

## From AIDS to the Coronavirus and Beyond: Let's Break the Shackles of History, Together



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Jan Sport, Jasmine Rice LaBeija, <u>Rosé</u>, <u>Castrata</u>, <u>Lagoona Blue</u>, <u>Pissi Myles</u>, <u>Brita Filter</u>, <u>Crystal Demure</u>, <u>Nicky</u> <u>Doll</u> celebrate diversity as part of VNSNY's recognition of #PRIDE2020 & COVID-19 Frontline Health Workers

As a public health nurse, a gay man and a New Yorker, I have lived, cared and lost through the AIDS crisis and the coronavirus pandemic. Across the span of four decades, I see far more similarities than I'd like in how we are dealing with both pandemics. I also see — and am fortunate to be part of — a better way forward, which starts with making plans to ensure that all vulnerable people in our society have access to and are linked to healthcare, bringing all communities to the healthcare table and learning as Americans that we are all connected to one another.

Yet it must be noted, especially at this moment in time, when PRIDE events are coinciding with ongoing Black Lives Matter protests throughout the nation, how deeply discrimination still tarnishes the freedoms we've fought so hard to win.



In the 1980s, I spent frightening and mentally exhausting months caring for my partner as his life was being quickly taken away by AIDS. Recently, I've been monitoring oxygen levels, arranging telehealth visits with our doctor, delivering trays of food, and compulsively washing hands and surfaces to care for my husband, who is finally on the long road to recovery from COVID-19 — neither of us knowing what would happen next at each step along the way. I was more than uncomfortable with frequent flashbacks of my experience during the AIDS crisis. The exhaustion itself, a new reminder of inner and outer protests from the past.

As a public health nurse, then and now, I have cared for so many others — individuals and, person by person, whole communities — suffering from these two devastating, isolating diseases.

A painful history can be seen in the cruelty and heartbreak of people dying alone, having no known treatment and not knowing what would be happening next. In the 1980s and 1990s, the isolation was because of stigma, fear of a disease about which so little was known, and fear, by association, of gay men, who were on the margins of society in the first place. As a young nurse with the **Visiting Nurse Service of New York** (VNSNY) doing infusions for desperately ill AIDS patients in their homes, I saw far too many patients and friends die of a disease that spared no one,(at that time) I redoubled my commitment to be part of VNSNY's pioneering health care force, which leads the way in not only delivering clinical care but also disseminating information, helping patients navigate stigma and isolation, and creating home health care programs to support vital quality care at home.

With coronavirus, it's the easy transmissibility that isolates people from their loved ones in their final days. Family and friends cannot see loved ones or mourn together. Health care workers — in head-to-toe protective gear — stand in for loved ones where they can. This includes some of my courageous, compassionate nursing colleagues in VNSNY Hospice, who have told me stories of convening tearful FaceTime goodbyes, holding a hand in the final moments, and blowing a kiss to a dying mother at a grieving daughter's request.

Coronavirus, like AIDS, preys disproportionately on people in black, ethnic and other minority at-risk groups and in underserved communities.



My younger self — a nurse during the AIDS crisis, comforting largely marginalized people facing what was then a certain death sentence — would have been surprised to see how little progress we've made in closing the gaps in health disparities. Progress remains painfully slow in making sure people have access to the care, food, housing and support they need to live healthy lives, whether during the current pandemic, a new mysterious disease, or in response to America's ongoing epidemic of chronic illnesses like diabetes, hypertension and heart disease.

At the same time, my younger self also would have been proud — and indeed I am — of how community health organizations like the one I still work for are addressing social determinants of health.



New York Pride March 2019 Stonewall 50

Through forward-looking collaborative partnerships, we bring comprehensive quality care directly into the home, taking a holistic view that includes making sure people have food in the refrigerator, adequate heat and air-conditioning, and a way to obtain and correctly take needed medications as well as other day-to-day necessities.

We in the LGBTQ community stand on stronger footing now than ever before. Forty years after the emergence of the AIDS crisis and fifty years after Stonewall, LGBTQ Americans find themselves living in a world of more emerging "normalcy," PRIDE, and marriage equality. When I am caregiving for my husband during an epidemic with so many unknowns, it is no small consolation to know that we are married under the law, with certain bedrock rights, as referenced in the NYC Department of Health LGBTQ Health Care Bill of Rights.

But there is more to do. LGBTQ New Yorkers who are 55 and older — the people I serve most closely in my role as LGBTQ Program Director for VNSNY — are once again in a high-risk group during a pandemic, and social isolation is again the order of the day. Even before the virus, LGBTQ seniors were much more likely than their non-LGBTQ peers to avoid the health care system as they age — which is when they need access most — and to report feeling more isolated and vulnerable, according to **SAGE**, the advocacy group for LGBTQ seniors. I am again proud of our organization for ensuring that every employee — from senior leadership to top managers, to administrative assistants and clinicians across all divisions — has taken SAGE training in how to provide safe, culturally sensitive and trusted care to this population.

This June, as we connect in PRIDE while social distancing, it is more important than ever to ensure that LGBTQ seniors of all backgrounds are able to age more safely and in better health. To help make that happen, VNSNY's **Center for Home Care Policy and Research** has teamed up with SAGE on a survey of LGBTQ New Yorkers age 55 and up. Data from the survey will be used to understand how older adults perceive and experience their own communities, to pinpoint barriers to aging well, accessing health care, transportation and adequate housing — and to create solutions. **We encourage all 55+ LGBTQ+ New Yorkers to fill out the survey.** 



Public Service Video for AdvantAge Survey, featuring Drag Artist and Founder of Wigstock, Lady Bunny



SAGE AdvantAge Initiative Survey of LGBTQ+ Older Adults in NYC\_www.vnsny.org/LGBTQ-SAGEsurvey

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To bridge isolation and create the connections we yearn for these days, we must continue to raise our voices — an important quality of being proud, but also of being *heard* on these essential matters of healthcare and aging. If we look closely across the decades, we can see the real path forward to healthier living and the antidote to dying alone: living, learning and moving forward *together*.