Joint Health/Medicaid Budget Hearing Testimony

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Thank you for the opportunity to testify before the joint hearing on the New York State Health and Medicaid Budget. Today I speak as a member of a statewide campaign to eliminate hepatitis C in New York State, an effort that includes Housing Works, VOCAL NY, Harm Reduction Coalition, Hepatitis C Mentor and Support Group, Coalition on Positive Health Empowerment (COPE), and my organization, Treatment Action Group. We speak on behalf of the approximately 280,000 New Yorkers who have been infected with hepatitis C, half of whom are unaware of their status. And we speak in support of $2.8M in funding for hepatitis C prevention and treatment for FY 2018-2019.

I grew up and live in the Bronx, where 2% of all residents have chronic hepatitis C, twice the national rate. Each year, more New Yorkers become infected with the hepatitis C virus; nearly 15,000 new cases were reported in 2016, over 4.5 times as many new infections as HIV. Nationwide, hepatitis C kills more Americans each year than all other infectious diseases combined, including HIV. Where the opioid overdose epidemic is the deadliest—in Western and Central NY, and in the Capitol District—hepatitis C rates are the highest. Furthermore, criminalization of injection drug use demands that the State's hepatitis C response include people with hepatitis C in State prisons.

Despite the magnitude of this public health threat, the New York State Department of Health has been flat funded for the last five years at $1.2M per year for hepatitis prevention and treatment programs. A $500K CDC grant for surveillance is ending this fiscal year, hampering our ability to adequately monitor transmission and direct resources where they are most needed.

New York has made great progress in providing access to treatment, including dropping Medicaid treatment restrictions for hepatitis C drugs. However, cost driven barriers remain. A study by the TRIO Network, a health electronic records database with over 31,000 people with chronic hepatitis C infection in the US, found that half of New York State Medicaid patients who received a prescription for hepatitis C cures in 2016 did not start treatment within 6 months. Researchers also found that treatment numbers have plateaued nationwide and started to decline, with preliminary data from NYS DOH suggesting fewer Medicaid patients were treated for hepatitis C in 2017. The TRIO study also found that 80% of treatment non-starts were due to prior authorization or insurance denials. This is simply unacceptable. New York providers are doing the hard work of finding and diagnosing patients only to have them denied cures, with some unknown number discouraged and lost to care.

I also want to take this opportunity to speak very strongly on behalf the New York State prison population. Globally, 15% of prisoners are have hepatitis C, more than HIV, TB and hepatitis B combined. Over 98% of all incarcerated people return to the community; cures achieved within the State DOC protect communities outside the walls and can pass savings onto Medicaid—if the State commits to eliminating hepatitis C in the State prisons and pursues aggressive negotiations for volume based discounts for hepatitis C drugs.

It wouldn't be the first time the State used our large population to strike a bargain with big pharma: volume based discounts for Truvada for PrEP were key to creating the conditions that allowed Governor Cuomo to declare the State's intension to end the HIV epidemic. Similar volume-based discount deals for hepatitis C cures for Medicaid would dramatically scale up treatment through Medicaid and DOC. Unlike HIV, we have a cure for hepatitis C—but where's the leadership? Where's the vision to end an epidemic?

The amount requested here falls far short of the $10.8M we know we need to put New York State on the path to eliminating hepatitis C as a public health concern, which the National Academy of Science, Engineering and Medicine has stated is feasible by 2030. Nevertheless, breaking the cycle of flat funding would be a significant step forward. We will continue to fight to reduce the harms of the opioid epidemic, but we can't continue to neglect the other consequences of opioid misuse and injection: increased HCV transmission. As a bare minimum the legislature should add $2.8M in hepatitis program funds, with $1.3 for prevention services, $500K to replace CDC funds, and $1M for linkage to care.

In order to progress towards WHO 2030 targets, NY State needs to cure approximately 25,000 people per year. With approximately 70% of hepatitis C patients covered under Medicaid, the program would need to cure 17,500 per year for us to stay on course. Uet state Medicaid has cured less than half that number in 2016-17.

There is no public health rationale for failing to act NOW. We should be investing, not retreating. Drug prices have fallen significantly and as a result, last year two drugs in phase III trials were pulled from the market and one company exited the market. Three companies remain but investment in hepatitis C drug development is over. The consequences of waiting are more deaths and infections, and potentially less competition in the marketplace.

We can be the first state to eliminate hepatitis C as a public health threat. Or we can continue to delay and deny, counting pennies—and lives lost.