was not, itself, a disease. For gay men this liberation movement meant no more shame about their desires and, for some, it meant many, many partners. When this epidemic started, messages that were meant to protect them from what

seemed to be an infection felt like they were being pushed back into the closet of denial. It was impossible to do effective surveillance or prevention work in this country without understanding what it meant to gay men in the early 1980s to be told stop having anonymous unprotected sex.

Someone once said to me but gay men had sky-high rates of syphilis and Hepatitis B in the years leading up to this epidemic, what were they thinking? My answer is, they were thinking I AM, FINALLY, NOT A BAD PERSON. Being men they went over board with the sex but it was very much BECAUSE this infection appeared just as these men were feeling comfortable and confident as gay men that it was able to infiltrate itself into the population. Of course they should have recognized that all that syphilis and Hepatitis B were not a good thing but, as you know, this just isn't how people think.

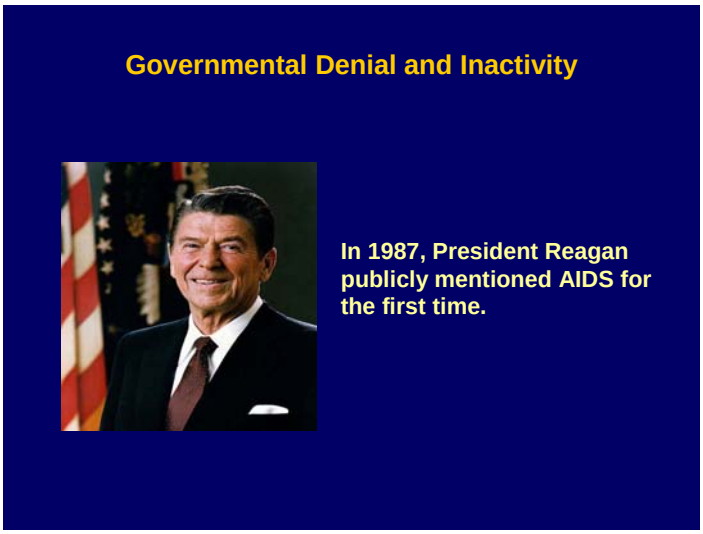
Albeit gay, as white men they were used to having access to decision makers in their communities. They were not satisfied with the little attention being given to something that was decimating their community. When their peers started dying from a new disease there was anger about the lack of action taken to combat it.

However, the political leadership of the United States was silent about this explosion of deaths among young men in the prime of their lives. This was in contrast to the publicity and political discourse that followed the initial outbreaks of Legionnaire's Disease in 1976 at the Bellevue Stratford Hotel in Philadelphia and Toxic Shock Syndrome in 1980.

Legionnaire's disease was named after the people who experienced the first outbreak -- members of the American Legion – an organization of veterans of the United States armed forces who served in wartime. Toxic Shock Syndrome attacked menstruating women. You can't get more mainstream than veterans and women of childbearing age. As soon as the first outbreaks were detected our health infrastructure mobilized and tackled the problem.

HIV, on the other hand, affected members of society that some people thought deserved what they got. However, the white gay community expected and wanted the same kind of discussion

and action that was taken with Legionnaire's Disease and Toxic Shock Syndrome when this syndrome appeared. They were to be disappointed.



Indeed the President of the United States at the time, Ronald Reagan, did not even mention the illness until 27,000 Americans were dead or dying from it. In early 1987, six years after the first cases were described, the US was the only industrialized nation that had not launched a coordinated education campaign. (Shilts) Six years into the epidemic the President finally uttered the word AIDS but had still not given an address on the topic. The President had not even met with his Surgeon General to discuss the epidemic. I clearly recall listening to a radio report of the President discussing **aid** to the Nicaraguan contra rebels, he slipped and said the word AIDS, corrected himself, chuckled (chuckled!) and went on with his discussion of Nicaragua. The silence was thundering. Finally on May 31, 1987, six years after the first reports, President Reagan gave his first address on AIDS. At that time 36,058 Americans had been diagnosed with AIDS and 20,849 had died. (Shilts) How did we know that? The work we do in HIV surveillance.

The white gay community's relationship to AIDS surveillance was paradoxical. They did not trust the government since it had shown little practice of protecting their rights in the past. However, they knew that in order to argue their needs they needed the numbers that surveillance could give them to show the severity of the epidemic. In New York City in the late 1980's, a CDC physician was working on setting up a surveillance project among outpatients with

HIV/AIDS. Once, when asked by a frustrated member of the community if public health officials realized how bad the AIDS epidemic really was, he responded “Exactly!”

The need for the numbers won out. Most people with AIDS were so sick that they were not working and died soon after diagnosis.

Consequently, it was felt that the risk of violation of confidentiality was outweighed by public health’s need to obtain the case reports and, by and large, the white gay community did not fight name-based AIDS reporting. Rather rapidly AIDS became a notifiable disease using a name-based reporting system in all 50 states. The acceptance of AIDS surveillance was assisted by the fact that, after the initial period of reporting that was done by calling CDC directly (through 1982), patient names were not sent to CDC.

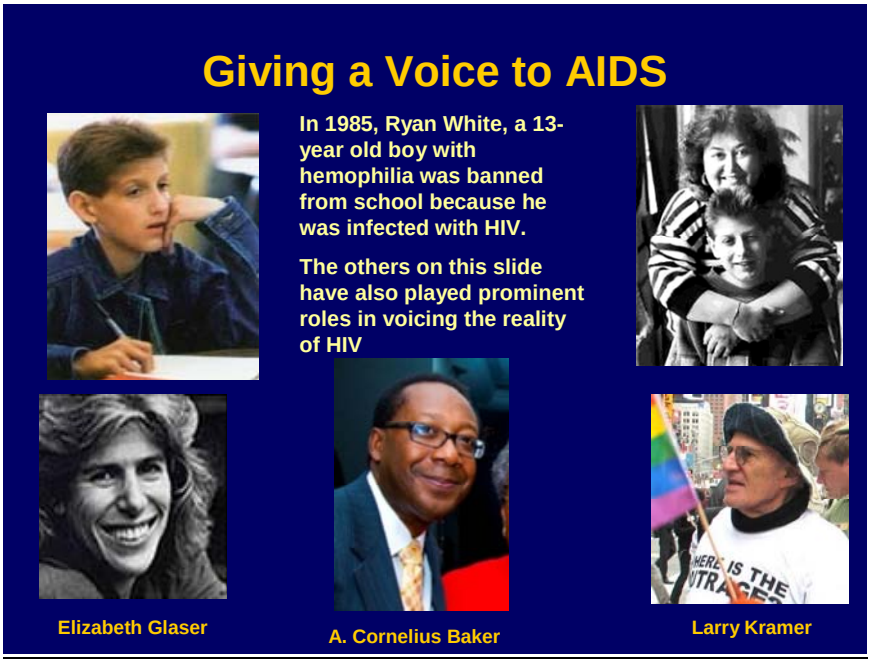
Politically, reporting of HIV infection was another matter entirely. Now public health (“The Government”) wanted the names, mode of transmission and other personal information on people who may not even appear ill. They were still working and had active lives. Many believed that they had more to lose if it became known that they were HIV-infected than did their sicker peers who had AIDS. Despite the availability of drugs to treat the major OIs, prior to the HAART era in 1996 there appeared to be little benefit to getting tested. Consequently, measuring the “leading edge” of the epidemic in the late 1980’s and early 1990’s relied on anonymous seroprevalence surveys conducted in public health clinics that treated people with STDs, TB or that provided family planning services.

Without an incentive to get tested for HIV before the appearance of AIDS-related clinical symptoms, HIV reporting was not a priority in the 1980s. By the 1990s as more effective treatments were developed and improved, the push for HIV reporting increased.

It would be inaccurate however to portray the epidemic in the mid 1980's as occurring entirely in white gay men.

Although they made themselves the most visible, the risk of infection was as high or higher for less noticeable men who had sex with men, many of whom did not identify as gay and were from a broad spectrum of race and socioeconomic groups. In the early days of this epidemic "gay" was code for "white" and "IVDU" was code for "black" or "Hispanic". There was very little discussion or recognition of the risk for black MSM. I personally believe that it was the virtual ignoring of infection among MSM of color that has put us in the situation we are now in with black MSM having HIV infection rates on par with countries in Southern Africa.

In addition to MSM and IDUs, hemophiliacs who received Factor XIII or IX blood clotting treatments were also notably affected by HIV. Some estimates suggested that before heat treatment of clotting treatment 90+% of severe hemophiliacs were HIV infected. The most legendary of these was Ryan White.



This slide shows a photo of him on the left and with his mother, Jeanne White Ginder, on the right.

Also on this slide are photos of others who have each played prominent roles in voicing the reality of HIV.

Elizabeth Glaser was infected with HIV in 1981 through a blood transfusion she received after giving birth. It was unknowingly transmitted to her daughter and son. In response to her children's illness and death she and her friends created the Elizabeth Glaser Pediatric AIDS Foundation. Their mission includes reducing and preventing HIV transmission from mother to child and accelerating the discovery of new treatments for other serious and life-threatening pediatric diseases. In 1994, Elizabeth died of HIV complications. Today, the Foundation continues to serve as a voice for children. It carries out its work to stop pediatric AIDS all over the world.

Cornelius Baker is a current colleague. A brief summary of his work includes serving as the executive director of the National Association of People with AIDS (NAPWA) and the executive director of the Whitman-Walker Clinic, which services the LGBT and HIV communities in Washington, DC as well as being the national policy advisor for the National Black Gay Men's

Advocacy Coalition. He works tirelessly for infected people but especially gives a prominent voice to black gay men.

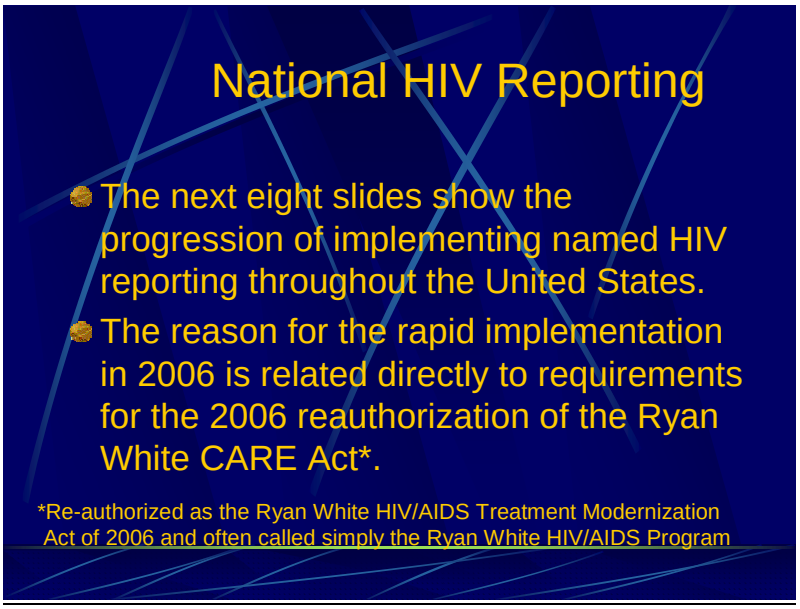
Larry Kramer's boundless outrage changed the course of AIDS. His shirt in this slide sums it up- it says "where is the outrage?" When I heard him speak about 5 years ago he was referring to breast cancer and said to the women in the room "Why are you so silent about this? Why are you not screaming about this?"

Since 2010 is the 20th anniversary of Ryan White's death I want to talk about who he was, in case some of you only associate his name with the care legislation. He and his family lived in Kokomo, Indiana and he was diagnosed with AIDS in December 1984 at the age of 13. He was then expelled from middle school. As a result he and his mother, Jeanne White Ginder, fought for his right to attend school, gaining international attention as a voice of reason about HIV/AIDS. It took multiple court hearings with testimony from medical experts for him to be able to attend school. However, his mother reports "It was really bad. People were really cruel, people said that he had to be gay, that he had to have done something bad or wrong, or he wouldn't have had it. It was God's punishment; we heard the God's punishment a lot. That somehow, some way he had done something he shouldn't have done or he wouldn't have gotten AIDS."

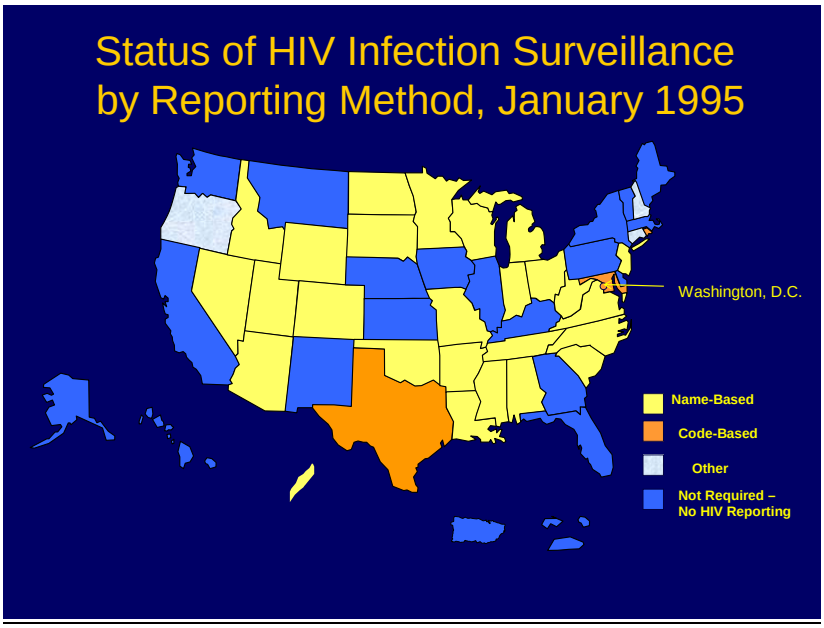
He died on April 8, 1990, at the age of 18, just months before Congress passed the AIDS bill that bears his name – the Ryan White CARE (Comprehensive AIDS Resources Emergency) Act. The legislation has been reauthorized four times since – in 1996, 2000, 2006, and 2009.

Another hemophilia related account of discrimination that gives you a flavor of what it was like in the 1980's was the Ray family of Arcadia Florida. In August 1987 a suspicious fire destroyed their home. The family included three young brothers infected with HIV and the blaze capped a week of bomb and death threats and a school boycott resulting from the brothers' return to classes at the start of the new school year. The Ray brothers had been a focus of national attention as a result of their parents' legal effort to have them reinstated in school.

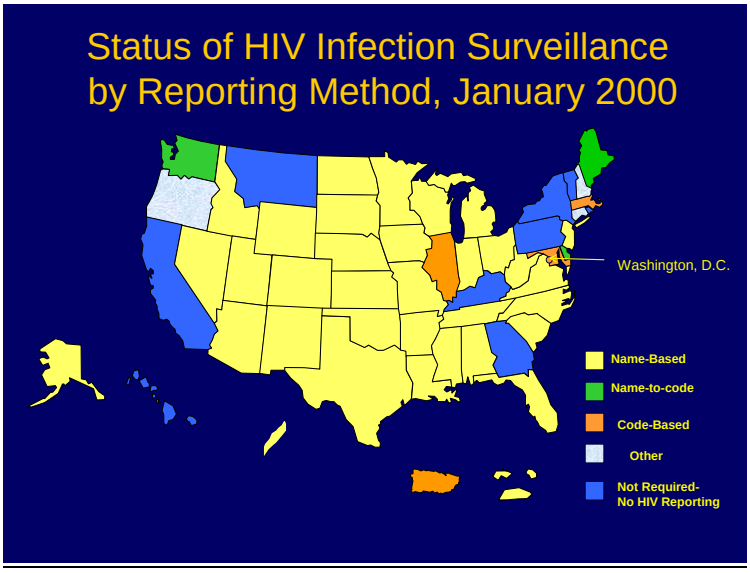
I want to turn now to the development of a comprehensive HIV surveillance system in the United States.



The next eight slides show the progression of implementing named HIV reporting throughout the United States. The reason for the rapid implementation in 2006 that you will see is related directly to requirements for the 2006 reauthorization of the Ryan White CARE Act. In 2006 the CARE Act was re-authorized as the Ryan White HIV/AIDS Treatment Modernization Act of 2006 and is often simply called the Ryan White HIV/AIDS Program.

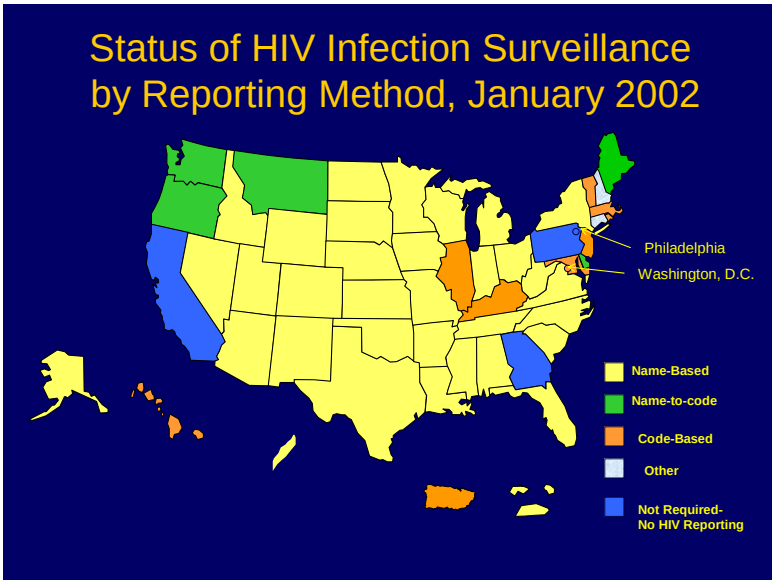


This is the state of HIV surveillance in January 1995. The yellow states had named HIV reporting; the orange states used various coded systems; blue states had no HIV reporting and the light blue states had other methods. This slide shows you the situation before the beginning of the HAART era- that is 1996 when highly active anti retroviral therapy allowed people with HIV to live longer -- it gave people a reason to find out they were HIV+ since HAART was extending lives. CDC did not accept HIV data from states that reported HIV using codes because they did not think they could be sufficiently unduplicated. So as I go through these slides be aware that any state that is not yellow did not have data that were part of the national HIV data set and statistical reports.

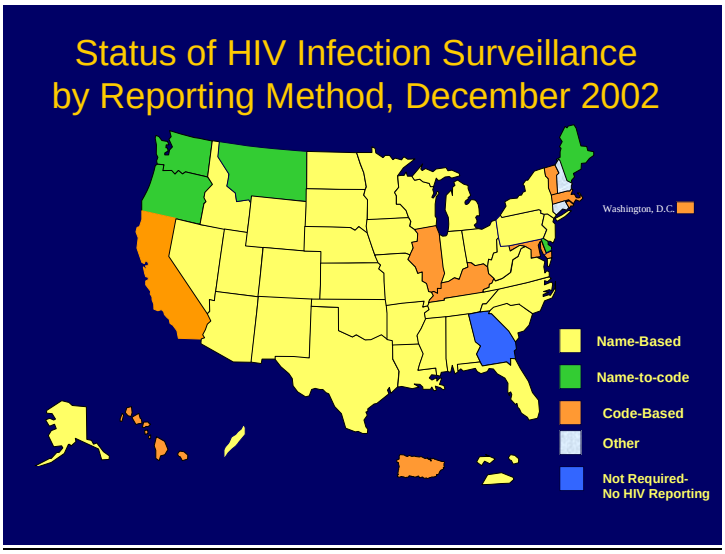


You can see a lot of progress since 1995- many fewer blue states with no HIV reporting system with Texas converting from a code based to a name based HIV reporting state and FL going from no reporting to named based reporting. However notice that, almost 20 years after the first AIDS cases were identified and reported we still did not have named (or code) reporting in CA and NY which together account for about a third of the nation's AIDS morbidity. CA is second only to NY in number of cases reported and alone accounts for ~14% of all cases in the country - NY ~18%. FL (10%) and TX (7%) follow.

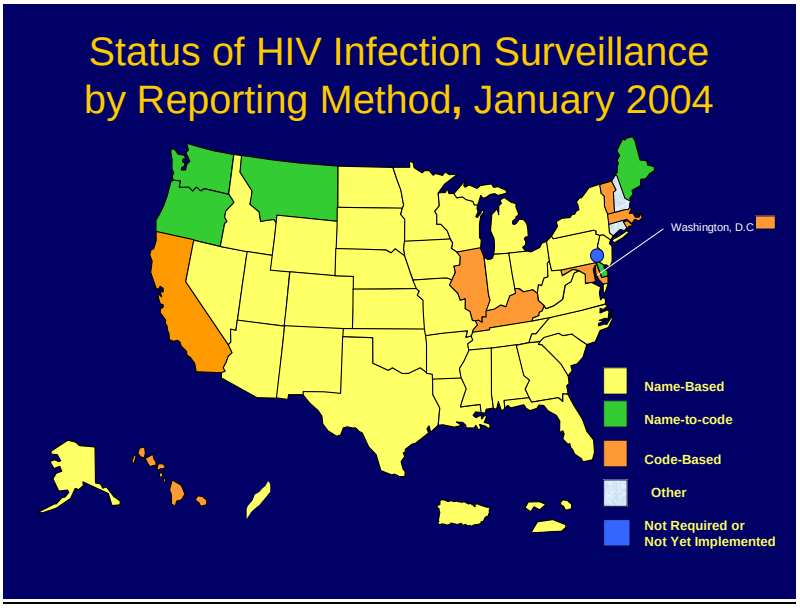
In this slide the meaning of the yellow, orange and blue and light blue colors mean the same reporting method as displayed in the previous slide. However, here you see green colored states. These states used a name to code system meaning the local health departments got the name but the state health department received only a code.



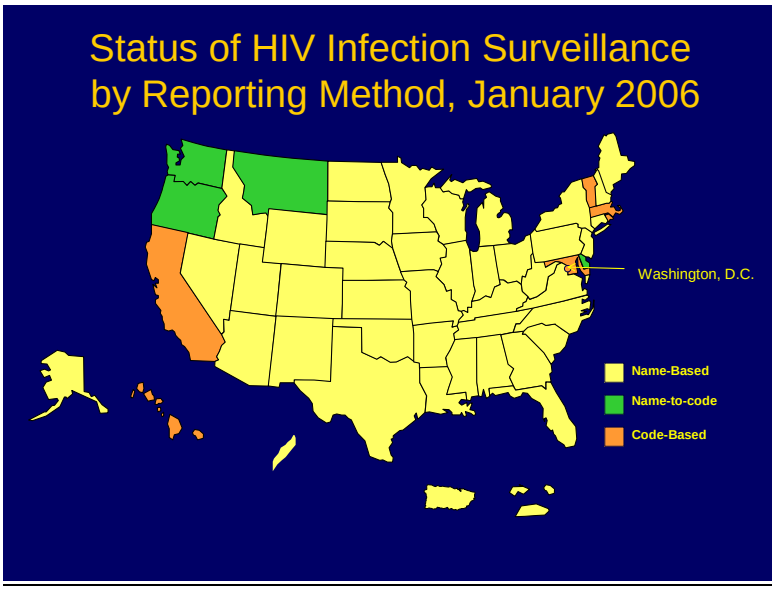
In this slide- January 2002, you see more progress with the important state of New York beginning name based HIV reporting.



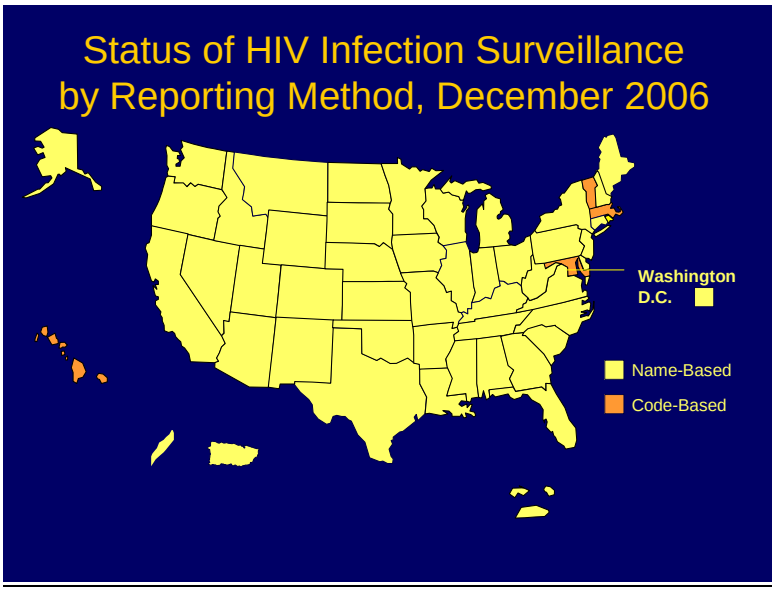
By the end of 2002 California started code based HIV reporting and leaving Georgia as the only state without an HIV reporting system.



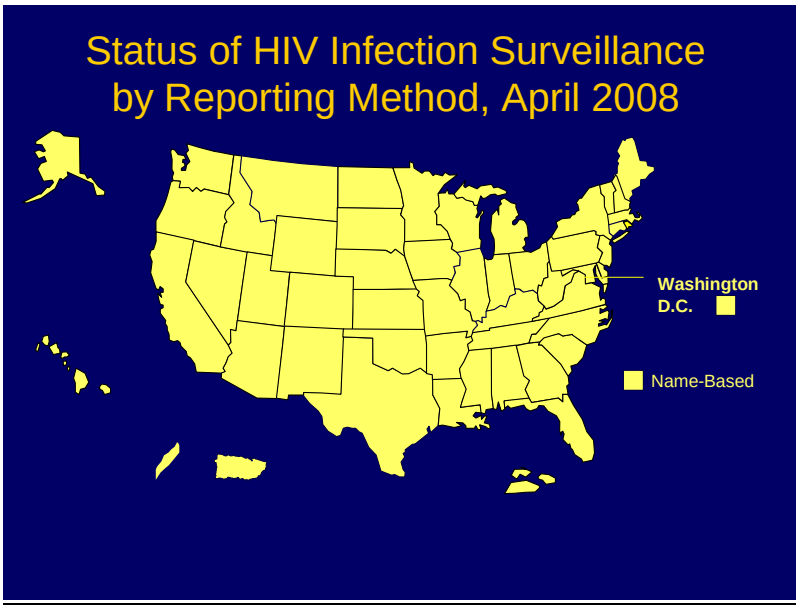
By the beginning of 2004 Georgia had named based reporting.



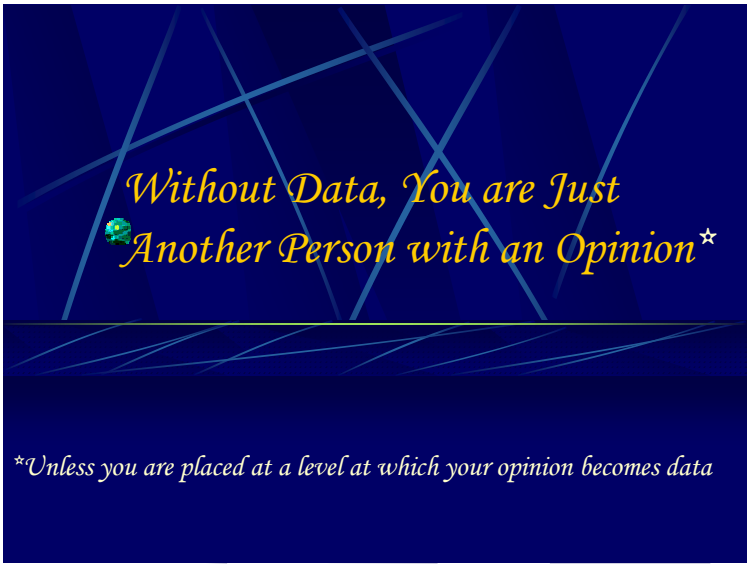
Between this slide - January 2006 and the next slide - December 2006 you will see that 2006 was a pivotal year for the change over to name based HIV reporting. CDC sent out a letter recommending named HIV reporting. In addition the belief that it was inevitable that the RWCA re-authorization would result in counting HIV cases for the formula allowed many states to overcome the political opposition to name based HIV reporting. CA introduced legislation to start the conversion to named reporting in this critically important state. Remember that CDC did not accept data from non name reporting states and so, without, CA we still did not, 25 years after the first AIDS reports, have a NATIONAL HIV reporting system.



Here we are at the end of 2006 – almost there



April 2008- Finally everyone has named based HIV reporting! However, CDC does not include states' HIV data in most parts of the national surveillance report for statistical adjustment reasons until they have a "mature" system, deemed to take 4 years. It will be 2012 -- 31 years after the first AIDS case reports -- that we will have a truly national HIV statistical report and that report probably will not come out until 2014.



I want to close with one of my favorite slides and thank the people who gave me feedback on this presentation. Lucia Torian from NYC gave me particularly detailed & helpful comments and Jim Vergeront, Director of Wisconsin's AIDS/HIV Program provided some of the visuals I used. Last I want to thank my staff who continue to teach me about surveillance and all of you who work in HIV surveillance at the city, state and national levels, who are out there every day caring about the quality of the data that we collect and doing our best to get the data analyzed and back out there to be used to stop this epidemic. Never forget that that is why we collect it. Thank you.