



30 Years of Striving and Surviving Thanks to the Ryan White Program

December 4, 2020 World AIDS Day Celebration





Building the Case for RW Services on Long Island

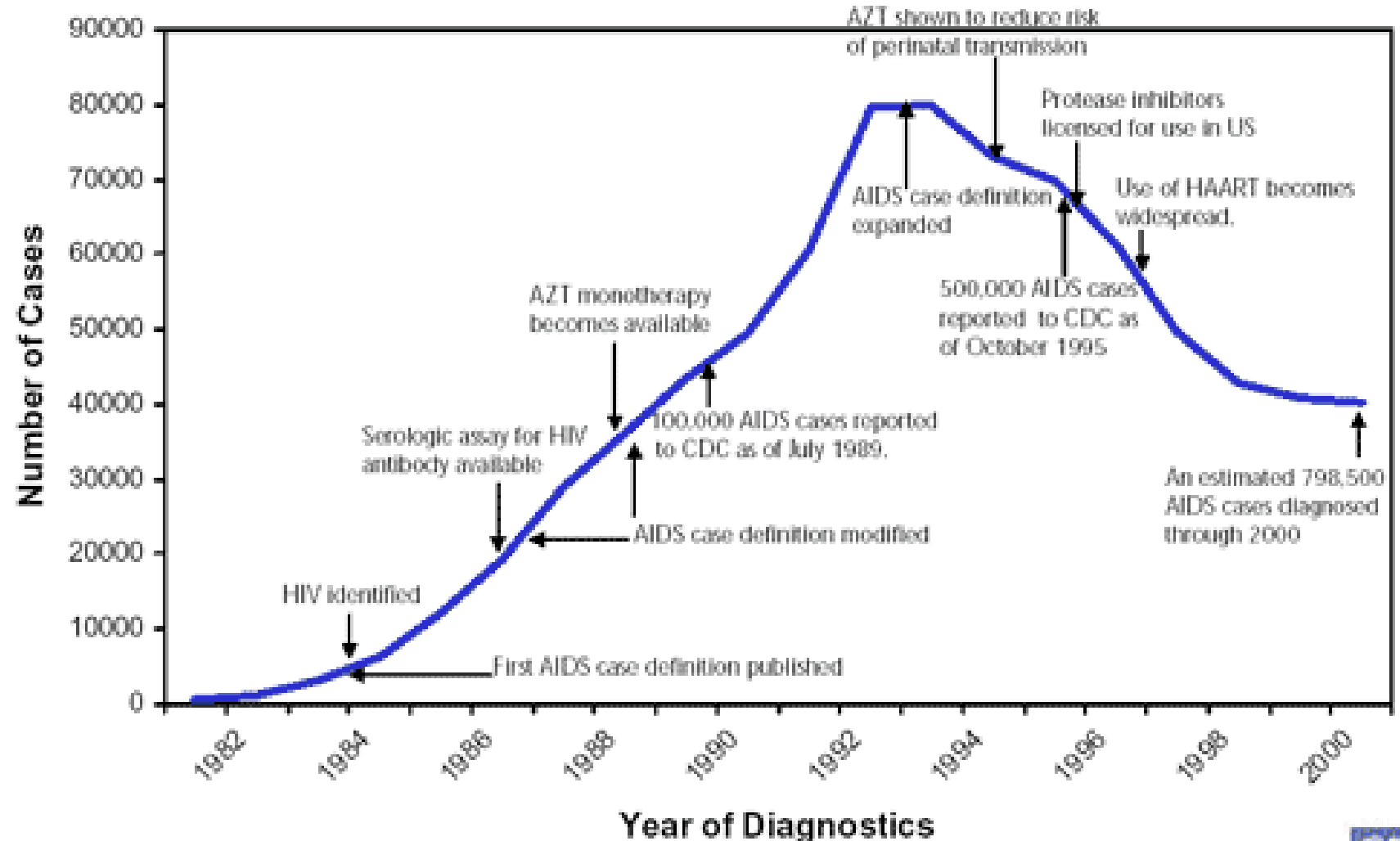
The impact of community planning



Evolution of an Epidemic

Estimated AIDS incidence* through 2000, United States

The first cases of AIDS were reported on Long Island in 1981.



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Developing a Service System

Early systems of care and services on Long Island

1983

- In 1983, NSUH organized an AIDS program. It was the first Long Island Hospital to do so.
- In June of that year, the School of Health Professionals at the State University of NY at Stony Brook presented a continuing education program entitled “AIDS: The New Epidemic”. The presentation was led by Rose Walton and Robert Hawkins.
- They were concerned with the absence of care services for people with AIDS on Long Island.
- More than 200 people attended this presentation, ushering Long Island’s biggest formal response to AIDS.

1984

- The Long Island AIDS Project opened an office, set up its hotline, and began to create a service organization.
- NYS initiated anonymous testing and Designated AIDS Centers (DACs).
- On Long Island, three hospitals became DACs - the Nassau University Medical Center (formerly Nassau County Medical Center), the North Shore University Hospital and the Stony Brook University Hospital.
- Together with the community service agencies, the local components of these programs became cornerstones of the service system for people with HIV/AIDS on Long Island.

1986

- The Long Island Association for AIDS Care was founded. They worked collaboratively with the SB School of Allied Health on educational programming.
- A consortium of NC agencies organized by NUMC and LIAAC was funded by the Robert Wood Johnson Foundation to develop a model for AIDS care in the suburbs.
- Housing for 6 clients with AIDS was established by the INN.

Expanding Services

Collaborative Efforts to Secure Funding for Long Island

1988

- Cases grew to **900** ranking the N-S Statistical Metropolitan Area in 17th place for AIDS Incidence.
- County government stepped up its role by making a commitment to bi-county cooperation in stemming the epidemic.
- The N-S Health Systems Agency was commissioned to develop a plan.
- A report was issued outlining the importance of education programs, alternatives to hospital based programs, and the development of multi-service plans for PLWH.

1988

- A demonstration grant was written which focused on case management and testing.
- A two year grant from HRSA was approved in the fall of 1988.
- The Long Island Minority AIDS Coalition was created in response to the rising number of infections in communities of color.

1990

- HRSA provided a one year extension to the demonstration grant.
- When the project ended, the State took over the funding of activities under the AIDS Institute through Ryan White Title II.



President George H.W. Bush signs Ryan White Comprehensive AIDS Resources Emergency (CARE) Act

- The legislation was signed on August 18, 1990 and named in memory of teen HIV activist Ryan White.
- The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 was established to help cities, states, and local organizations to provide services to persons living with HIV. The legislation was reauthorized in 1996, 2000, 2006, and 2009 and is now known as the Ryan White Treatment Extension Act of 2009 or the Ryan White Program.
- It is the nation's largest HIV-specific federal grant program.



Ryan White

The Indiana teen who became a national spokesperson for AIDS education, treatment, and funding, dies of AIDS-related illness at the age of 18.

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The Ryan White Program Comes to Long Island

- Between 1988 and 1990 the number of HIV positive individuals on Long Island continued to increase.
- In the fall of 1991, representatives in the region realized that Long Island might be eligible for Ryan White Title I funds if they could accelerate the pace of documenting the number of AIDS cases locally.
- So, representatives from the region began reaching out to the large hospitals.
- These efforts allowed the region to apply for funds a year earlier than expected since the region was able to document the 2,000 cases necessary to be eligible for funding.
- **In 1993, the region received its first Ryan White Title I award of \$1 million dollars.**



Building the Continuum of Care

- Even with the new funding, gaps in services were increasing and barriers to care were everywhere.
- With the creation of the Nassau-Suffolk HIV Health Services Planning Council and the development of the Comprehensive Services Plan, a blueprint for the response to the epidemic was laid out and continues to serve as the backbone of our service system today.
- Throughout the development of Long Island's HIV care system consumers have been integral in service provision, policy making, activism and the support systems that make up our rich continuum of care.



Ryan White Services On Long Island

ACCESS. CARE. QUALITY.



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Fast Forward to 2020

30 years since the Ryan White Program began...

Service System

- The Long Island region now receives over 5.5 million in Ryan White and Minority AIDS Initiative funding each year.
- Part A funds support 15 providers on Long Island.
- Funded services include: Outpatient Ambulatory Health Services, ADAP, Medial Case Management, Oral Health, Mental Health, Medical Nutrition Therapy, Early Intervention Services, Legal Services, Medical Transportation and Emergency Financial Assistance.
- In 2019 Ryan White Part A served 2,926 clients providing over 75,461 units of services.
- **93%** of PLWH with any care were virally suppressed!

Planning

- The region has an active planning body (The Nassau-Suffolk HIV Health Services Planning Council) that is responsible for conducting needs assessments, prioritizing services and allocating funds that ensure a cost effective and comprehensive system of care.
- The Council continues to rely on strong consumer participation which is integral to helping shape the service delivery system.
- The region continues to coordinate with other Planning Bodies, Ryan White Parts and the state to update the Comprehensive Service Plan (now referred to as the Integrated Plan).





Because of the Ryan White Program we are: Striving and Surviving

Facing HIV AIDS through access, care and quality until we
get to ZERO new infections!

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Facing AIDS

Together for our communities

