

# Treatment ISSUES

## How to Beat an Outbreak: Part 1

by Frank Spinelli, MD

In September 2012, I was at home fixing dinner one night when I received a series of text messages from an acquaintance I'll refer to as "Joe." He wrote asking if I knew about the meningococcal meningitis outbreak affecting gay men. Joe had just learned that his friend—a healthy HIV positive man in his thirties—had died the night before. Twenty-four hours later, his friend's roommate called to inform him that hospital officials were urging all recent close contacts to begin prophylactic medication because the cause of death was likely due to meningococcal meningitis.

Joe read online that persons exposed to meningococcal meningitis should begin a course of the antibiotic, Ciprofloxacin, as soon as possible to halt the progression of the disease. Since it was late, Joe was unable to get in touch with his physician and thinking time was of the essence, he decided to reach out to me.

Understandably, Joe had every reason to be concerned. Just as I was about to dial his number, I received a phone call. It was from a colleague who had also come in contact with the same man who had just died. He and his partner were worried because they had seen the victim just days earlier, just as Joe described. They too had received the same call from the deceased man's roommate. The rapidity with which their dear friend succumbed to this disease left them unsettled. After reading about meningococcal meningitis on WebMD they began to panic. Unsure if they should go to the emergency room, they called to ask me for my advice.

First I inquired if they had any symptoms at all. Initially, symptoms of meningitis resemble the flu, with progressive headache, vomiting, and a sudden high fever (over 101.3). Within hours to days, patients may develop difficulty thinking, a stiff neck, sensitivity to light, and coma. All three reported no symptoms but said their friend's roommate told them the victim had been vomiting the night before he died and was experiencing severe headaches and high fever for two days. Unfortunately, their friend made a fatal error and never went to see his doctor.



Frank Spinelli, MD and Demetre Daskalakis, MD, MPH

Like many of my colleagues who treat gay and bisexual men, I was keenly aware of the deadly bacterial meningitis outbreak affecting them in New York City. By August the disease had sickened 22 and killed seven men over the past two years. The specific strain linked to all the cases in New York City is part of serogroup C. It's the same strain that first surfaced when a woman came down with meningitis in New York City back in 2003. Unfortunately, the speed with which meningitis kills has made identifying people at risk difficult.

Meningococcal disease, caused by the bacteria *Neisseria meningitidis*, infects the protective lining around the brain and spinal cord. Once symptoms have progressed, the disease is fatal without treatment. Even with treatment, up to one-third of all patients die. Fortunately, there is a vaccine to prevent the illness.

At first, the meningitis outbreak in New York City seemed to infect only HIV-positive men, but by March half of the men sickened were HIV negative. Three of the last five men sickened had died. Initially, it was unclear why

# How to Beat an Outbreak: Part 2

by Demetre Daskalakis, MD

Although we heard about the outbreak of meningitis among men who have sex with men in New York City in September 2012, the epidemiology and department of health alerts focused mainly on the community of men living with HIV. After months of administrative hurdles, I started a vaccine campaign in January 2013 that focused on men attending bars and clubs. With vaccines provided by the New York City (NYC) Department of Health and Mental Hygiene (DOHMH), I went to an after-hours club with 30 doses, a backpack filled with needles, alcohol pads, and a sharps container. I was ready to open a small vaccine clinic. On my first night, starting at 2 AM, I vaccinated 18 people, and most looked at me like they had no idea what I was talking about. They seemed to have never heard that a deadly outbreak was occurring in their community. The next week, I ran my first vaccine event at GMHC with only a small group of men coming to our after-hour clinic located in the David Geffen Center for HIV Prevention and Health Education.

In February 2013, the story changed and the NYC Department of Health and Mental Hygiene was interested in getting a broad population of HIV-negative and -positive

MSM vaccinated against this infection. More cases and deaths occurred. The outbreak seemed to be spreading across the city and to both HIV-positive and -negative men. Soon thereafter, the story caught the attention of mainstream media. Many men suddenly wanted the vaccine but had nowhere to get it. The process was rife with barriers. We heard a litany of issues: “My doctor doesn’t have the vaccine”; “My insurance copay is so high I can’t afford to get it”; “I don’t have insurance”; “I don’t have a doctor.” This need then generated a response that proved that different stakeholders in population health could work together to make a difference.

Recognizing this need, NYC DOHMH and the Health and Hospitals Corporation (HHC) committed to providing vaccines for me to use at GMHC and clubs throughout the city to vaccinate the men at risk for this infection. By combining the generosity of NYC with the community clout of GMHC, we were able to get the word out that GMHC was offering a solution to the barriers; namely to get rid of them. One Facebook posting publicizing free vaccination went immediately “viral.” Thousands of people read and shared this announcement and made the meningococcal vaccine something in high demand among gay and bisexual men in NYC. Working with GMHC, we created clinics

the current outbreak was affecting only gay and bisexual men. Only two of the men knew each other and there was no evidence they infected each other. Since the bacteria is spread by close contact—such as kissing, sharing a toothbrush, a cigarette or even a cup—it is easily passed from one person to the next. Usually outbreaks occur in settings where people socialize or live in close quarters, such as in a college dorm or army barracks. In these cases it’s easier to track everyone down and vaccinate and provide prophylactic medication. Trying to track down gay men that congregate in bars and dance clubs is far more complicated.

“We are very concerned about the outbreak of meningitis among men who have sex with men in New York City,” stated Jay Varma, MD, Deputy Commissioner for Disease Control, DOHMH. “We have identified two groups that are at highest risk of contracting meningitis: HIV-infected men who have sex with men, and any men, regardless of HIV status, who regularly have intimate contact with other men met through a website, digital application (App), or at a bar or party. Vaccination is the best defense against this dangerous infection. We urge men who meet these criteria to get vaccinated now and protect themselves from this disease before it is too late.”

My partners and I at Chelsea Village Medical immediately began offering the vaccination to men who had sex with men (MSM). Despite the fact that most insurance companies weren’t covering the cost of the vaccine, many patients decided to pay the out-of-pocket cost, which averaged around \$150 a shot (the Department of Health recommends two injections for HIV-positive individuals).

In an effort to inform the gay community about the outbreak, Gay Men’s Health Crisis (GMHC) in conjunction with the Callen-Lorde Community Health Center sponsored a panel discussion about HIV-positive gay and bisexual men and the meningitis outbreak in New York City in 2012. Panelist included Paul Bellman, MD, Gal Mayer, MD, and a representative from the New York City Department of Health and Mental Hygiene, Monica Sweeney, MD. I attended the discussion along with fellow GMHC Board member Demetre Daskalakis, MD, who was concerned that the strain was spreading with the help of social apps such as Grindr—which help gay and bisexual people meet one another—as well as the wide array of online social networks.

Daskalakis had already set up vaccination sites at bars, clubs, nightclubs and parties in order to administer the meningitis vaccine. It was a stroke of genius on his part to cull his resources and connections by asking the Department of Health to supply vaccines for him and his team in order to administer them at the GMHC testing center. This would be the most accessible place for individuals to get the vaccine absolutely free of charge.

***At first, the meningitis outbreak in New York City seemed to infect only HIV-positive men, but by March half of the men sickened were HIV negative.***

that occurred twice weekly for several months to provide vaccine to men at risk. Some days the demand was crushing. There were lines out the front door of the testing center and often part way down the block. There were days that we were giving out a vaccine every 1.5 to two minutes. Initially vaccination was being done by me, solo, but Dr. Spinelli and then NYC Volunteer Corps nurses and doctors became involved in providing shots. Ultimately, this effort became a very efficient vaccine delivery system.

Meanwhile, club-based vaccinations continued. I provided vaccines at several venues across the city, including clubs in Manhattan and Brooklyn that were willing to allow access. Despite efforts to extend to other venues, many event organizers were not willing to have vaccines at their event. Demand at the venues that allowed me in was overwhelming. We had lines of people asking for the vaccine and were covered by several media outlets. The team of DOHMH and GMHC effectively created a public health response that was met with significant support by the gay and bisexual community in NYC.

Several nights stick out in my memory. My favorite occurred at a club in Brooklyn. The promoter of the venue worked to get everything organized the night I came. I arrived in the basement venue around 11PM with my husband/vaccine assistant and was greeted by “Nurse Pickles.” The promoter had created a drag persona to help me get his clients vaccinated.

Needless to say, this was a huge success. In the three hours that we were there, we provided vaccines to 70 men, over half of the people who attended the party. Community support on the grassroots level was critical in getting the word out both inside and outside these venues. Twitter, Facebook, and email LISTSERVS alerted men that vaccine events were occurring, and they came in droves. To date, the GMHC and club-based campaign has provided nearly 2,600 vaccines, approximately 20% of those reported by the NYC DOHMH.

In August 2013, the New York State Department of Health supported Mount Sinai Hospital to do a vaccine event at the Fire Island Pines Care Center and the Cherry Grove club called the “Ice Palace.” Working with local HIV testing groups, this vaccine event was the most successful of the non-clinic based events. In four hours, I administered nearly 300 vaccines. The demand was fueled by emails from the Pines Community Association, GMHC, and an events promoter, Daniel Nardicio. I was asked to vaccinate one of the drag performers at the Ice Palace on stage to remind people of our vaccine drive. As I ran back from the stage, my line of five people waiting for vaccine became a line of 40.

In late summer 2013, the NYC DOHMH declared victory over this outbreak. No new cases were identified after

the February 2013 reports that sparked our response. We continue to provide vaccines at GMHC. Many living with HIV are returning for their second dose and others late to the table continue seeking this shot. With the NYC DOHMH still recommending broad vaccination, GMHC continues to provide this important service.

We have learned from the early days of the HIV epidemic that the only way to deal with an outbreak is to work to pull down administrative barriers to allow us to “do the right thing.” I vaccinated several men who survived those “bad old days” of AIDS who commented that there was an eerie echo to the lost youth of the early 1980s. This story, however, has a happy ending. Taking action by combining the forces of charity, community based organizations, and government organizations can make a difference. We had an intervention for this infection: education and vaccination, and it worked. By mobilizing the effort and championing “the right thing,” this vaccine campaign, along with similar work by the NYC DOHMH and other organizations stopped an outbreak. We must take the lesson we learned from this outbreak response and be ready to address the next one.

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## **What’s Happening to the AIDS Generation 25 Years Later?**

On May 9, 2013 a group of activists, researchers, and clinicians convened a remarkable town-hall meeting in New York City. Its goal was to explore what it meant to have lived through the worst of the AIDS “plague years”—from 1980 to 1995—and how it has molded those whose lives were most deeply affected.

But even organizers were stunned by the turnout. More than 500 people packed a hall at Baruch College to attend, “Is This My Beautiful Life? Perspectives From Survivors of the AIDS Generation.” More than 800 registered to receive updates.

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Hosted by Tony-winning actor Stephen Spinella of *Angels In America*, a six-member panel offered perspectives from their own lives. Activists Peter Staley and Jim Eigo, AID For AIDS founder Jesus Aguais, Jeannine Bookhardt-Murray, MD, aging researcher Mark Brennan-Ing, PhD, and Joe.My.God blogger Joe Jarvis shared research findings and personal stories about what the AIDS Generation has been through and how that experience had affected their lives.

After individual presentations and a panel discussion, moderated by New York University researcher Perry Halkitis, the event was turned over to attendees. They asked questions, shared their experiences, and discussed their unmet needs. Many were HIV-positive middle-aged gay men, but the range was broad, including HIV-positive and -negative people, men and women, activists and caregivers and those who'd lost lovers and friends and entire communities.

As audience members stepped up to the microphones, they added depth and resonance to themes that have bubbled to the surface among a broad array of constituencies since the December death of AIDS activist Spencer Cox at only age 44.

The depth of feeling was clear among sometimes tearful expressions of gratitude just to be among "people like us" who understood what they'd been through—reflections of themselves that were otherwise absent in their day-to-day lives.

Many noted that the thriving community support groups of the Eighties and Nineties are long gone. Attendees were incredulous about how shared knowledge of the history of the epidemic, the losses and suffer-

ing, and the activism around it appear to have vanished from broad discussion.

Participants spoke of both sadness and anger at feelings of abandonment by the community—and especially by "Gay Inc." Many said the fight for LGBT civil rights—marriage equality in particular—has airbrushed HIV and AIDS issues entirely out of the picture. "We've been rendered invisible, deliberately, because we don't fit the nice shiny narrative," said one attendee.

The hundreds of people who showed up on May 9 may indicate that the AIDS Generation faces additional life challenges—about which little data has been collected—above and beyond the usual facets of aging.


Those include isolation; stigma; the stresses of living with chronic disease; elevated risks of depression, substance abuse (especially meth), and possibly suicide; stigma within the gay community; and something that may resemble post-traumatic stress syndrome.

Audience members were still discussing experiences and asking questions of the panelists as they were shoed out so the hall could close. It was abundantly clear to the organizers—and, we hope, to the 14 nonprofit groups that cosponsored the event—that a large number of "wounded AIDS warriors" have needs in midlife and beyond that are neither being studied nor addressed.

So, are you a member of the AIDS Generation? Do you think of yourself as "walking wounded"? If so, are you getting what you need? Or, are you a service provider, researcher, or activist? If so, what are you doing to help?

Consider this a call to arms.


*John Voelcker is one of several members of the Medius Working Group, which organized the May 9, 2013 event and continues to work for recognition, study, and treatment of the issues facing the AIDS Generation. He was a member of ACT UP New York, and now runs Green Car Reports. Watch videos of "Is This My Beautiful Life? Perspectives from Survivors of the AIDS Generation" at [youtube.com/user/MediusWorkingGroup](http://youtube.com/user/MediusWorkingGroup).*

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