

Nothing About Us Without Us: Civic Engagement and the HIV Community

Track 2: Our Voices

Policy and External Relations Work Group
New York City HIV Planning Group

Iris House Conference
May 6, 2019

Agenda

- Introduction of NYC HIV Planning Group (HPG) and Policy and External Relations Work Group (PER)
- Review of 4/9/19 HPG Presentation
- Brief History of HIV Activism in New York City
- Overview of Civic Engagement for New York City HIV Planning Group
- Restrictions on Lobbying for Organizations Who Receive Federal Funds
- Issue 1: Safe Injection Facilities
- Issue 2: Sexual Health Education in Schools
- Issue 3: Sex Work
- What Next?

New York City HIV Planning Group (NYC HPG): *We Slay Stigma*



Photo credit William Nazareth

- The NYC HPG was created in 1994 with a primary goal of **reducing the incidence of new HIV infections in New York City.**
- The NYC HPG is a joint effort of community and governmental representatives and agencies that works to inform the New York City Health Department's HIV prevention efforts.
- In particular, the HPG helps New York City Department of Health learn from impacted communities about how best to meet local HIV prevention needs. Input from those communities helps the New York City Department of Health in its decision making processes around the allocation of CDC prevention funds.
- You can join us! For more information contact Linda Battle at lbattle@health.nyc.gov or (347) 396-7689

Policy & External Relations (PER) Work Group

The NYC HPG Policy and External Relations (PER) Work Group works to support policy initiatives related to the New York City Health Department's efforts to end the epidemic, and to strengthen relationships across institutions and communities across New York City.

The members of the NYC PER Work Group in 2019 are:

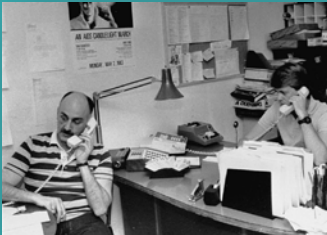
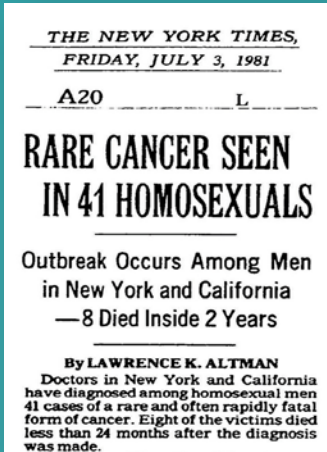
- Adrian Guzman*
- Alexander Borsa
- Bianca Lopez*
- Diane Tider
- Leah Richberg
- Margaret Paschen-Wolff
- Mary Brewster
- Rachel O'Sullivan
- Sabastian Roy-Noriega



While HPG cannot lobby or advocate, PER seeks to help educate community members about state bills introduced in the 2019-2020 state legislative session that are relevant to New Yorkers affected by HIV.

After review of a significant number of proposed laws, PER narrowed its focus to 5 – choosing those with greatest impact on the greatest numbers of people, and then chose 3 of those for a community brainstorm at the April 9th HPG meeting.

A Brief History of HIV Activism



- In June 1981, the Centers for Disease Control and Prevention (CDC) publishes “Pneumocystis Carinii Pneumonia” and “Kaposi’s Sarcoma and Pneumocystis Pneumonia Among Homosexual Men – New York City and California” MMWRs
- One month later, the New York Times publishes “Rare Cancer Seen in 41 Homosexuals.”
- In January 1982, 80 activists gathered in New York writer Larry Kramer’s apartment to discuss “gay cancer” and raise funds for research, founding Gay Men’s Health Crisis.
- In September 1982, the CDC uses “AIDS” for the first time and releases its first case definition.

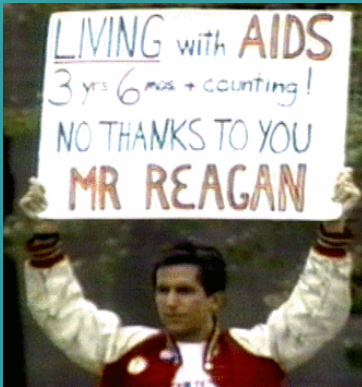
History of HIV Activism



- In June 1983, advocates take over the National AIDS Forum plenary stage in Denver and issue a statement on the right of persons with AIDS to be involved in AIDS policy decisions (“The Denver Principles”).
- Demonstrations and rallies continue to take place in New York City and across the country.

History of HIV Activism

- In January 1985, the CDC revises the AIDS case definition, noting that AIDS is caused by a newly identified virus. CDC issues provisional guidelines for blood screening.
- In September 1985, over four years since the first cases were reported and with estimates of Americans with HIV ranging from 500K to 1M, President Ronald Reagan publicly mentions AIDS for the first time. Two years later, he makes his first public speech about AIDS.



History of HIV Activism in New York City



GAY RAGE: Demonstrators mass outside Health Dept. offices in lower Manhattan yesterday to protest a city decision to cut in half its estimate of the number of AIDS-infected New Yorkers. Four were arrested as protest leaders called the city decision a maneuver to cut health services to AIDS victims.

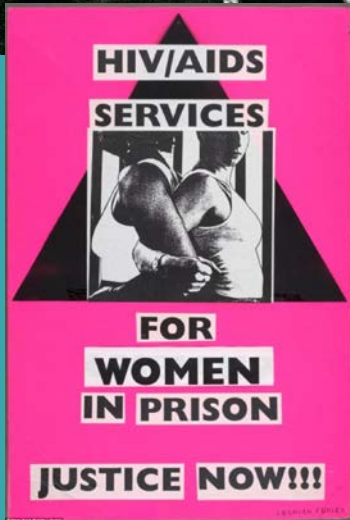
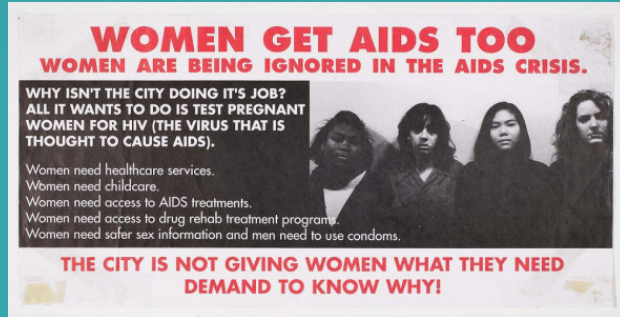
- In March 1987, advocates form AIDS Coalition to Unleash Power (ACT UP) in New York City and begin holding protests at City Hall and City agencies, elected officials' offices, Wall St., hospitals, churches, public parks, and other venues.



Homosexuals Arrested at AIDS Drug Protest
Police officers removing demonstrators from the intersection of Broadway and Wall Street yesterday. Seventeen homosexual-rights protesters were arrested outside Trinity Church during a rally to demand quicker Government approval of drugs that might combat acquired immune deficiency syndrome. Hundreds of protesters stayed behind police lines, but some crossed the barricades and sat in the street to block traffic. They were arrested, charged with disorderly conduct and released.



History of HIV Activism

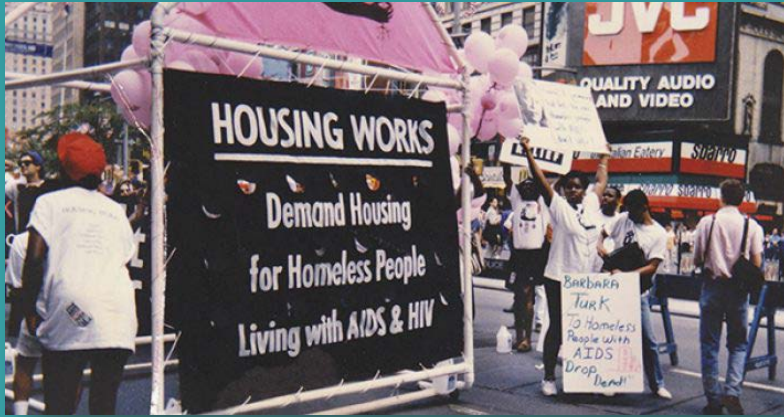


- In 1988, Elizabeth Glaser started the Pediatric AIDS Foundation.
- In April 1989, people of color marched in Oakland, CA to demand programs & funding for AIDS prevention and education in their communities.
- Women's groups and ACT UP also protested women and minorities' lack of inclusion in clinical trials and lack of treatment access.

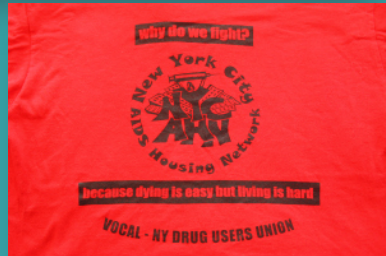
History of HIV Activism in New York City



History of HIV Activism in New York City



- In 1990, four members of ACT UP founded Housing Works, dedicated to serving homeless New Yorkers living with HIV/AIDS.
- In 1999, activists founded Voices of Community Activists and Leaders (VOCAL-NY), then known as New York City AIDS Housing Network (NYCAHN), as a progressive AIDS housing network.



More info on activism can be found at <https://critpath.org/advanced-hiv/activism/>

Overview of Civic Engagement - Where to Begin?

- ✓ Identify a public health issue
- ✓ Identify communities potentially affected by the issue
- ✓ Gather information, including data, from key stakeholders
- ✓ Know your audience (e.g., Who Represents Me? NYC at <http://www.mygovnyc.org/>)
- ✓ Educate the public using balanced, objective information and mechanisms that allow them to form their own independent opinions or conclusions

Overview of Civic Engagement – Resources & Toolkits

- “A How-To Guide to Advocacy for People Living with HIV” by Positive Women’s Network-USA at <https://www.pwn-usa.org/training/advocacy-guide/>
- “Policy Action Center” by AIDS United at <https://www.aidsunited.org/Policy-0024-Advocacy/Policy-Action-Center.aspx>
- “AIDS Watch” by AIDS United at <https://www.aidsunited.org/Policy-0024-Advocacy/AIDSWatch.aspx>
- “Understanding HIV” by Advocates for Youth at <https://advocatesforyouth.org/issue/hiv/>
- “Policy, Advocacy, and Stakeholder Mobilization” by World Health Organization at <https://www.who.int/hiv/topics/vct/toolkit/components/policy/introduction/en/>

Restrictions on Lobbying for Agencies that Receive Federal Funds: NYC HPG

- The New York City Health Department receives federal funding from the CDC to support its HIV prevention activities, and is thus subject to various restrictions on its ability to lobby.
- These restrictions apply to any activity by the New York City HIV Planning Group (HPG), and by its work groups and members acting as agents of the HPG and/or supported by Health Department resources and staff.

“Federally-funded lobbying, either directly or indirectly (i.e., ‘grassroots lobbying’) is prohibited by law”

Restrictions on Lobbying for Agencies that Receive Federal Funds

“Direct lobbying by grantees: Except in certain cases of state and local government communication, as part of their normal and recognized executive-legislative relationships, as discussed above, grantees are restricted from using federal funds to attempt to influence deliberations or actions by federal, state, or local legislative or executive branches. This includes communications to a legislator or executive official that refer to and reflect a view on specific measure (legislative or executive).”

Restrictions on Lobbying for Agencies that Receive Federal Funds

“Grassroots lobbying. No appropriated Federal funds can be used by CDC grantees for grassroots lobbying activity directed at inducing members of the public to contact their elected representatives to urge support of, or opposition to, proposed or pending legislation or appropriations or any regulation, administrative action, or order issued by the executive branch of any Federal, state or local government. Grantee communications from which an external audience may infer that it should contact legislators concerning specific legislation should be considered carefully because they may run afoul of the prohibition, unless the communications fall within certain recognized exceptions to the definition of ‘lobbying’ or ‘influencing legislation.’ It is this restriction on grassroots lobbying that prevents grantees’ calling upon the public to take action and direct efforts on the part of grantees to encourage participation by others in advocacy.”

Restrictions on Lobbying for Agencies that Receive Federal Funds

Note:

- Restrictions apply not only to legislative matters, but executive matters, including regulations, administrative actions, and executive orders.
- Restrictions apply to lobbying at the local level, too, including that directed at city councils, county commissions, and other local legislative bodies, and regulations and administrative orders issued by state and local executive branch officials.

Restrictions on Lobbying for Agencies that Receive Federal Funds

Select allowable activities:

- ✓ Conducting research on policy alternatives and their impact
- ✓ Educating the public on health issues and their public health consequences
- ✓ Educating the public on evidence associated with potential policy solutions to health issues
- ✓ Educating the public using examples of best practices or success stories from other jurisdictions
- ✓ Developing information to inform the public on potential policy solutions and their impact
- ✓ Working with other agencies within the executive branch on policy approaches and implementation
- ✓ Conducting educational campaigns that explain both the advantages and disadvantages of certain public policies or that demonstrate the efficacy and possible ineffectiveness of certain measures, as long as those communications are widely disseminated, balanced in their analysis, and avoid an express call to action with respect to specific legislation

Restrictions on Lobbying for Agencies that Receive Federal Funds

Select prohibited activities:

- ✘ Encouraging the public or other entities to support or oppose specific action proposed or pending before the federal, state, or local government often referred to as “grassroots lobbying”
- ✘ Direct lobbying of the Congress or of a state or local legislature, other than certain communications in the course of normal executive-legislative relationships
- ✘ Advocacy to perpetuate or increase their own funding from the federal government

“Even when operating within what are thought to be legal limits, attention must be paid to the appropriateness of policy positions, Congressional intent regarding the use of appropriations, and the appropriateness of our grantee activities.”

Issue 1: Supervised/Safe Injection Facilities (SIFs)

State Legislation Relevant to Supervised Infection Facilities

- **A60 (Rosenthal)/ S498 (Rivera)** – State law that would enact the Safer Consumption Services Act which provides for the establishment of a program to provide safe injection sites
- **S8975 (Akshar)** – State law that would prohibit supervised injection sites, and make it unlawful for any person to own, operate, work in, or volunteer at one

Issue 1: Supervised/Safe Injection Facilities (SIFs)

- Supervised injection facilities (SIFs) are one of many overdose prevention strategies available to public health authorities. They have been shown to improve individual and community health, increase public safety, and reduce the health and social consequences of injection drug use through medically supervised use of injected substances.
- SIFs offer hygienic spaces where people who inject drugs can inject pre-obtained substances with sterile equipment.
- Medically trained staff are on-site to respond to potential overdose events, although these staff do not assist with injection. Most established SIFs refer or provide access to a host of on-site health, mental health, substance use, and social services that supplement existing harm reduction and syringe exchange services through increased opportunities for engagement, education, and treatment.
- In June of 2017, the American Medical Association, the largest body of physicians in the United States, declared their full support of the legalization of SIF.

Issue 1: Supervised/Safe Injection Facilities (SIFs)

Community Feedback

- Ability to induct medication-assisted treatment (MAT) and medical care, behavioral health services, Narcan trainings, referrals for detox services. Discuss low-threshold Buprenorphin induction unavailable in most healthcare settings.
- Ensure it is clear SIFs would not be pushing people into treatment, but would be able to provide linkages to treatment/detox. SIFs would be client-centered and focused on the needs identified by the clients.
- A concern was raised about what happens after they inject their substances. What are the best practices? How long do they stay at the SIF after they inject?
- Having a SIF would normalize injection drug use and decrease the stigma associated with being an injection drug user. The group felt as though there is increased stigma and fear among the IDU community and that this will prevent them from accessing services.
- Request a commitment from law enforcement not to harass clients coming/going from SIF.
- SIF would have someone available to assist with best injection practices to decrease risk of abscess.
- Group didn't like the name Supervised Injection Facility; preferred overdose prevention site or safer consumption space.
- Group suggested that we provide concrete examples in communities that have had successful SIFs.
- Group discussed having peer mentors at the SIFs and to discuss the importance of peers in harm reduction programming.
- Discuss the neutral impact of SIFs.
- Language should not be technical but should be language that the “average” lay-person would understand.

Issue 2: Sexual Health Education in Schools

City/State Legislation Relevant to Sexual Health Education in Schools

- **Int 1348 (Cumbo)** – Local law that would require the New York City Department of Education (NYC DOE) to report information regarding sexual health education.¹¹
- **Resolution 0716 (Levin)** – Resolution calling upon NYC DOE to adopt the policy recommendations of the Mayor’s Sexual Health Education Task Force and provide comprehensive sexual health education on a regular basis, across all grade levels.¹²
- **A1904/ S791 (Richardson/ Montgomery)** – State law that would require comprehensive, medically accurate, and age-appropriate sex education instruction in all public schools, grades 1-12, and require State agencies to create the curricula; the law would allow the New York City Department of Education Chancellor or a board of education to adopt a City curriculum that substantially complies with the state curriculum¹³
- **A1083/ S1030 (Gottfried/ Rivera)** – State law that would establish the Healthy Teens Act, an age-appropriate sex education grant program¹⁴

Issue 2: Sexual Health Education in Schools

- According to the Sexual Health Education Task Force of New York City, *comprehensive sexual health education* is a holistic approach that “incorporates medically accurate, affirming, age-appropriate, and culturally competent information about anatomy, physiology, family involvement, personal safety, healthy relationships, sexually transmitted infections including HIV, contraceptives, sexual orientation, pregnancy, media navigation and literacy, and more It also foster[s] equity, rights, respect, and healthy relationships.”¹
- Currently, there is no mandated specific health or sexual health education curriculum in NYC public schools.¹
- Under New York State’s health mandate (developed by the state’s Education Department) public schools are not required to teach sexual health education. All school districts statewide are required to offer HIV/AIDS education, however, the decision to offer sexual health education is made by local school districts.¹

Issue 2: Sexual Health Education in Schools

Community Feedback

- *Present information broken down by age, borough, race, ethnicity*
 - Importance of highlighting disparities and health equity/using a disparities and health equity lens when thinking about comprehensive sexual health education
 - Consider social determinants of risk factors
 - Make sure content is respectful of different religions and cultures; address cultural and religious barriers to implementing comprehensive sexual health education.
- *Present factual information*
 - STIs, unplanned teen pregnancy, HIV in NYC
 - Providing condoms does not cause youth to or increase the number of youth who are engaging in sexual activity.
- *Cater to political leaders*
 - In the letter, don't assume that political leaders are knowledgeable about this topic
 - Discuss benefits that other states may have experienced through their approach to sexual health education (to generate feeling of competition among politicians)
 - Compare state by state
 - Look into political, social, and economic contributions of LGBTQ populations, people with disabilities
 - Bring up dollar value of comprehensive sexual health education

Issue 2: Sexual Health Education in Schools

Community Feedback

- Main suggestion for topics to address in the letter:
 - *Creating an LGBTQ-inclusive and otherwise welcoming environment through sexual health education is crucial to improving students' overall health and school outcomes.*
 - Ensure that curricula discuss a range of relationships, sexualities, sexual well-being, etc.
 - Creating an inclusive environment would not only improve the sexual health of LGBTQ students but would also improve overall health and school outcomes for all students.
 - *Involve youth, parents/guardians, and all school staff members in sexual health education planning and implementation.*
 - Include parents/guardians in the curriculum develop process through PTA meetings, emails, newsletters, school websites, etc. and provide parents/guardians with factual information about the value of comprehensive sexual health education.
 - Train all school staff, not just teachers, in comprehensive sexual health education.
 - Involve youth in the planning process, including through the development of youth-led social media campaigns and curricula

Issue 3: Sex Work

State Legislation Relevant to Sex Work

- **A654/ S2253 (Paulin/ Hoylman)** – State law that would repeal provisions related to the loitering for the purpose of engaging in prostitution offense⁸
- **S728 (Montgomery)** – State law that would prohibit the use of the possession or presence on the premises of condoms and other sexual and reproductive health devices, including PrEP, PEP, and HIV treatment medication, as administrative evidence of prostitution- or trafficking-related offenses in any criminal, civil, or proceeding⁹
- **A982/ S3181 (Gottfried/ Lanza)** – State law that would provide for confidentiality of records in proceedings to vacate convictions for offenses resulting from sex trafficking, labor trafficking, and compelling prostitution¹⁰

Issue 3: Sex Work

- People who engage in sex work/trade – whether by choice, circumstance, or coercion – and those who are profiled as sex workers¹ – face risks and challenges in the forms of: criminalization; stigma and discrimination; coercion, violence, and trauma; and unmet housing, food, health care, vocational, and other needs
- The charges most often brought against people engaged in sex trades in New York City – and sometimes those not engaged in commercial sex – include **loitering for the purposes of prostitution**, which is particularly leveraged against people of color; transgender, gender nonconforming, and gender nonbinary people; and undocumented people.² This runs counter to New York State's stated goal of ending the epidemic, increasing the risk for HIV when condoms are taken from people or destroyed. People avoid carrying condoms for fear of profiling, overpolicing, harassment, and prosecution.

Issue 3: Sex Work

Important Updates

- On Feb. 25, 2019, New York State Senators Jessica Ramos and Julia Salazar published an op-ed in the New York Daily News announcing their intent to decriminalize sex work. They stated: “[We] along with Sen. Brad Hoylman and Assemblyman Richard Gottfried, are working with Decrim NY to introduce a bill to rewrite the state’s penal code to decriminalize the sex trades in New York State. We aim to repeal statutes that criminalize consensual sexual exchange between adults and create a system that erases prostitution records for sex workers and sex trafficking survivors so they can move on with their lives. We recognize the tremendous public education required to pass such a bill, but we believe New York can and should be the first to decriminalize sex work fully. We call on our colleagues to join us.”¹¹
- To learn more: <https://www.decrimny.org>



Issue 3: Sex Work

Community Feedback

- Look at the focus groups that occurred on FOSTA/SESTA and the information they were able to gather to bolster the points listed
- Highlight ways to engage with potential survivors of sex trafficking that are outside the court system in order to combat the comment that decriminalizing sex work would create more trafficking opportunities
- Highlight that CBOs and other agencies are required to provide trainings on how to identify trafficking
- Look at supply and demand – particularly highlighting why there is a demand for sex work
- See if there are talking points that can be taken from the criminalization of substance use
- Look at cooperation from NYPD and their anti-stigma work
- Take a humanizing angle, that providing services as opposed to criminalization of people is a better way to treat the community and cost effective
- Outline how decriminalization is not legalization: What is the difference?
 - Look at how each might impact taxes
 - Look at how regulation might actually be ideal for all parties involved
- Make sure that Decrim's angle on to erase the criminal history of those who have been arrested for sex work
- Define & Differentiate sex work/trade vs trafficking
- Highlight interventions that work other than arresting

Issue 3: Sex Work

Community Feedback

Questions that were raised within the break out session

- Are there lessons learned from Nevada's regulation?
- Is there data from the NYPD about how this might impact trafficking?
- Studies from the Nordic model?
- Are there economic analyses about decriminalization?
- Are there individuals who are within governmental agencies (NYPD or DOC) who can work with us?
- Are there individuals who are walking the line about decriminalization who can be "flipped"?

What Are Your Thoughts?

What Next?

- What are the issues you feel strongly about?
- Start small, seek out and sign onto existing work, or create your own where you see a need.
- Here's one way to find your elected officials:
 - <https://www.commoncause.org/find-your-representative/>
- And here's an example call script from Positive Women's Network Complete Guide to Advocacy tool kit:

(Relatively) Fast Ways to Take Action

- + Call your members of Congress.
- + Write a letter to your legislators.
- + Mobilize others by creating an action alert.
- + Sign onto or create a sign-on letter

Call your Senator RIGHT NOW using the HIV Hotline: 866-246-9371. Below is a sample script to use once you're connected. *(If you're from Alaska, Arizona, Colorado, Indiana, Kansas, Louisiana, Maine, Ohio, Pennsylvania, South Carolina or West Virginia, you have a special script—[click here](#))* "Hello, I am a constituent of Senator [NAME]. I am calling because I am a person living with HIV/advocate for people living with HIV, and I am gravely concerned about the introduction of the Graham-Cassidy bill, which will cause millions of people to lose health care coverage, and will especially affect seniors and people with disabilities. The American people have spoken – we do not support any repeal of the Affordable Care Act. Has Senator [NAME] taken a position on the Graham-Cassidy bill yet? [If yes], What is it? [Yes or No]: Please tell Senator [NAME] that I urge her/him to oppose the Graham-Cassidy bill and ANY further attempts to dismantle healthcare and cut Medicaid." Then, mark your calendar with a reminder to **call back every day**.

What Next?

- Let us know if you or your agency are interested in signing on to any of the PER letters discussed today!
- The NYC HPG meets the 2nd Tuesday of every other month from 1:00-5:00pm at the LGBT Center – 208 W 13th St @ 7th Ave, and meetings are open to the public, please join us! Our next meeting is **June 11th**.
- The PER Work Group has meetings scheduled on 5/14, 6/4, 7/2, 8/6, 9/3, 10/8, 11/12 at Mount Sinai, 275 7th Avenue, Suite 1505 from 3:00-4:30pm.
 - Email diane.tider@mountsinai.org for more information

Thank You!



Photo credit William Nazareth

Big thanks to the NYC HPG, the New York City Department of Health, our colleagues, clients, communities & you!