CITY COUNCIL
CITY OF NEW YORK

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TRANSCRIPT OF THE MINUTES

of the

COMMITTEE ON HEALTH

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April 11, 2011
Start: 1:15 pm
Recess: 4:15 pm

HELD AT: Council Chambers
City Hall

B E F O R E:
MARIA DEL CARMEN ARROYO
Chairperson

COUNCIL MEMBERS:
Council Member Inez Dickens
Council Member Mathieu Eugene
Council Member Helen D. Foster
Council Member Joel Rivera
Council Member Deborah L. Rose
Council Member Peter F. Vallone, Jr.
Council Member Albert Vann
Council Member James G. Van Bramer

A P P E A R A N C E S (CONTINUED)

Monica Sweeney
Assistant Commissioner, Bureau of HIV/AIDS Prevention and Control
New York City Department of Health

Eric Rude
Director of the Office of Viral Hepatitis Coordination
New York City Department of Health and Mental Hygiene

Joseph Masci
Director of Medicine
Elmhurst Hospital Center

Jules Levin
Executive Director and Founder
National AIDS Treatment Advocacy Project

Graham Murray
HIV survivor
Widower, Partner died of hepatitis-B related liver cancer

Ronni Marks
Facilitator
Hepatitis-C Mentor and Support Group.

Brian Edlin
Professor of Medicine, SUNY Downstate College of Medicine; Associate Professor of Medicine and Public Health at Weill Cornell Medical College at the Center for the Study of Hepatitis-C

Deborah Levine
Vice President of Community Development
National Black Leadership Commission on AIDS

Kevin C. Lo
Program Manager, Hepatitis-B Programs/Affairs Associate
Charles B. Wang Community Health Center.

A P P E A R A N C E S (CONTINUED)

Tom Marino
Director of Clinic Operations / Administrator,
Hepatitis-C Clinic
Harlem United Community AIDS Center

Daniel Raymond
Policy Director
Harm Reduction Coalition

Daniel Tietz
Executive Director
AIDS Community Research Initiative of America

Joseph Akima
Counseling, Testing and Referrals Project Manager
Asian and Pacific Islander Coalition on HIV and AIDS

Henry Pollack
Associate Professor of Pediatrics
Division of Pediatric Infectious Diseases
NYU School of Medicine

CHAIRPERSON ARROYO: [pause] Sergeant, you ready? Good afternoon, everyone. My name is Maria del Carmen Arroyo, I'm the Chair of the Committee on Health here at the Council Today, the Committee's conducting a hearing on a complicated issue, HIV/AIDS and Hepatitis co-infection education, prevention and treatment in our city. As many of you know, 'cause I know that in these hearings we usually preach to the choir, the hearing was original scheduled in late January and, you know, Mother Nature had other plans, and we had to postpone it. So, we are here today, better late than never, to have this conversation. And one of the things that make this so appropriate for a conversation in that in 2011, even today, after the decades of challenges and fighting the HIV epidemic in our country, our City remains the epicenter of the HIV epidemic in the United States. It is estimated that more than 107,000 New Yorkers are living with HIV, and thousands more do not know that they are infected. HIV attacks the body immune system and leaves a person vulnerable to illness. It is for this reason that it is imperative that we know our

status, and if positive for HIV virus, seek prompt medical treatment. Hepatitis is also a significant health public--public health concern. This virus is an infection that affects the liver and it is estimated the 1.2 million people are living with chronic hepatitis-B and that 3.2 million people are living with hepatitis-C. The hepatitis-B and C virus can be found in the blood and certain bodily fluids, and it is necessary that individuals infected with hepatitis take precautions to ensure the virus does not spread. Co-infection is a concern for individuals that have either HIV/AIDS or hepatitis. HIV/AIDS and hepatitis are among the top ten leading causes of infectious disease deaths worldwide. In total, it is estimated that from two to four million people are co-infected with HIV and AIDS, and hepatitis-B, and that four to five million people are co-infected with HIV/AIDS and hepatitis-C. The prevalence of HIV and hepatitis co-infection is due to similar means of transmission in a potentially vulnerable populations. Given the danger of co-infection, it is important for people to take necessary precautions to protect

themselves. This includes knowing one's status, engaging in safe sex, abstaining from drug and alcohol use, getting vaccinated, and more importantly, receiving prompt and continuous medical care. Co-infection can make it more difficult to treat both conditions and results in further medical complications. It is for this reason that education and prevention care critical in reducing the prevalence of co-infection be available. Additionally, any effective HIV/AIDS prevention plan must also incorporate viral hepatitis prevention. Today we will hear from the Department of Health and Mental Hygiene, the Health and Hospitals Corporation, medical professionals, advocates, and more importantly, patients, to consider what the City is doing to prevent and treat hepatitis and HIV/AIDS co-infection, and whether we could be doing more. And I'm sure the answer to that will probably be yes, right? I would like to thank the staff for their hard work and I always miss the opportunity to thank them in advance of the hearing: Lacey Clarke, the Counsel to the Committee to my right; and Joe Mancino, the Policy Analyst, to my left;

and our Fiscal Analyst is Pamela Corbett who will probably be around at some point. I also want to recognize my colleagues who are here from the Committee. We have, who was here first, Council Member Dickens, and Council Member Vann, and Member will be flowing in and out as the afternoon progresses. I want to remind everyone that if you're here to provide testimony and you have not already done so, you have to fill out one of these slips. If you don't do that, we won't know you're here and have something important to tell us, and we certainly want to hear what you have to say. And Jerry and Nick will keep us on target if we're making too much noise, if you're using the cell phone in here, he's going to kick you out. You know, that kind of stuff. So, welcome, everyone. And we've been joined by Council Member Rose, and I have been hanging out all day since this morning's Aging Committee that I co-chaired with a couple of my colleagues. Thank you, my colleagues, for being here; thank you all for being here, and I look forward to your testimony. I want to make sure that we know who's here. Dr. Joseph Macky?

JOSEPH MASCI: Masci.

CHAIRPERSON ARROYO: Masci. I understand that you should be at this table. Unless you want to testify on your own. Please join the panel. Thank you. From the New York City Health and Hospitals Corporation; Dr. Monica Sweeney, from the New York, Assistant Commissioner from the New York City Department of Health and Mental Hygiene, and our endearing AIDS expert in the City; and Eric--

ERIC RUDY: Rudy.

CHAIRPERSON ARROYO: Rudy. I didn't think it was Rude. [laughter] Also, from the Department of Health and Mental Hygiene. You can choose who's going to provide testimony. We will, first, and we'll follow up with the questions after everyone has done their piece, okay. Thank you for being here, you may begin.

[pause]

MONICA SWEENEY: Good afternoon, Chairwoman Arroyo, and Members of the Committee on Health, and to my Councilman, Councilman Vann. I'm Dr. Monica Sweeney, Assistant Commissioner for the Bureau of HIV/AIDS Prevention and Control, at

the New York City Department of Health. On behalf of Commissioner Farley, I would like to thank you for the opportunity to discuss the education, prevention and treatment measures we currently undertake with regard to HIV/AIDS, hepatitis co-infection in New York City. Today, I will speak to you about the epidemic, describe the Health Department's programs and initiatives, and identify some of the key challenges we face in addressing this problem. Public health measures have been effective in preventing HIV transmission in New York City, with the number of new HIV diagnoses falling by almost 40 percent, between 2001 and 2009, the last year for which complete data are available. And that is in the environment of expanded testing, the diagnoses are still falling. Declines have been noted from many demographic groups, but decline is most notable among injection drug users, who in 2009 accounted for 185 new HIV diagnoses, an 81 percent decrease from the 984 new diagnoses made in 2001. Despite this great accomplishment, other challenges remain among this population. One of which is co-infection with hepatitis-B and hepatitis-C. As

you are aware, hepatitis is a general term that means inflammation of the liver. Hepatitis-B, called hep-B, is a blood borne and sexually transmitted infection. It is spread by direct contact with infected body fluids, usually by sharing needles or by having sex without a condom. There is a safe and effective vaccine to prevent hepatitis-B, and medical treatment is available to suppress viral activity, and slow progression to chronic liver disease. Hepatitis-C sometimes called hep-C is the most common chronic blood borne infection in the United States. Hepatitis-C is a blood borne infection spread primarily through direct contact with blood of an infected person. People who are likely to have chronic hep-C include those who received a blood transfusion before 1992, and past or current injection drug users. There is no vaccine to prevent hepatitis-C. There is medical treatment available for hepatitis-C, which can sometimes eliminate the virus from the blood, or slow the progression to chronic liver disease. Both viral hepatitis-B and C are leading causes of chronic liver disease, such as cirrhosis, liver cancer or

liver failure. Because both chronic hepatitis-B and hepatitis-C are often without symptoms, many people who have these infections are--potentially fatal infections--are unaware of their status, until they have advanced liver disease, including liver cancer. Which may be 20-30 years after the initial infection. As many as 232,000 New York City residents are estimated to be living with chronic hepatitis-B or C; approximately 129,000 New York City residents with chronic hepatitis-C and the remaining 103,000 residents have chronic hepatitis-B infection. The Health Department recognizes the enormous scope of the viral hepatitis epidemic and its disproportionate impact on City residents already affected by serious health and socioeconomic conditions. It is clear that New York City, as the center of the HIV/AIDS epidemic, is also the center of the viral hepatitis epidemic, and the full extent of the burden of the both diseases has yet to be felt. Viral hepatitis-B and C are both underdiagnosed. Appreciating the unique challenges of this issue, Commissioner Farley met with 30 member committee of viral hepatitis experts and community leaders

in 2010. The Commissioner has since directed staff to develop an accurate estimate of new infections so that we can understand the true impact, and most importantly effectively direct our public health efforts. When someone is infected with both HIV and viral hepatitis, it is called co-infection. It can be HIV and hepatitis-B, HIV and hepatitis-C, and infection sometimes with all three at once. Co-infection is much more serious since it is well-known to be associated with faster progression liver disease than infection with hepatitis-B or C alone. It is estimated that up to 90 percent of persons living with HIV and AIDS, who inject drugs, are co-infected with hepatitis-C. Of the 108,886 persons living with HIV/AIDS in New York City, 15 to 30 percent are estimated to be co-infected with hepatitis-C. That means 16,300 to 32,600 people. Hepatitis-C is the leading cause for liver transplant in the U.S. and is a leading cause of death among people with HIV. Chronic hepatitis-B infection has been found in six to 14 percent of HIV positive individuals, or anywhere from 6,500 to 15,200 City residents. The Health Department

employs a multidisciplinary and collaborative approach to serve and respond to the changing viral hepatitis epidemic that meets the needs of New York City's diverse population. Viral hepatitis activities are integrated into many of the services provided by the Department of Health. Including hepatitis-A and B vaccinations at immunization and STD clinics, hepatitis-C testing at STD and TB clinics, throughout the correctional system, and in many funded HIV/AIDS services and substance use treatment providers. The Health Department provides training in viral hepatitis, and co-infection with HIV to hundreds of medical and health service providers, clinical and nonclinical providers, in all neighborhoods of the City. Using materials offered in Spanish, Chinese, Korean, French, Arabic, Russian, and Urdu. And available, free by calling 311, or through the Health Department's website. The Health Department has expanded its HIV testing effort with special emphasis on areas with high prevalence of disease, and with concurrent diagnosis. And concurrent diagnosis is when a person is diagnosed with HIV and is diagnosed with

AIDS within 30 days in the New York City diagnosis, and one year by CDC diagnosis. In 2008, we launched The Bronx Knows, together with a cadre of community partners. This is the largest municipal testing scale up in the City's history. Which to date has conducted over 400,000 voluntary HIV tests in The Bronx, in the past two years. At the end of last year, on World AIDS Day, Mayor Bloomberg helped us launch Brooklyn Knows, which aims to test an estimated 580,000 Brooklyn residents who have never been tested for HIV, and link individuals to quality care and support services. Additionally, all nine of the Health Department's STD clinics offer voluntary, routine HIV screenings free to patients. Many also offer voluntary hepatitis-C screening for individuals meeting specified criteria, such as those who ever injected drugs, even if only once, have a history of liver disease, a tattoo or body piercing by a nonprofessional, are HIV positive, had a transfusion or a transplant before 1992, been on long term hemodialysis or had unprotected sex with someone who has hepatitis-C or ever injected drugs. In 2010, STD clinics conducted almost 600

hepatitis-C tests. In an effort to combat the viral hepatitis epidemic, over 15,000 hepatitis-A and B vaccinations doses were distributed last year for City residents, at high risk for hepatitis-B infections, in a variety of settings, including correction facilities, STD clinics, need exchange programs, and HIV programs. In addition, over 16,000 doses of hepatitis-B vaccine were administered in the adult immunization clinics. This vaccination is targeted for adults who are uninsured, are seen at Health Department clinics, and are administered free. The Health Department provides direct support to all state license syringe service programs, in New York City, through generous funding from the City Council. City Council funds not only subsidize the very successful public health intervention of direct syringe exchange and sterile syringe access, but also funds hepatitis-C counseling and testing, hepatitis-C prevention and education, education regarding the care and treatment of hepatitis for those who are positive, as well as linkage and escort to medical care, for those who are known to be hepatitis-C positive. All of these syringe

service programs also conduct HIV screening of clients. In addition to the direct provision of services at STD clinics, and the integration of HIV and hepatitis-C screening and prevention activities at syringe service programs. The Health Department also funds other partner organizations to conduct both HIV and hepatitis-C screening, among highly impacted populations, including people who inject drugs and young men who have sex with men. Such community based organizations screen and link to care high risk populations for comorbid medical conditions, that increase risk of either HIV infection or transmission, including sexually transmitted infections, substance abuse and depression. To further address the epidemic, the Health Department produced and will be distributing soon a viral hepatitis awareness video, available in multiple languages, that gives basic information, discusses the risk, and encourages vaccination and testing, for viewing in health clinics, physicians' offices and YouTube. A new comprehensive website devoted entirely to viral hepatitis will launch in late May, and will

feature a citywide hepatitis-C and B services locator, the first of its kind in the country. Moreover, the Health Department produced and updated a City health information bulletin, focused on hepatitis-C management, and is on target to produce a similar bulletin on hepatitis-B, which is sent to all primary care providers in the City. For nonclinical providers, the Office of Viral Hepatitis Coordination newsletter, is distributed to over 1,200 clinics, community organizations and institutions in New York City. The Health Department also organizes several hepatitis-C taskforces, and a citywide hepatitis-B coalition to increase the resources available in the community, and provides viral hepatitis training onsite and in various venues, including HIV and STD training centers. City Council Members express the importance of this issue: HIV/AIDS hepatitis co-infection. And the personal impact the epidemic has in their own districts. To that end, City Council Member Arroyo, Chair of the Health Committee, along with Council Members Chin and Koo, sponsored a groundbreaking hepatitis awareness breakfast last October, to educate

lawmakers and the public on this issue. We welcomed the opportunity to participate in that event, and look forward to future collaborations with the City Council. Though the Health Department focuses many of its energies on HIV/AIDS hepatitis co-infection, there are still many challenges. Along with the rest of the country, we have had to act to reduce many services, including already scarce viral hepatitis services in the wake of budget cuts. Several years ago, the Ryan White Planning Council cut funding for all hepatitis-C programs, provided for HIV co-infected patients. While hepatitis-A and B vaccination program provides tens of thousands of free doses of vaccine to many New York City residents who need it most, the federal government has discontinued the funding that we used to provide hepatitis-B vaccine to thousands of individuals on Riker's Island. Grant funds that were once used to sustain already limited hepatitis-B and C testing have dried up. And we can no longer provide this service even as a new rapid hepatitis-C test has been approved by the FDA, that would make testing both easier and more

economical. There are a number of possible solutions to these budget constraints. Most of which rely on the creative collaboration of various partners and integration of services, so as to better utilize existing resources. In 2010, both the Institute of Medicine, and the U.S. Department of Health and Human Services, released recommendations on addressing viral hepatitis. One strategy that New York City may be particularly suited for is the utilization of primary care physicians and community health centers, located in many of the neediest communities, to provide these services. If given the additional funds required, clinicians in these settings need only additional training to act as the medical home for individuals with viral hepatitis or co-infected with HIV and AIDS. This would address a significant gap as there are limited sites where people with chronic hepatitis can receive care, especially if they have no insurance. The Health Resources and Services Administration has initiated pilot projects, including in New York City, which will hopefully demonstrate that if properly funded to increase

their capacity, the vast network of community health centers can play a vital role in identifying and caring for New York City residents with viral hepatitis. The Health Department is also in the forefront of another strategy, funded by the Centers for Disease Control and Prevention. We're working toward integrating viral hepatitis, STD, HIV/AIDS and tuberculosis prevention, vaccination and testing services, to make full use of the existing infrastructure and expertise to address all four diseases in those City residents affected by more than one of these conditions. The goal of the three year initiative is to identify those neighborhoods, settings and populations in the City in which these diseases overlap. We will then stretch our collective budgets and collaborate on the more effective approaches to provide prevention and treatment services to those most affected. Both the Institute of Medicine and HHS recommended that people in, at risk for viral hepatitis be educated in prevention techniques and be tested and linked to critical services before the disease exerts its greatest possible impact on the healthcare system.

Controlling the continuing HIV/AIDS epidemic and number of hepatitis infections, requires a coordinated effort at the federal, state and local levels. Unfortunately, today's fiscal climate is further constraining an already limited pool of available public health funding. Although these services are costly, an early investment can soften the blow in the future of even more costly liver disease treatment and transplant surgeries resulting from viral hepatitis, and those co-infected with HIV/AIDS. With this in mind, it is our collective responsibility to direct resources as efficiently and effectively as possible, to control these diseases. The Health Department appreciates the Speaker's and the Council's commitment to this issue. And when appropriate, I will be happy to answer any questions.

CHAIRPERSON ARROYO: Anybody else? Yeah. Okay, so Dr. Sweeney, I understand that you have a date that you have to get to at 2:00. No, it's an important meeting, I'm kidding [laughter]

MONICA SWEENEY: Thank you.

CHAIRPERSON ARROYO: So, what we're going to do is forego the questions and put HHC on

the hot seat alone. So [laughs] if you don't mind. But I'd like to acknowledge that we've been joined by members of the Committee, Council Member Rivera, Council Member Foster, and Councilman Vallone, thank you all for joining us. Dr. Sweeney, you put in, I think we're in disagreement about the number of HIV folks in the City. We, in my opening testimony, included 107,000, you have 108,800 and change, so we missed a thousand, almost 2,000 patients. So I want to see how, where that discrepancy lies. It may be internally here, or maybe we should look at the numbers that you're looking at.

MONICA SWEENEY: It is our latest year of complete data. And the data changes based on late reporting. So you may have gotten data from source earlier than the latest data for the latest year, for which we have complete data, 2009.

CHAIRPERSON ARROYO: Okay, thank you, I appreciate that. I just, I'm concerned, we usually have this, pretty much the same numbers, but in this case we didn't. I wanted to, to ask about incidents by borough and neighborhoods. I

know that for HIV and AIDS we can pull up a Department of Health surveillance report, that gives us the HIV/AIDS cases, newly reported, and the ones that we're carrying forward by neighborhood. Is the information on hepatitis-C and B available in the same way?

MONICA SWEENEY: It is definitely not as robust in terms of being able to do it exactly as well as we are able to do it for HIV. But that is one of the mandates that the Commissioner gave at, in 2010, to the Committee, to a group after he held the Committee hearing, to make the data around hepatitis as robust as it is for HIV/AIDS.

CHAIRPERSON ARROYO: When do you think that that information will be, or when do you think you'll get there.

MONICA SWEENEY: You know, the other, the other issue is, you know, hepatitis-C especially is somewhat of a hidden disease. It's associated with, often with, illegal activity; but it's also not required reporting by law, the way HIV is. So, we will never have it as robust, until it is as required as it is for HIV.

CHAIRPERSON ARROYO: Okay. I'm afraid to ask this question, but--and it's probably a statement related reporting issue--would you like to see that as one of the mandated reporting elements that providers or laboratories have to provide to both this City and the State?

ERIC RUDE: I'm sorry, I just wanted to make a correction, and this is my fault, 'cause I was trying to get information to Monica. Pardon--Oh, my name is Eric Rude, I'm the Director of the Office of Viral Hepatitis Coordination for the New York City Department of Health and Mental Hygiene. It, hepatitis-C and B are both reportable diseases by law, it's true, but Monica was trying to describe the difficulty in which the reports are received to the Department of Health. It's something where reporting systems are not as robust as HIV reporting systems, and the underreporting is severe. There's very little reporting that happens to the extent that HIV does, and it's assumed that we are under counting the number of hepatitis cases, both B and C. And if it were, you know, if there were some integrated surveillance system in place, that

costs money obviously, and needs to be staffed, then perhaps we could have much better surveillance. But unfortunately surveillance is just that, too, it's reports. Sometimes the reports are duplicated, sometimes people get tested more than one year, and they're double counted. So surveillance counts are not an accurate representation of the number of actual cases.

CHAIRPERSON ARROYO: Okay. So, I'm not the sharpest knife in the drawer, by any means. But I also know that this City and this State has, have spent a significant amount of work and energy around ensuring that the HIV and AIDS reporting surveillance systems are I think by far the best in this nation and across the world. You cannot sit here, you cannot sit here, and tell me we cannot, and are having trouble doing the same for hepatitis-B and C. So, with that said, we will have a conversation about how we make that happen for these two diseases, as well. It is unacceptable for us not to be at the cutting edge of how we can make this report possible. The question that I asked around incidents, and rate,

by borough and by neighborhood is for us, as members of this Committee, and in this Council, to understand the need that we have in communities, whether we have $10, and how we're going to invest those dollars, because community X has got a greater incidence of that disease, than community Y. We are on the same team, as far as I'm concerned. And it troubles me to hear you say that this is a challenge. Because you have, and I'm going to refer to you, the Department of Health and Mental Hygiene, and this City has set an incredible benchmark for how to monitor HIV and AIDS, across this nation, across the world. We need to be doing the same for hepatitis C and B.

MONICA SWEENEY: Understood.

CHAIRPERSON ARROYO: So, I will be reaching out through Committee staff for us to talk about how we make that happen. Council Member Dickens has a question, or questions.

COUNCIL MEMBER DICKENS: Thank you so much, Madam Chair. This is not so much as a-- well, partly a question. Because of the increase in co-infection between HIV/AIDS and hepatitis, the speaker and I sponsored a breakfast at Union

Theological Seminary just last week, for more than 150 women of the clergy, of all denominations, concerning just this subject. Were you aware of that?

MONICA SWEENEY: I was not aware.

COUNCIL MEMBER DICKENS: All right. Then that was a severe oversight that you were not noticed, because it would've been important that you be there, because we also had videos that we made of the prominent women in the clergy in order for them to, so that we can use a video for public awareness. Tomorrow, are you aware that tomorrow the United Association of Ministers is having a meeting regarding the severe cuts to HIV/AIDS and the hepatitis programs? And they're focusing not just on that, but on the funding to block, are you aware of that meeting?

MONICA SWEENEY: I, I have, I have no awareness of that meeting.

COUNCIL MEMBER DICKENS: Mm-hmm. Because they're concerned about the three levels of government, fed, state and city, the severe cuts and the negative impact that that, those cuts will have on awareness, rapid testing, early

education, medical assistance, etc. You're not aware. If I told you about it, could you have staff to attend that meeting?

MONICA SWEENEY: Sure. If we had known previously, we could have.

COUNCIL MEMBER DICKENS: No, but if I tell you today? The meeting is tomorrow.

MONICA SWEENEY: Can we get somebody?

COUNCIL MEMBER DICKENS: Evening.

MONICA SWEENEY: Yes, we can get someone by tomorrow evening.

COUNCIL MEMBER DICKENS: All right, well then, before you leave, would you please, I'd like to write out the information for you. Madam Chair, if that's okay with you, permission.

MONICA SWEENEY: Yes, thank you.

COUNCIL MEMBER DICKENS: Thank you.

CHAIRPERSON ARROYO: The, the subject of the--colleagues, any questions? Okay. The subject of--Oh, Council Member Vann, go ahead.

COUNCIL MEMBER VANN: Yeah, thank you, Madam Chair. Good afternoon--

MONICA SWEENEY: Good afternoon.

COUNCIL MEMBER VANN: --my Assistant Commissioner. It just occurred to me, I'm trying to understand this stuff, is there, your colocation, is there something unique about the colocation of HIV and AIDS with either hepatitis B or C, A, B or C? Is there any particular form of hepatitis more apt to be collocated with HIV and AIDS than any other? Does it--?

MONICA SWEENEY: Yes, hepatitis-C and HIV are often co-infec--the co-infection, much more readily exists than the other hepatitis.

COUNCIL MEMBER VANN: Is one becoming infected the same way for the most part? Is it the--

MONICA SWEENEY: Hepatitis-C, the primary route of transmission is through injection drug use. There is some sexual transmission, and there is a very small mother-to-child, very small mother-to-child transmission. But the primary way is injection drug use.

COUNCIL MEMBER VANN: We still have a significant number of drug addiction or drug addicts who are using, still injecting in New York

City?

MONICA SWEENEY: The important issue about that is that New York City has 13 syringe exchange programs, and so as I stated earlier in the testimony, the number of people who are injected through injection--who are infected through injection drug use has decreased by over 80 percent from 2001, to 2009, the last year for which we have complete data. So we've gone from almost 1,000 people a year getting infected with hepatitis-C, through injection drug use, to the last year, 184. And one of New York City's leading experts on drug use says even though they use drugs, still their mode of transmission was probably heterosexual. So, the--the availability of clean needles and syringes in this City has made IV drug use as transmission for HIV and hep-C has gone down considerably.

COUNCIL MEMBER VANN: Hep-C cannot be transmitted through sexual activity?

MONICA SWEENEY: Yes, it's sexual and IV drug use, both. But drug use, having the predominant, is the predominant mode of transmission.

COUNCIL MEMBER VANN: Can be either/or?

MONICA SWEENEY: It can be either/or.

COUNCIL MEMBER VANN: But predominately the use of--

MONICA SWEENEY: Intravenous drugs, yes.

COUNCIL MEMBER VANN: You know what percentage generally? Just, I'm just trying to get a--

MONICA SWEENEY: What we, what we have a percentage of is that the number of people who are infected with HIV, it is estimated that a third of them are also co-infected with hepatitis-C. And that's 108,886, and about a third of the ones who are, whose transmission risk was intravenous drug use, that a third of those are infected with hepatitis-C.

COUNCIL MEMBER VANN: So, in terms of prevention--my last question, Madam Chairman--in terms of prevention strategies, are they different? Are we trying to prevent HIV and AIDS any different from how we would try and prevent--

MONICA SWEENEY: The same prevention strategies, the use--not coming in contact with blood during drug use, intravenous drug use, and using condoms, it's the same form of prevention. And it is the best way to prevent transmission of hepatitis-C, and HIV. The other thing is, is that some of the people who were infected early on with hepatitis-C had received blood transfusions before 1992. That is no longer a problem for transfusion or for transplantation. So those two ways of transmitting it are things of the past, pretty much. And so it's down to blood and sexual transmission.

COUNCIL MEMBER VANN: Okay, thank you. Chair.

CHAIRPERSON ARROYO: Thank you, Council Member. We've been joined by Council Van Bramer, who I saw walk in. Oh, there he is. And Council Member Rose a question, or a couple of questions.

COUNCIL MEMBER ROSE? Yes, thank you. What does your public education awareness program look like?

MONICA SWEENEY: It's an education

program that is in multiple--well, all over the City, in multiple communities, and it is for both providers and for consumers, for patients. And, and as I stated in the languages, the various languages that I gave.

COUNCIL MEMBER ROSE? And what is the frequency by which these are, these public awareness programs or events are given?

ERIC RUDE: Very, they're quite, they occur quite often for HIV. They don't occur near as often or as often enough for hepatitis-B or C, due to the lack of funding.

COUNCIL MEMBER ROSE? So, funding, so do you not speak about co-infection when you're doing HIV education?

ERIC RUDE: Absolutely, every time, not only in the HIV programming, but also STD programming, tuberculosis, correctional health, mental hygiene, etc.

COUNCIL MEMBER ROSE? But, separate and aside, H--hepatitis-C and B, aren't dealt with as frequently because of funding?

ERIC RUDE: Not by the Public Health Department, but there are many agencies in

the City that do provide services for hepatitis-B and C, and they often will provide public awareness activities and events, including testing and/or public service announcements, that are, that can be viewed by the public.

COUNCIL MEMBER ROSE? And what efforts are, or do you make to make sure that the professionals delivering these, these public awareness sessions are culturally competent?

ERIC RUDE: They often, well they have to be, only because there are, especially with hepatitis-B, it impacts mostly immigrant populations. So, it's very often that the public awareness campaigns are in languages other than English.

COUNCIL MEMBER ROSE? And are these, the speakers of these language native? And ethnic, or representatives of these ethnic groups? Or are they people who just speak that particular language?

ERIC RUDE: They are absolutely from the communities from which they, or for which they speak, and work within as well as perhaps are affected by the disease themselves.

COUNCIL MEMBER ROSE? And when you make referrals to other agencies, I guess when you do your public awareness, at that point do you also make referrals for people who might need to avail themselves of additional services?

ERIC RUDE: That is one thing that we can do very, very well, at the Department of Health. HIV has been doing, has a very large referral resource database, and they've had so for a while. We, in hepatitis, have recently been able to compile a very good list of referral resources, and as Dr. Sweeney said in her testimony, it is now available online, and it's searchable by borough, as well as by service.

COUNCIL MEMBER ROSE? And, this is my last question, and do you find that there are enough agencies to make referrals to, that represent the different cultural and ethnic groups that are being impacted by the co-infection of HIV/AIDS and hepatitis-C and B.

ERIC RUDE: That's a very good question, I'd say not enough. We probably have at least one representing each possible ethnicity, but not nearly enough for a City the size of New

York, and its diversity.

COUNCIL MEMBER ROSE? Do you determine what groups are funded, or does that come from another source?

ERIC RUDE: Regarding hepatitis, and that's all I'm speaking for, there is no funding from the Department of Health to the community.

COUNCIL MEMBER ROSE? Okay, thank you so much, Madam Chair.

CHAIRPERSON ARROYO: Is this on? Why? Why? [laughs]

ERIC RUDE: We--

MONICA SWEENEY: We look at all funding streams and so far--

ERIC RUDE: [laughs] You know, why don't you answer that? [laughter]

MONICA SWEENEY: We--At this point the funding that is for hepatitis is from the CDC and from HRSA. And they cover the communities across New York City, and so for individual--so the needs are being met so far, the needs that the services that are being provided are by HRSA and CDC. That doesn't mean that we couldn't use more

money.

CHAIRPERSON ARROYO: Okay. So, I'll go back to the first question I posed regarding data around borough, specific to boroughs and neighborhoods, and we, I now understand that we're really not comfortable with how we're capturing that information. How do we make a case to the CDC or anybody else that we have an incredible need in this City to provide services throughout the City? So, I just will reiterate the importance of us being able to mount a campaign for additional funding, regardless of whether it's from the Department of Health and Mental Hygiene, HHC, the City Council, but certainly to draw down money from other levels of government, and if we're not confident that we can demonstrate the need, we're going to lose opportunity, if the data's not available to us. So, I'm going to say again that we need to get on the ball with certainly mirror image of the HIV/AIDS surveillance that we do in the City, that I know collectively we are very proud of, because we've put so much energy into making sure that it's available to us, and it helps us make the

case for why the City needs so many more resources than do other municipalities and counties in the State. So--

MONICA SWEENEY: I will, I will say a late breaker this morning, one of our researchers at the Department of Health, doing something to always try and stay on top of, or in front of the epidemic, and what's happening in HIV, had written to the CDC for money to test for hepatitis-C in all of the MSM being enrolled, 500 in this one particular medical monitoring project. And at first the CDC had said no, and he went back and talked to them again, and just as of Friday, they said, "Yes, we'll give you money to test the 500 people that are being followed for their HIV to test for hepatitis-C." But based on the data we have now, and we certainly need better data, which we will get, but based on that data, we have been advocating for getting money and, on Friday, we were told that we were getting some for testing this particular group of high risk individuals.

CHAIRPERSON ARROYO: Well, you know, and the other opportunities are, you know, we have provides that we contract these ser--out

for services. Primary care providers and, you know, having this information not coming as a mandated service report, by laboratories and, you know, somehow work it out so that you can eliminate the duplication of cases, so that we have as pure a number as possible, is really, really important. Council Member Van Bramer.

COUNCIL MEMBER VAN BRAMER: Thank you very much, Madam Chair. I wanted to ask you a few questions about where MSMs are in all of this, and the extent of concern that you have and what's being done to address it. And I confess if you said this before I arrived, but how many people are estimated to be co-infected?

MONICA SWEENEY: We estimate that 129,000 people are co-infected with hepatitis-C and 103,000 are co-infected with hepatitis-B.

COUNCIL MEMBER VAN BRAMER: And where are the MSMs within that?

MONICA SWEENEY: We call that a high risk population, which is why I just mentioned that this special cohort of 500 MSM that are being enrolled in this medical monitoring program, are going to be tested for hepatitis-C as

well as the services around HIV.

COUNCIL MEMBER VAN BRAMER: So we don't--

MONICA SWEENEY: They are a special risk population.

COUNCIL MEMBER VAN BRAMER: Yes.

MONICA SWEENEY: For hepatitis-C and B.

COUNCIL MEMBER VAN BRAMER: Yes. Yes, I believe I'm in that special risk population. As a gay man, but do we know how many of those 129,000 or 123,000 are MSMs? Do we, do we track that information?

MONICA SWEENEY: I, I don't have that data. Do you have that data for hepatitis? How many MSM?

ERIC RUDE: No, I'll confirm with Monica that we don't track that, and it's difficult to track. And, but I will describe the highest risk population for MSM, who have co-infection with HIV, it tends to be, they are newly, they're usually injection drug users, it's not often sexually transmitted. It would be mostly through injection drug use. Sometimes

through sexual practices that involve blood, transfer of blood. But this is an emerging, emerging area of research and internationally as well as here in the City, people are looking at that. It's very difficult to, if someone is acutely infected with hep-C, it's very easy to treat them, but once they have developed the hepatitis-C virus, then it becomes much more difficult. So if we were able to figure out who they were, as soon as they were infected, we would be able to address the problem.

MONICA SWEENEY: I just have to give a correction. I talked to you about the numbers of people co-infected. Hepatitis-C is, in the City, estimated to be between 16,000-332,600. That's co-infected with HIV and hepatitis-C. In hepatitis-B, which is 16 to 14 percent of people co-infected with HIV, that's been 6,500 and 15,200.

COUNCIL MEMBER VAN BRAMER: So did, so did I just get you right that most of the MSMs who are co-infected are IV drug users? Is that--?

ERIC RUDE: Again, the research is emerging, but that's the primary method of

transmission. Although, it has been shown to be transmitted through blood during sexual practice, which you could call sexual transmission.

COUNCIL MEMBER VAN BRAMER: Right, but we don't know yet the extent or where the trends are, if it's on the increase, if it's not.

ERIC RUDE: We, for New York City, do not know; however, there are other metropolitan areas internationally that have shown that it's increasing.

COUNCIL MEMBER VAN BRAMER: And do we know why? Just because of--

ERIC RUDE: Because of the prevalence of HIV and hepatitis-C, and the increase in injection drug use.

COUNCIL MEMBER VAN BRAMER: Hm.

ERIC RUDE: Among that population, I'm sorry.

COUNCIL MEMBER VAN BRAMER: So you're seeing an increase in intravenous drug use among MSMs?

ERIC RUDE: We're, this again is anecdotal information, and this is from the research that has been done in places like

Australia and Europe. And we're, they're seeing that younger MSM are being infected with acute hepatitis-C.

COUNCIL MEMBER VAN BRAMER: Hm.

MONICA SWEENEY: Just one important thing that I, I mentioned that this cohort of 500 MSM, if we get to test them and we just heard today that CDC's going to give us money to test this 500 men in the national health behavioral surveillance of 500 MSM, so we will be able to test that 500 and that will give us an idea of the percentage of that cohort who are infected. Which is not perfect, but nothing is perfect, 'cause we can't of course line up everybody who's positive and test them. But that will give us an idea of the percentage of MSM who are, who have hepatitis-C who are HIV positive.

COUNCIL MEMBER VAN BRAMER: Right. So, I understand you're saying we don't know the full extent of what we're dealing with yet, but what, what are we doing to prevent more co-infections?

MONICA SWEENEY: The same prevention methods that are suggested and that we

have interventions for prevention of HIV, are the same prevention methods to prevent hepatitis-C co-infection, and in New York City, we have 13 syringe exchange programs, which people can access, of course, free. That's one good way of decreasing hepatitis-C in the City, is needle, the use of clean needles, and not sharing needles or works. And the other is that we have a, the major condom distribution program in the United States, if not the world, that we hope people take advantage of. And I just will say that the program has, is doing very well because when we did a survey and people said what other things they needed, we have increased the kinds of condoms that we're distributing, and having very good uptake on it. We have 300, over 300 MSM venues that we specifically stock, and we have over 93 of those venues that are regular organizations that we give condoms to, and serve to see that they don't have needs that we're not meeting in terms of condom distribution. So that if we could get everybody who uses drugs to use clean needles, we could go down from the 184 infections that we had last year, that we thought

were due to injection drug transmission, we could get that down even farther from the almost thousand eight years ago.

COUNCIL MEMBER VAN BRAMER: And are the 13 needle exchange sites adequate?

MONICA SWEENEY: No. So we're going to be working on getting some more.

COUNCIL MEMBER VAN BRAMER: How are we, how are we going to do that? I think we have one in my district, that I support. So, what do we, what do we need in terms of capacity and how do we get there?

MONICA SWEENEY: I will tell you that we are working, I met with someone from the harm reduction, who runs a harm reduction unit in The Bronx, just a week or so ago, to talk about their needs in that area. And so this is something that is handled by our harm reduction unit, but we work with them as HIV units, so we'll be getting together to talk to them about additional needs. But this is one in particular that came up just a week or so ago, in an area in The Bronx, that said that they had inadequate services.

COUNCIL MEMBER VAN BRAMER: And in Queens?

MONICA SWEENEY: I, I don't know, I can't say right this minute about Queens. That is an area of expertise by a different Assistant Commissioner, but I will certainly meet with her after this and discuss it.

COUNCIL MEMBER VAN BRAMER: Sure, I mean, I don't mean to put anyone on the spot, but if--

MONICA SWEENEY: Oh, no, that's fine.

COUNCIL MEMBER VAN BRAMER: If, if we know that the answer is no, we don't have enough, then if we know that, then, then maybe you have a sense of what you do need and what's preventing us from getting what we need, so is it a matter of funding? Is it politics? Why don't we have what we, what we need?

MONICA SWEENEY: It's because it isn't static, and it's evolving, and so as you see additional needs and areas that need it, then we address it.

COUNCIL MEMBER VAN BRAMER: Okay, I

mean, I would, I would like to know what you have in Queens, in particular, for sure, and that is the borough that I live in, and I represent a portion of Queens.

CHAIRPERSON ARROYO: So, Council Member, if I, let me help you out with this. If we can get a report from the Department of Health on where these programs are located, how much funding each gets, and how many patients they're handling during the course of the year, that would be helpful. So, that we cannot have on in everyone's backyard, but if we know where they're located, there certainly is more opportunity for collaboration and working with community providers on making sure that even if I don't have one in my district, that the population in my district can be informed where they can access services. So, we can start from that.

MONICA SWEENEY: Yes, we can get that, sure.

CHAIRPERSON ARROYO: 'Cause I see that you are hard pressed not to throw DOHMH under the bus.

MONICA SWEENEY: I am DOHMH.

CHAIRPERSON ARROYO: [laughs] I know, I know.

MONICA SWEENEY: The one other thing that I will say is in, in this City and State, if people are aware, they can also get syringes from a pharmacy, without, without a prescription.

CHAIRPERSON ARROYO: Okay.

MONICA SWEENEY: And we--

CHAIRPERSON ARROYO: Council Member, were you--?

COUNCIL MEMBER VAN BRAMER: Yeah, I think I'm done for now.

CHAIRPERSON ARROYO: Okay, thank you. Commissioner Sweeney, I know that you're pressed for time, I want to get a couple more questions, and this is not a budget hearing, but in, in understanding a little bit more, or surprised to hear that we are not comfortable with the amount of information or data that we have, around the hep-C, hep-B incidents in the City, communities, etc., and I think we have a, do we have a better handle on understanding co-infection between hep-C, B and HIV? Have we captured

everyone? Do we know that the numbers that we have are an absolutely close to reality number?

MONICA SWEENEY: These are estimates.

CHAIRPERSON ARROYO: Okay.

MONICA SWEENEY: And what I gave for HIV and co-infection with hepatitis-C, we give estimates of 15 to 30 percent, and with B, six to 14 percent, they are definitely estimates.

CHAIRPERSON ARROYO: And I get it, that we're not going to be able to count every single person, but opportunity for education in the community, so that people know that if you fall into X, Y, Z category, that you ought to be speaking with a primary care provider around testing, so that we can know status, both on HIV and the hepatitis viral infection population. Because I think community education helps us to raise the numbers just by raising awareness, and many people may not know that they're in a high risk, or in a risk category, that should be checking to find out their status. DOHMH has presented to, or through the Mayor's Preliminary Budget, reduction of, in HIV programming, and it's

a pass-through to HHC, and that's, I understand has been targeted for elimination in the budget. How do we make up? Assuming we have lost our mind, and we agree with you, that this reduction is an appropriate one, how do we make, how do we make up the gap for that service not being there?

MONICA SWEENEY: I have to say that I did not come specifically prepared to talk about budget, but I will say that any cut to HHC funds had to do with a service that had funding from some other source. I do, I do know that that was considered when the discussion took place.

CHAIRPERSON ARROYO: Yeah, that's what the State, that's what the agency wanted us to believe when they came to testify, and then it turns out that's not necessarily the case. So, I think we need some clarification on--that was targeted for reduction, funding that is very necessary to enable HHC to carry out that work, that they're doing phenomenally well with, and that it's no longer eligible for State matching funds is not accurate. As we understand it. So, the question remains, what happens with this population, HHC's, HHC's work in this regard,

because DOHMH has thought it appropriate to cut this service?

MONICA SWEENEY: I can only--

CHAIRPERSON ARROYO: Okay. So--

MONICA SWEENEY: --I can only respond to the conversation--

CHAIRPERSON ARROYO: --so let's, let's make sure that that's one of the questions that in the Executive Budget Hearing, that we hold for the, this Committee, that the Department of Health will be prepared to give us an alternative.

MONICA SWEENEY: I just wanted to ask, were you, were you speaking of cofactors when you, the cofactor budget when you were talking about that? 'Cause that cut--

CHAIRPERSON ARROYO: A, the Department of Health and Mental Hygiene has presented a preliminary budget--

MONICA SWEENEY: Yeah.

CHAIRPERSON ARROYO: --that includes elimination of funding that goes to HHC for HIV testing services. And it has been eliminated in the preliminary. Because, as we were explained, to, it is no longer eligible for

matching funds. Post that hearing, we have learned that that's not accurate.

MONICA SWEENEY: I'm sure that we will get back to you for that information. I thought it was co-factors you were referring to, but we'll get back to you with the--

CHAIRPERSON ARROYO: No, no, I'm, I'm referencing specifically the pass-through that goes to HHC for HIV testing.

MONICA SWEENEY: Yeah, that's passed.

CHAIRPERSON ARROYO: Colleagues, any more questions? Okay, Commissioner, thank you for your time.

MONICA SWEENEY: And thank you.

CHAIRPERSON ARROYO: And again, I just reiterate, giving that, given that the Commissioner has had a committee pulled together to deal with the issue of understanding how we can better provide and utilize resources to care for our hepatitis-B/C infected residents, and those that are co-infected with HIV and Hep. We look forward to talking about a very healthy, robust data management system, that helps us, all of us

together, fight for every single dollar that this City can be eligible for, so that we can indeed treat, but more importantly prevent the spread of infectious diseases in our City. Thank you, Commissioner.

MONICA SWEENEY: Thank you very much. And I look forward to working with the Council on any of these opportunities that we have again. And I will get the information from Council Member Dickens for tomorrow evening, if, if that's available.

CHAIRPERSON ARROYO: And I think, Eric, are you staying with us? Okay, good. And you can stay right there. Don't push that mic away from yourself, you know, keep it right there, 'cause I know that [laughs] more questions will come, especially after we hear Dr. Masci's testimony. And now I understand your hesitation when I called the panel to the table. But thank you for being here and for sitting through this. But you may begin your testimony.

JOSEPH MASCI: Thank you. Good afternoon, Chairperson Arroyo and Members of the Health Committee. I'm Dr. Joseph Masci, I'm

Director of Medicine at Elmhurst Hospital Center, which is part of the New York City Health and Hospitals Corporation. I'm also a Professor of Medicine and a Professor of Preventive Medicine at Mt. Sinai School of Medicine. And on behalf of HHC, thank you for the opportunity to discuss HIV/AIDS-Hepatitis-C co-infection. I'll begin with an overview of HIV/AIDS services and discuss hepatitis-C and current treatment protocols. All eleven HHC acute hospitals are state designated AIDS centers that provide comprehensive HIV/AIDS, both inpatient and outpatient care services to their patients, to help them achieve better, the best possible outcomes. The centers work with pediatrics and obstetrical departments, as well, to deliver the specialized HIV care that infants, children and pregnant women need. Coler-Goldwater, one of HHC's long term care facilities, also provides specialized care to individuals with HIV who require ongoing medical care in a skilled nursing setting. Through HHC's health plan, Metro Plus, we operate a special needs plan, or SNP, for people living with HIV/AIDS. Lastly, any New Yorker can come to any HHC hospital or diagnostic

and treatment center and quickly obtain confidential HIV testing, as well as expert treatment and counseling regardless of his or her ability to pay or immigration status. HHC is committed to improving patient outcomes by delivering comprehensive, high quality HIV related medical care and supportive services, and by increasing access to HIV testing so that people are able to learn of their HIV infection earlier in the course of the disease and can be linked to life prolonging treatment. HHC has been very fortunate in this endeavor over the last several years, to receive considerable resources from the City Council, to support an expanded routine HIV testing program. In Fiscal 2010, more than 188,000 individuals were tested, and more than 17,50 individuals tested positive. Since the program began in 2006, more than 840,000 individuals have been tested for HIV and more than 8,400 individuals were diagnosed with HIV. Through the efforts of HHC staff, more than 60 percent of these individuals were linked to HIV primary care within the month they were diagnosed, and 90 percent were linked within, to care within

90 days. HHC is the largest provider of HIV primary care in New York City. It's estimated that between 15 and 30 percent of people who have HIV are also co-infected with hepatitis-C. The estimates vary, some people who are infected do not show symptoms of disease and testing for hepatitis-C may not be consistent among populations. As you know, hepatitis-C is a disease that inhibits the proper functioning of the liver, and is the leading cause of death due to liver disease in the HIV infected population. Hepatitis-C is one of the three most common forms of hepatitis; the other two are A and B. HIV and hepatitis-C share some common routes of transmission, as you've heard. People who are at very high risk of becoming infected with hepatitis-C are injection drug users. This is also a main source of HIV infection. It is important to recognize that it is needle sharing behavior that transmits hepatitis-C, so high risk behaviors may also include the use of street hormones, getting a tattoo or body piercing from an unlicensed establishment, and other behaviors, not just the use of injection drugs. Others at

high risk of infection include men who have sex with men without protection, and through heterosexual transmission, especially for those with multiple partners or engaging in anal intercourse. We estimate that of the 19,000 HHC patients who are HIV positive, approximately 25 percent are co-infected with hepatitis-C. For these individuals, the effects of hepatitis-C are more serious, treatment is complex, and some options may not be available due to contraindications or other complicating factors, such as alcohol or drug abuse. However, hepatitis-C is a treatable disease and treatment options are steadily improving. There are two new classes of prescription drugs currently in the food and drug administration Phase III trial phase, with the possibility that one or two will be available later this year (that may be as early as June). At Elmhurst Hospital Center, we provide care to, in our immunology clinic, to approximately 1,180 patients in 2010. Of this group, 97 are co-infected with hepatitis-C and are under treatment or monitoring by our Joint Infectious Disease Liver Clinic. 62 have

infection with Type I hepatitis-C virus. This is one of the four genotypes of hepatitis-C. And this is the type that's least likely to respond to current therapies. In total, 70 of our co-infected patients have either declined therapy, have a contraindication for treatment, or are among those for whom hepatitis is not causing significant liver damage. All persons with known HIV infection should be screened for hepatitis-C infection regardless of whether they self-report the common risk factors for acquiring hepatitis-C. Hepatitis-C is diagnosed by having a positive antibody, a protein response the body makes against the virus test. For some people with HIV, this hepatitis-C test may be negative, because their immune systems are weakened, therefore if person with HIV do have risk factors for hepatitis-C or have abnormal liver tests, we order a more specific test that can detect hepatitis-C in their blood. Guidelines from the New York State Department of Health recommend a baseline test for hepatitis-C for newly diagnosed HIV infected patients, and yearly testing of patients thereafter. The next step that we at HHC take is

to conduct an assessment for signs of liver disease, drug or alcohol abuse, depression or other mental health diagnoses that have major effects on patients' health outcomes, and eligibility for treatment of their hepatitis-C disease. Persons with hepatitis-C should be offered vaccination for hepatitis-A and B, to prevent other harmful liver diseases. We also provide education as a guide to maintaining a healthy liver. Many commonly used medications and supplements can harm the liver, such as acetaminophen or Tylenol cold medicines. While some supplements like milk thistle can improve liver health, others like St. John's Wort may interfere with the patients HIV therapies and cause harm. All patients with HIV and hepatitis-C co-infection should have an ultrasound of their liver yearly to screen for hepatocellular carcinoma, a type of liver cancer associated with hepatitis-C that is much more common when one also have HIV infection. Based on State Department of Health guidelines, the decision whether or not to treat an HIV hepatitis-C co-infected individual must be made in consideration of several factors.

These include one, contraindications and relative contraindications to therapy. For example, persons with severe anemia or low blood counts, kidney disease or significant depression, are not able to tolerate the medications. The major medication used, interferon, can induce thoughts of suicide and severe depression even among patients without such history. Whether or not the patient has acute hepatitis-C, the likelihood of response to treatment, the likelihood of progression of scar tissue or fibrosis of the liver in the absence of treatment, the patient's immune system status--by that I mean patients who are profoundly immunocompromised may suffer a dramatic decline in their immune response if they're treated for hepatitis-C. The extent of their current liver damage and the status of their HIV disease, treating the HIV will slow the progression of hepatitis-C virus, but liver disease may affect a person's ability to take the HIV medications. Furthermore, risk factors for effects of treatment, those I mentioned before, including severe depression or thoughts of suicide, as well as lowering of the person's white

blood cell count, which places the risk, person at risk for infection, lowering the red blood cell count, causing anemia, lowering of the platelet count, the cells needed for clotting, which places the person at risk for bleeding. This risk assessment becomes quite complex, as persons with HIV and hepatitis-C frequently have these conditions already. The motivation for treatment and barriers to adherence to therapy have to be evaluated. CD4 count to measure the immune system, persons with low CD4 counts are already at too high a risk for infection and the interferon medicine for hepatitis-C cannot be given to some of them, since it would further lower their CD4 counts. After this review, if it's determined the treatment may prove to be beneficial, the patient's physician should discuss the benefits and subsequent risks of various treatments. Currently, there is only one treatment option: a special formulation of interferon called Pegylated Interferon, that requires weekly injection, and this is combined with ribavirin pills that are taken daily in combination, and the treatment courses for at least one year. The outcomes of

those with HIV hepatitis-C co-infection are considerably worse than those with hepatitis-C mono-infection. First, the HIV infection speeds the progression of liver damage from hepatitis-C. Second, there's significantly more barriers to care and more contraindications to the medications affecting patients' eligibility to be even offered treatment for hepatitis-C. Third, there's a lack of qualified HIV hepatitis-C experts trained to treat this population. Finally, the response rate to these medications is much poorer among patients with HIV infection compared to those with hepatitis-C mono-infection. Investigational drug trials are currently underway to evaluate new forms of drug treatment. Not only the two drugs that I mentioned, but an additional half a dozen or so drugs that are currently in clinical trials. This is very exciting news that offers much promise. The two new protease inhibitors that I'm talking about work by inhibiting the replication of hepatitis-C virus and are expected to be approved by the FDA later this year. In addition, there are several new classes of drugs being developed that are or will be in study at centers

in New York City. There are strategies now being employed that may improve outcomes. For instance, HIV infected patients may have more fatty liver disease, by virtue of their HIV infection or its treatment. So by reducing the fat content of the liver, a person may respond better to interferon and ribavirin. Also, a new genetic marker was discovered last year, which showed that among persons that had this marker, their overall response rate to medications is higher. Employing such strategies could help identify those individuals who would have better response rates than providing medications where risk outweighs the benefit. For those who are unlikely to benefit, or cannot take the current medications to treat hepatitis-C, it is essential that we have the resources to monitor their HIV/hepatitis-C co-infection, and provide education on ways to improve liver health. Examples include imaging the liver on an annual basis, and if suspicious cancerous mass is identified, making referral to a liver surgeon for biopsy and possible removal. Another example is provision of medications to end, to prevent end-stage liver disease,

complications of end-stage liver disease include enlargement of blood vessels in the esophagus, resulting in bleeding or building up of body fluids in the abdomen, and the person turning yellow from jaundice. For those who develop end stage liver disease, there are considerable measures that can be taken for including some. Liver transplants, which are must riskier for patients with HIV infection. Nationwide, 30 percent of all liver transplants are done because of hepatitis-C disease. However, very few transplant candidates have HIV co-infection. Now I'd like to discuss what can be done to prevent or reduce the spread of both HIV and hepatitis-C. Current State Department of Health recommendations for prevention and thereby reduction of the spread of these viruses include avoiding practices that transmit both HIV and hepatitis-C--chief among these are high risk sexual practices, including unprotected sex, and needle sharing among injection drug users; providing counseling and treatment for active drug users to reduce or eliminate drug use; for those who continue to be active drug users, counseling them to use sterile

equipment at all times and to properly dispose of their syringes after one use; advising those who have contact, that is household contact, with persons infected with hepatitis, to avoid sharing items that may be contaminated, such as toothbrushes and razors; encouraging uninfected, long term sexual partners of persons co-infected to continue to follow safe sex guidelines to prevent transmission; and encouraging those seeking tattoos and body piercing to use only licensed establishments. Of course, education and awareness are large components of any prevention strategy, whether it is for HIV or hepatitis-C. By holding this hearing, the Council is contributing to the public discourse on the growing problem of HIV and hepatitis-C co-infection. I ask the City Council to help us spread the word of the importance to be tested for both HIV and hepatitis-C infection. The spread of hepatitis-C is a large and underreported problem worldwide. It is further compounded by HIV co-infection. I believe this topic is one that needs to be discussed in the public forum more often. I appreciate the opportunity to come before the

Council to have this discussion. I conclude my written testimony with some thoughts about the impact that earlier diagnosis and therapy can have on an individual. A healthy, 25 year old man can expect to live another 53.1 years. That same man with HIV infection, who is promptly diagnosed and takes HIV therapy according to State Department of Health guidelines, can expect to live another 52.7 years. But, if he has hepatitis-C co-infection, his lifespan will be markedly reduced, to only ten to 30 years beyond the diagnosis, unless the hepatitis-C is controlled or cured. We will have the opportunity to change this outcome, as we did with HIV infection alone, as the new diagnostic technologies and medications become increasingly available. I'll now be happy to answer any questions you may have. Thank you.

CHAIRPERSON ARROYO: Thank you, Dr. Masci. First and foremost, thank you for the part of the testimony that helps, certainly me, I don't know if I can speak for my colleagues, a bit simpler to understand the complexity of managing and dealing with a population that is not just hep infected, but co-infected with, with HIV and AIDS,

as well. So, thank you for that, because they're simple to understand from this perspective. And I think more importantly, how often does the general public get to hear this kind of information for the sake of just being informed, to be able to determine whether or not they should be seeking the advice and counsel of a healthcare professional, for a screening. So, thank you, for this testimony. A couple of questions regarding your--Council Member Eugene Mathieu, hi, I did not see you. You have questions? Okay. I asked the Department of Health regarding the distribution incidence of cases, HHC is an institution that has facilities in four boroughs, and working on Staten Island, right Council Member?

COUNCIL MEMBER ROSE: [off mic] Thank you, yes.

CHAIRPERSON ARROYO: [laughs] But do you have information or data on how the cases that are being followed, you estimate that 19,000 HHC patients are HIV positive, and 25 percent are co-infected with hep-C. Do you know what the distribution of those cases are across the City?

JOSEPH MASCI: I think we know the

approximate distribution, based on national data and based on our own experience. Nationally, the--and I think Dr. Sweeney initially made this comment--between 75 and 90 percent of HIV infected injection drug users are co-infected with hepatitis-C. Nationally, among MSM, who are infected with HIV, approximately eight to 15 percent are co-infected with hepatitis-C. Citywide data I don't have. I didn't come prepared to present that.

CHAIRPERSON ARROYO: Could you come up with data?

JOSEPH MASCI: We could, we could certainly extract that type of data from our HIV programs at all the HHC hospitals, because we do very robust screening for hepatitis-C.

CHAIRPERSON ARROYO: I'm going to put you on the spot and if you can, by all means, help us to understand. I'd like to believe that you, in your system, are handling this very complex population, probably more so than private institutions, in that it might be representative of what's going on in the City. And in the absence of DOHMH, having information or data that

you feel really comfortable with coming to a conclusion about, in the borough of Queens, the next neighborhood, the incidence is higher than in any other, and if we had ten dollars to spend, we better dedicate some of that money to that neighborhoods. Which is where I'm trying to get us to, at some point. It is not my practice to beat up on the City agencies that come before us to testify. I am focused more on how can we ensure that where the need is, we bring the resources. And that is the reason why I feel so strongly about having access to data, that can help us understand where the needs are in the City, so that we can ensure that we target services to those communities.

JOSEPH MASCI: May I just expand--

CHAIRPERSON ARROYO: Sure.

JOSEPH MASCI: --a little bit on my answer to that?

CHAIRPERSON ARROYO: Sure.

JOSEPH MASCI: As you can see from our own Elmhurst data, despite the 25 percent overall co-infection incidence, we have less than ten percent in our clinic. Why is that? Elmhurst

is in a quiet neighborhood, as you know. We have a lower proportion of injection drug users in our HIV program, than we have men who have sex with men, and women who have contracted disease through heterosexual exposure. So this gives you some idea of the range and some means short of getting the data and handing it to you today, of making some projections as to where the high incidence neighborhoods might be. They're going to conform to the high incidence neighborhoods for injection drug use.

CHAIRPERSON ARROYO: Okay. And what can we say about the general population? So we're talking about co-infection in this hearing. Obviously it is the focal point of the hearing, but we had a discussion at the Aging Committee this morning where we're discussing mental health disorders and issues among the aging population. And in particular in senior centers, but only two percent of this City's seniors access services at senior centers. So we're talking about 98 percent of the senior population in the City, what can we say about the general population that--

JOSEPH MASCI: The incidence of

hepatitis-C?

CHAIRPERSON ARROYO: Yes.

JOSEPH MASCI: I think all we have are pretty crude estimates, and there are a couple of reasons for that. As the clinicians in the audience would bear me out, I think, hepatitis-C is not an infection that is typically diagnosed as an acute hepatitis. We're not talking about HIV specifically, we're talking about the general population. It's diagnosed in general rather haphazardly, I would say. Some patients presenting with advanced liver disease are recognized as having hepatitis-C. It's the rate patient who has completely asymptomatic hepatitis-C, and that is the majority of patients with hepatitis-C, who's actually tested for it. So there's no equivalent to the effort that's gone on with HIV, to offer extensive testing to the community, the new State law with the opt-in provision, etc., and hospitalized patients and clinic patients, etc. There's been no parallel initiative with hepatitis-C to give us this information, really, on a widespread basis. And I, not to drone on, but I think it's worth

remembering that hepatitis-C virus was discovered 20 years ago. We didn't know the cause of this disease until 20 years ago. It took a decade to formulate treatment regimens, even the imperfect ones we have now, and it's taken time since then to establish their effectiveness and outcome data. So, hepatitis-C has lagged behind HIV, for any number of reasons that we could speculate on: the intensity with which it's been studied, from an epidemiologic standpoint, from a population standpoint, and even from a treatment standpoint.

CHAIRPERSON ARROYO: Thank you for that, that helps to put it in perspective. That, not withstanding, we, you know, we're having the conversation and I, the anxiety, I have to tell you, that I'm sensing here about how--you know, how fast can we really get a mirror image of surveillance in the data that we have, that you know, anyone who's doing some kind of research around HIV and AIDS, can go to the New York City Department of Health website, and pull up any number of reports for years. And, and we need to create that same data surveillance for hepatitis, in the different categories, and maybe a

particular one around the co-infection, as well. And I'm going to beat that horse until it comes back to life. Okay, I have a little bit of time left in the Council, so I hope, at least certainly for the remainder of this term as Chair of this Committee, that we engage in that conversation, and work to create efforts and resources to make that possible. And more importantly, how do we design the best model for prevention and intervention and treatment? Council Member Mathieu?

COUNCIL MEMBER MATHIEU: [off mic] Thank you very much. [pause] [on mic] Thank you very much, Madam Chair. And let me say thank you to the members of the panel, for this very, very important, you know, the very important information that you bring to us. Since HIV/AIDS and hepatitis are two very dangerous and serious disease affecting people in Brooklyn, and New York, and the United States, I'm reading from your testimony, doctor, and you say that it is important to recognize that it is the needle sharing behavior that transmit hepatitis-C. So, high risk behavior may also include the use of the

street hormones and getting a tattoo or body piercing. What HHC has in place? Because we know people there are, you know, they love doing, having the tattoo on the body and piercing their ear. This is very, very, a big practice in our City, and everywhere in United States. But what HHC, you know, is doing to prevent, to help people, or to prevent people getting HIV/AIDS or hepatitis-C, by, you know, having those behaviors? What is in place?

JOSEPH MASCI: I would have to say there's nothing systematic in place. There are many people who get tattoos and body piercing, and unfortunately much of this is done in less than optimal conditions. If you were to ask me are patients who present to us for other reasons and happen to have a history of tattooing, are they offered hepatitis-C testing routinely, I would have to say the answer is no. The, increasingly they are offered HIV testing, voluntarily, and routinely, and as the State law becomes more clarified, this will become more universal. But hepatitis-C testing, as I indicated earlier, has lagged behind HIV testing, in that, that group, as

well.

COUNCIL MEMBER MATHIEU: Do you have the number, approximately, the study see, how many people contract hepatitis-C by tattoo or by piercing the ears, approximately?

JOSEPH MASCI: I, I don't h--I can give you an approximate number, it's a very small fraction of the hepatitis-C patients, since the bulk of the patients are accounted for, of the patients we identify, by either injection drug use or high risk sexual behavior, it leaves single digit percents by other routes, and it's in that cate--it's in that ballpark, I would say.

COUNCIL MEMBER MATHIEU: Uh-huh. But anyway, if it's ten or 20, I believe it is even too many.

JOSEPH MASCI: Of course.

COUNCIL MEMBER MATHIEU: Because it's about life, it's about the health of the people. Don't you think that HHC should do something to see what can, what can be done in term of prevention? In term of, you know, people contracting H--you know, hepatitis-C by tattoos and the piercing of the ear?

JOSEPH MASCI: I think there, you know, this highlights one of the differences between HHC and DOH. DOH licenses tattoo parlors, etc. HHC, although we do many things in the community to educate people about various health issues, we are, in the end, a hospital system, that receives patients who need hospital care. So, we certainly could conceive of strategies that might identify more patients in this category, who have hepatitis-C. I think it would be ultimately the tip of the iceberg in that group that we would identify through the, in the hospital setting. But, you know, we could certainly have further discussion about that, and effective, cost effective means of doing it.

COUNCIL MEMBER MATHIEU: Thank you. And also in your testimony, I'm reading this part, "encouraging talking about," you said, "encouraging those seeking tattoos and body piercing to use only licensed establishment." Why they got the license for? Is that because of any medical knowledge? Or the way they practice, you know?

JOSEPH MASCI: That I would have to

defer to the Department of Health who does the licensing.

COUNCIL MEMBER MATHIEU: Yeah, because [laughs] if they have a license, and we know that having tattoo or piercing the ear, can give to those people disease, what make them different from all the people who are doing the same thing? Their license and what? Based on what they have their license? Do they have any medical knowledge or medical--do they practice, you know, their job differently? What--Because I think there are, through them, also, the people can still get hepatitis-C. Why they get the license for?

ERIC RUDE: If I may, I can answer that. The licenses is based on attending classes and being, you know, going through infection control, you know, classes. They do learn that they're supposed to be using different needles for each of their clients, they're told that they need to use different pots of ink for each of their clients. It's when you get tattoos that are not done by someone who has that knowledge that the issue is much more acute.

COUNCIL MEMBER MATHIEU: I know that you know that in medicine, I used to learn when I was an, you know, in medicine, that the best medicine is prevention. You know that. You know, it's, costs less money, people don't suffer, and this is the best medicine that we believe. But those people who get the license, is there any reinforcement of the law, to know exactly the practice what they learn, in other to prevent infection or contamination of those people? Is there anything in place to oversee them and to ensure that they do exactly what they're supposed to do?

ERIC RUDE: Not, not, I don't know of any such procedure.

COUNCIL MEMBER MATHIEU: So, do we know that there are not tattoos - - also hepatitis-C to the people? Because I don't, what I'm trying to figure out, I don't see why they are different from the other people, and why they got the license. If we cannot have something in place to oversee them, and to verify that, all right, those people, the way they're practicing, the way they're practicing their job, you know, make a

difference from the other one.

ERIC RUDE: I'm more than happy to get back to you about how the, the procedures that people learn during their licensing is followed up by the Department of Health.

COUNCIL MEMBER MATHIEU: Thank you very much. Let me, can I say one, one more? Thank you, one more. You know, in the testimony also, I know in the - - of those with HIV/hepatitis-C co-infection, are considerably worse than those with hepatitis-C mono-infection, and they are different, I think there are four cases. And you said in the third one, that there is a lack of qualified HIV/hepatitis-C expert trained to treat this population. This is a serious disease, very serious. So what HHC or the hospital, the authority, and the, you know, who are responsible to treat people, to give people the proper treatment, what they are doing to fill the lack of experts qualified to treat HIV and hepatitis-C? What they are doing? We know there is, you know, a lack of qualified expert. Is there anything that has been done to--?

JOSEPH MASCI: Yes. Again, you

know, I speak for my own hospital and can project to the other HHC facilities to some degree. We're in a state of transition. HIV specialists, which is a State designation, where we have to qualify as HIV specialists, the emphasis traditionally was not on also treatment of hepatitis-C. That is changing now. As we train our new fellows, and our younger faculty come into the facilities, they are increasingly knowledgeable in the treatment of hepatitis-C. But I must say, hepatitis-C, especially in the setting of HIV co-infection, but even in the setting of mono-infection, is, as you might get from some of my testimony, an extremely complex disorder, that requires, just like HIV does, a multidisciplinary team approach. Psychiatric disturbances are common on therapy, etc. Adherence to therapy is critically important, as it is with HIV. So, we're trying to modify our HIV systems of care to more effectively also address the issue of the co-infected patients. So at Elmhurst, for example, we established a joint HIV gastroenterology/hepatology clinic, where we have the combined expertise of the infectious

disease/HIV experts and the hepatitis experts. We learn from each other, we care for patients in collaboration, etc. Other HHC facilities have configured their care systems in various ways, to accommodate this, this progressing problem. But absolutely, HHC is quite aware of it, and is trying to tackle this problem in the most effective way possible. But I do want to stress the complexity of caring for a patient with hepatitis-C. It is, it is full of areas of uncertainty as to risk benefit, and with new drugs on the horizon, there's now uncertainty as to who should wait for treatment, that will be potentially more effective, and who should be treated immediately with therapy, which is potentially not very effective.

COUNCIL MEMBER MATHIEU: Thank you. I'm sorry, this is the last one, the last one, the last one.

JOSEPH MASCI: Sorry for the long answers, too. [laughter]

COUNCIL MEMBER MATHIEU: But, and you say that you are, they are in transition--

JOSEPH MASCI: Yes.

COUNCIL MEMBER MATHIEU: --to put the team together. We know in term of hepatitis-C separately, HIV and all the disease, - - disease, we have a lot of knowledge. Those disease have been there, have been there for a long time. I know that, you know, the combination between HIV/AIDS and hepatitis-C combination that may be complex, but our knowledge of those separate disease has been there for long time. What is the biggest challenge to have this team, team of qualified treating expert together? What is the biggest challenge? It is, is it the knowledge or resources?

JOSEPH MASCI: Well, it, it's, it's both. I think you're right, the knowledge has been there for a long time, the knowledge is getting increasingly refined. They have now these genetic studies where we may be able to identify people who are more likely to respond to treatment, etc. We didn't know that a year ago. As far as the resources go, the State designated AIDS centers, and particularly, and also specifically, I should say, through the special needs plans, have developed these

multidisciplinary teams, to try to provide one-stop shopping care for all elements of HIV service. Now, what we are trying to do at my facility, is to use those same resources and also bend them toward the needs of the hepatitis-C subpopulation, as well. So, if you ask, is it, is it a matter of knowledge? No. It is--is it a matter of resources? I would say, to some degree. I think the, you know, resources to treat hepatitis-C, if we didn't have HIV at all, would require the same sort of effort that we've made in HIV. So, we are working in a time of limited resources, we recognize that, and we're trying to modify our systems for HIV care, to incorporate effective care of hepatitis-C, and I think we're doing it effectively, at this point.

COUNCIL MEMBER MATHIEU: Thank you very much, Chair. Thank you, sir. Thank you, Madam Chair, thank you very much.

CHAIRPERSON ARROYO: [off mic] Thank you. [on mic] Thank you, Council Member. I have two, one last question and a request. I, and I've, often say in, during the hearings, if you see chatting going on, it's not that we're not

paying attention, is we're trying to, we're plotting [laughs] on how what next steps can possibly happen. And the one question I asked the Committee staff is City Council Members get printed brochures on different topics, from not being a victim to a scam for seniors, to you know, how to deal with an issue of tenant/landlord court. I've posed a question around hepatitis/HIV co-infection, do we have a brochure that speaks to the issues and from the perspective of prevention and education in the community? Where out in the community regularly, whenever we go out, we take these little pamphlets with us. So, if we don't have one, to work together with us, so that we can develop one that the Council Members can use in their community outreach efforts, that give the warning signs and what to look for, and if you've done this and you should be talking to a healthcare professional. So, that's a request. And along the lines of that, can we, is it possible for the Department of Health to give us a listing of the licensed tattoo establishments in the City, so that in our public education campaign, that we provide a very strong statement.

If you're going to do that, do it safely, and these are the places that are licensed that you should be talking to, as opposed to just going anywhere. Okay, so, that's the request. The question, hepatitis is not a routine test that providers are doing to every single patient that comes into the clinic, the way they test for cholesterol or diabetes or some other--

JOSEPH MASCI: No. No, it's not.

CHAIRPERSON ARROYO: Why? Why?

JOSEPH MASCI: It--it, you know, as far as what's done routinely, outside of the setting of HIV clinic where it is done routinely--

CHAIRPERSON ARROYO: No, no, no--

JOSEPH MASCI: But I know.

CHAIRPERSON ARROYO: I'm speaking generally--

JOSEPH MASCI: General primary care.

CHAIRPERSON ARROYO: General primary care.

JOSEPH MASCI: This, you know, the guidelines for screening of populations, they generally begin with the Institute of Medicine,

and the U.S. Preventive Services Taskforce. Neither at this point suggests routine testing for hepatitis-C of the entire population. Many of their--

CHAIRPERSON ARROYO: Well, hepatitis, 'cause we have A, B and C.

JOSEPH MASCI: Same for all of them.

CHAIRPERSON ARROYO: Okay.

JOSEPH MASCI: Except for, well-- Once we get started dealing with subpopulations, it gets away from your question. You're talking about general screening of anyone who walks into clinic.

CHAIRPERSON ARROYO: Correct.

JOSEPH MASCI: No, these tests are not recommended as routine screenings tests. Now, there are many diseases for which we don't offer routine screening. And this is an example of a set for which we don't. Many of the recommendations of the U.S. Public Health Service and the Preventive Services Taskforce, are based in part on science and part on cost effectiveness. The overall incidence, prevalence of hepatitis-C

in the U.S. population, you heard the figures, I think three to four million people are projected as infected with hepatitis-C in the United States. And it's possible that the argument has focused on that relatively low incidence, as an argument against routine screening. What we saw in the history of HIV testing was syndromic testing, and testing by risk behavior; and obviously we felt that that was inadequate, and that's why we've gone broader now. I think testing by risk behavior, even, in hepatitis-C is not very complete or effective right now. I think syndromic testing, and by that I mean patients who present with liver disease, of uncertain etiology, are virtually always tested for hepatitis-B and C.

CHAIRPERSON ARROYO: Isn't it a little too late at that point?

JOSEPH MASCI: Yes.

CHAIRPERSON ARROYO: I mean, I don't, no, I don't want to be facetious, I'm trying to understand. I get it that it's not recommended. Cost effectiveness, I guess is a point that we can talk about at another opportunity, but which is more cost effective:

identifying those earlier on in their disease manifestation, and they're really sick are now costing a great deal more to, to provide services to? And I'm, I'm not a medical expert, I'm just someone who asks some really simple questions. It would appear logical for us to treat earlier on, it's more cost effective that way, than if we have syndromic. Right, that's the word, syndromic?

JOSEPH MASCI: Now, in the--Yes, first of all, let me make it clear that these are not my recommendations.

CHAIRPERSON ARROYO: No, no, no, no, I understand that.

JOSEPH MASCI: And sec--secondly--

CHAIRPERSON ARROYO: I absolutely understand that.

JOSEPH MASCI: --if we took the general population and the natural history of hepatitis-C, leaving out HIV co-infection again, the majority of people with hepatitis-C, neither progress to cirrhosis nor to liver cancer. The majority of the patients live their life with no symptoms. And there's no clear evidence that treating those patients benefits them. For the

subset of that group that will progress to cirrhosis or heap--or hepatocellular cancer, there is a point in time where intervention with hepatitis-C treatment might have altered that outcome. But starting with a disease that overall has a lover prevalence, and the majority of patients with the infection don't appear to fall into a category that would benefit from this rather toxic therapy, all those issues come into play, I think when they're making these judgments. And again, this is, this is not my judgment. If you asked me what my opinion was off the record, should we test everybody for H--hepatitis-C, I'd give you that, but we're not off the record. [laughs]

CHAIRPERSON ARROYO: Okay, and I'll ask you off the record. Because if for no other reason, just for my own personal knowledge, as I, as I move in the work of this Committee, understanding the difference between reasonable and just an expectation that's not really appropriate given everything considered. I don't want to spend a great deal of energy on the things that are not, that don't make real sense. You

know, because if common sense were so common, we would all have it. I'd like to think that I have a little bit of it. So, you know, as a, as a matter of just information, understanding why isn't it required, why is, it is a mandated reporting result, yet we don't have the data that we, we need to be able to make a case for having more funding to empower our providers, community organizations, to have the programming necessary to, to provide services to those that need it, and more importantly prevent future infections. So, with that, I want to thank you both for being here. And welcome a conversation, I certainly will follow up with some questions of my own. So, thank you.

JOSEPH MASCI: Thank you.

CHAIRPERSON ARROYO: For your time. I want to bring up the next panel. I think we have about four panels that we're going to be hearing from. We're going to, it's about, it's 3:00 o'clock. We're going to put a clock of three minutes, and then I'm going to hopefully walk us through how we can make the best use of those three minutes. I'm going to call up Ronni Marks,

the Hepatitis-C Mentor and Support Group. Ah, there you go. Jules Levin, New York NATAP, and you're going to tell us what that acronym stands for--

JULES LEVIN: Sure.

CHAIRPERSON ARROYO: Right? And Graham Murray, I'm not sure where you're from, you didn't indicate.

GRAHAM MURRAY: - -

CHAIRPERSON ARROYO: Okay, the next panel will be Dr. Brian Edlin, SUNY Downstate College of Medicine; Kevin C. Lo, Charles B. Wang Community Health Center. Do you want to add another one to this panel?

FEMALE SPEAKER: Sure.

CHAIRPERSON ARROYO: And Deborah Levine from National Black Leadership Commission on AIDS. So, if you guys can be ready for when the panel concludes. So, I know that you guys have spent a great deal of time preparing testimony. And it is important that we have it, and we will have it for the record. In the three minutes that the clock will give you, if you can talk to us about what the concern and the issue

is, so that we can make the best use of those three minutes, rather than read verbatim from, from your testimony, I find that that's the most impressive kind of testimony that we usually get. Okay? Thank you. Begin when you're ready, identify yourselves for the record. We'll go through the panel and then we'll go back and forth if necessary. Okay.

JULES LEVIN: Hi, my name is Jules Levin, I'm the Executive Director and Founder of NATAP, the National AIDS Treatment Advocacy Project. So that's one minute right there. [laughter] So, unfortunately, three minutes is a tremendous disservice, after spending two hours speaking to government officials who I think to some degree, although I would exclude Eric Rude, to some degree the other two don't really work in this field very much, or don't understand some of the issues, which is why we're here today. For example, it's, I estimate there are more like eight million people, perhaps, in the United States with hepatitis-C, based on various things that I could explain to you if I had more time. The CDC official number is more like about three

to four million. Brian Edlin who's here today to testify presented at a conference several years ago, it was five million, including the homeless. And more recent research done at Mt. Sinai here in Manhattan, suggests, due to high incidence that they found in immigrant populations, we could have as many as eight million people in the United States with hepatitis-C. So, the City figure of 250,000 with hepatitis-C may be as much as 500,000 or perhaps as much as 700,000 in New York City with hepatitis-C. The figure that Monica Sweeney suggested of 16,000 with co-infection in New York, I think it's closer to 70,000. I've been working in hepatitis-C since 2000. Dr. Masci was the Chair of the Ryan White Council Health Committee when I first came to New York City officials to talk about hepatitis-C co-infection ten years ago. Since then I've done a lot of policy work in Washington, held several briefings in Congress. I had hepatitis-C language and B language put in the Ryan White Care Act in 2006. So, I've been working on, in this area for many, many years. I think there's more like 70,000 co-infected people in New York City. Three-quarters, I estimate, of

people in the United States, have hepatitis, are undiagnosed with hepatitis-C, if we go with the eight million figure; if it's more like the four or five million figure, two-thirds are undiagnosed with hepatitis-C. So, we're facing a tremendous situation here, which is really the iceberg below the surface. I'd also like to say that Dr. Masci, so you brought up, and thank you very much for your comments, and my impression that you're interested in this, in this area, in this problem. And so, you brought up the issue of the fact that we don't have surveillance. And there is no surveillance, essentially, in the United States for hepatitis-C. We do estimates based on what we think. And the estimates are really, they don't really do service to the situation. And so, I would like to suggest to you, and since I only have three minutes, it was at the end of my talk and it's in the testimony, that I agree, but what we really need is a New York City hepatitis-C testing program, and B. We should do a citywide--that's the only way[time bell] to--the only way to find out the prevalence of hepatitis-C and the incidence in New York City is by doing a New York

City testing wide, citywide testing project, which I think could be done for $3 million. And I would like the City Council to help us find the $3 million and to do a City testing program. And we could house it at the DOH under Eric Rude's office, the Department of Viral Hepatitis. And I think that--well I think he would like to do that. We've had these discussions before today.

CHAIRPERSON ARROYO: Okay.

JULES LEVIN: And just to, a little bit of background for one minute on who I am, besides working extensively in policy on HIV and hepatitis for ten years, my organization and myself and my staff, we've been doing community based treatment education for ten years in New York City. We've done hundreds and hundreds of treatment education symposiums, all over New York City. Also, nationally, in all the major cities around the country, we've done five or six hundred of these events. We have one coming up on hepatitis-C, at NYU Medical Center in a couple of months. We expect to have 500 people there. And let me just say that hepatitis-C and co-infection, as was discussed a little bit here, primarily

affects marginalized patient populations. Just the constituents that everybody on this panel represents. It affects mostly disproportionately African-Americans, Latinos, IV drug users, people on the margins of society, on the margins of, of the health system. And it's the leading cause of death in HIV. It's not just what Dr. Masci said is the leading cause of death amongst liver disease and HIV. It's the leading cause of death in HIV, and has been for a long time. AIDS is no longer the leading cause of death, it has been overtaken by hepatitis-C co-infection. And this is--and I'll end by just saying, this is a particularly acute problem in New York. I have to say that in the last ten years, New York has probably responded better than any other City in the United States to co-infection, but that's also in part because no other City has really responded very well. And I think that New York City is the, as was said already, is not just the epicenter for HIV--I think you may have said that--it's also the epicenter for IV drug use, for co-infection and for hepatitis-C.

CHAIRPERSON ARROYO: Okay. We'll

talk. $3 million doesn't seem like a whole lot of money.

JULES LEVIN: Well, it's not. I think it would actually cost $5 million.

CHAIRPERSON ARROYO: That's not, no, so, so, we'll talk. [laughs] Okay. Please, continue.

GRAHAM MURRAY: Good afternoon. My name is Graham Murray, I live in Brooklyn. And I'm here to provide testimony on behalf of my late partner, Joe York, who passed away about four years ago, from liver cancer. Joe also had HIV/AIDS and hep-B. So, Joe probably became infected with HIV somewhere between 1981 and '83, there were no actual tests then. And like most others living with the disease, he sometimes managed well, sometimes he had periods of sickness and opportunistic infections. But after 25 years, he was fairly, you would say, healthy. And he was thinking of going back to an acting career, right before he got his diagnosis of liver cancer. That happened very suddenly, one, one evening, he had a pain, very sharp pain. We went to St. Vincent's, it wasn't diagnosed at the time. Six weeks later

we went back, the pain reoccurred, and the doctors at first said, "Well, maybe it's his gall bladder" and so forth. They did a CAT scan and found a tumor the size of an orange. So, Joe had about five months to live at that point. And you know, like everyone with HIV, this is, this is not a simple thing. I mean, he had blood work done every two to three months. Doctors were looking at liver counts, and they were usually off, they were usually high. And I would sometimes press them, like "Why, you know, something's wrong here." The standard explanation from the healthcare providers from his primary care physician would be that, "Well, this is the effect of the HIV meds." And one time he actually turned jaundiced for a period of a few days. And I was quite alarmed, and I thought, "This must be something to do with the liver." I mean, even I knew that much. But again, it's the kind of thing that it comes and goes, it's not a, it doesn't present itself acutely and then stays there, until it really presents itself acutely, and then it's too late. So, Joe began to see, see an oncologist at Mt. Sinai, and upon reviewing his medical

history, the cancer specialist said it was most likely years of damage done by hepatitis-B, that it caused this. And that was very common knowledge in the world of oncology, that hepatitis-B progresses to liver cancer, it's a very, a very typical point there. So, Joe was infected in 1987 with hepatitis-B. He didn't remember receiving any specific treatment at the time. His doctors at the time felt that really the, that should be the least of his worries, he should, he was lucky to be alive with HIV. The whole focus was on surviving with the meds. This was back in the '80s and then into the '90s, new medications [time bell] were developed. And so, the, the focus on hepatitis-B was really lost. And I think that, that the monitoring and the, you know, the careful following from his, his doctors, could've been a lot better. So, Joe went through a period of one chemo embolization. After three weeks, the tumor metastasized, everything grew 1,000 percent, and it was just basically there was, there was no treatment at that point. So, the cost actually was astounding, the cost of those last few weeks of trying to try this

therapy, and went to Nexavar, which was $8,000 a month. And you know, the cost was incredible. Had there been, you know, more focus earlier on, the outcome could've been better. So, what I say is, while there's still much to be learned about the long term effects of HIV, and the meds used to treat HIV, the one thing is clear, that the effects of hepatitis-B are well understood, and from Joe's experience, the medical community has not been vigilant about testing, vaccination, monitoring and treatment. And I'll also say, from my experience as well, as a person who has been living with HIV for now 25 years, and who recently has been diagnosed with Stage IV liver disease with cirrhosis, that I will say that, that this is a major problem, it's, the medical community doesn't know how to respond and how to put these things together. There were warning signs there for Joe, in his lab work, by direct observation, and they weren't acted on, and I think with better education and awareness, with the broader community, including people like myself and for medical practitioners, there can be a better outcome for others with liver disease. So, thank

you for allowing me to present this. [clapping]

RONNI MARKS: Good afternoon, my name is--

CHAIRPERSON ARROYO: You can do better than that. [laughter, applause]

RONNI MARKS: Good afternoon, my name is Ronni Marks, I am here today--

CHAIRPERSON ARROYO: Ronni, pull the mic closer to you.

RONNI MARKS: Oh, sure.

CHAIRPERSON ARROYO: Otherwise Jerry's not going to be happy.

RONNI MARKS: I am here today as a hepatitis-C patient and the facilitator of a hepatitis-C patient support group. I am also a baby boomer. The Institute of Medicine, the CDC, and other groups have recognized that baby boomers represent about two-thirds of current hepatitis-C patients. As my generation grows older, the serious health effects of long term hepatitis-C infection, including cirrhosis, liver failure and liver cancer, will become a major burden on society. Improved diagnosis, treatment and support services have the real potential to reduce

the dramatic increases in healthcare costs, as well as the human misery this trend is projected to cause . I was diagnosed with hepatitis-C in 1997. I contracted the virus from a blood transfusion. It doesn't matter how any of us contracted the virus, it just matters that we have a serious illness. At the time I was diagnosed, the hepatitis-C virus was newly identified and patients were virtually on their own to cope with the diagnosis and learn about their illness. There was no internet, no patient support groups, and no advocacy organizations. I had, I went on treatment, I failed to respond, and I decided to dedicate myself to ensuring that hepatitis-C patients would not face the isolation and lack of information and support that I faced in 1997. Since 2000, I have coordinated and facilitated the midtown Manhattan hepatitis-C support group. And I'm pleased to say that it's become one of the most important and successful groups throughout New York. However, we need many support groups throughout the five boroughs. As a support group facilitator, and a hepatitis-C patient, I know the sense of isolation the disease can cause, and the

stigma that we can feel. But despite being four times more prevalent than HIV/AIDS, public awareness of hepatitis-C is very low. Even many primary care physicians and other healthcare practitioners, know little about hepatitis-C. The lack of public awareness and understanding just fuels the patients sense of isolation and makes it more difficult. But more important, for them to gain accurate information about hepatitis-C and its treatment. This year, the urgent need for improved access to information, has led me to form a nonprofit organization called the Hepatitis-C Mentor and Support Group, to foster the formation of patient support groups in New York, and to provide patient mentoring services. We are on the verge of a major breakthrough in the successful treatment of hepatitis-C. In the past, only 40 percent of hepatitis-C patients could get rid of the hepatitis-C virus, through long and difficult treatment. And many patients liken this treatment to chemotherapy. It's really horrific. But within the next few months, once new medications begin to become available, a much higher percentage of hepatitis-C patients will be able to

eliminate the virus, and to be cured. These patients will be able to lead healthy lives [time bell] with a much lower risk of liver cancer or liver failure, and the need for liver transplants. Meeting this need will reduce long term healthcare costs, as well as the human toll. Every week, I receive calls from newly diagnosed hepatitis-C patients from every walk of life in New York. They all feel the same need for accurate information, for hepatitis-C and for support to manage the disease, its treatment with dignity and fellowship. Please help us increase public awareness of hepatitis-C, and the promise of its successful treatment. Help us make sure that all New York City residents have access to hepatitis-C testing, treatment and care. Thank you.

CHAIRPERSON ARROYO: Thank you for your testimony. [applause] I have, Jules, your recommendation of funding to the Department of Health and Mental Hygiene to focus more effort on the issue that we're discussing today. Is this a sentiment that's shared with your colleagues in the advocacy field?

JULES LEVIN: I don't think there's

anyone in the room who doesn't support it.

RONNI MARKS: Absolutely.

CHAIRPERSON ARROYO: DOH? [laughter] Okay. That, that makes it simple. Because usually when there's debate about something, it's when it gets a little bit more complicated to accomplish. I look forward to a conversation around that effort, and how we in the Council can be helpful to make that happen. Thank you for your testimony.

RONNI MARKS: Thank you.

JULES LEVIN: All right, thank you.

CHAIRPERSON ARROYO: Deborah? Dr. Edlin and Kevin. Kevin Lu? Lo? Lu? Lo? Thank you. He didn't give it to us. Give it to the Sergeant, he'll yell, they yell at us if we don't cooperate. [laughs] I'll keep it, though. Okay, the next panel will be Daniel Raymond, Harm Reduction Coalition; Tom Marino, Harlem United Community AIDS Center; and Daniel Tietz, oh! Daniel, hi, ACRIA [phonetic]. If you can be ready to bat up. [laughs] Okay. The Yankees lost yesterday, I'm not happy. [laughs] Okay. Identify yourselves for the record, speak into the

mic, and you may begin when you're ready.

BRIAN EDLIN: I'm, I'm Dr. Brian Edlin, I'm a Professor of Medicine at SUNY Downstate College of Medicine, and Associate Professor of Medicine and Public Health at Weill Cornell Medical College at the Center for the Study of Hepatitis-C. I'm going to try to focus a little bit on hepatitis-C today, just because that's the one that I'm more familiar with. It's, I have to say it's, I would, it would, I think it would be great to have a longer conversation with you. It's extremely frustrating to sit here for hours listening to testimony and to hear you asking questions to which there are abundant answers, that you didn't entirely get, partly because I think the Health Department's not in a position to advocate for its own resources perhaps, and because of the fact that Jules mentioned, which is that we all have spent our time working on this epidemic. Dr. Sweeney and the, and her agency are responsible for the health of New York City, with regard to every illness and public health threat that exists. And we really, I would be very anxious to try to provide you with

more in-depth, focused and intensive answers to your questions than you were able to get today. Our nation's, and New York City in particular, has mounted a concerted effort to address the HIV epidemic, it's been extremely effective. You know about it, have known about it for a long time; unfortunately, we can't say the same for the viral hepatitis epidemics. The effort to respond has been insufficient. The size of the viral hepatitis epidemics and hepatitis-C, for example, in particular, is at least four to five times the size of the HIV epidemic; and yet we do much, much, much less about it. Research is less, prevention is less, clinical care is not available, and, and treatment is, is not available, even though unlike for HIV, hepatitis-C is a curable infection. With six to twelve months of treatment, we can cure many people of this infection. We don't even bother, as you heard earlier, to screen for it. You asked repeatedly about the prevalence of hepatitis-C in, you know, by borough by borough and district by district. That information is readily available, but unfortunately it will require testing people for

hepatitis-C. The populations at high risk all across the City are not tested for this infection. It is lunacy that we're going to test 580,000 people in Brooklyn, so that Brooklyn knows about HIV infection, and not test those people for hepatitis-C. There are five times as many cases of hepatitis-C as there are HIV in Brooklyn, and three-quarters of those, unlike HIV infection, three-quarters of those are undiagnosed. Those are people who don't understand that they have the disease. So, I think I, you know, in my ten seconds remaining, you know, the Department of Health and Mental Hygiene--

CHAIRPERSON ARROYO: I don't know if you notice, I didn't cut anybody off, right? [laughter]

BRIAN EDLIN: Thank you.

CHAIRPERSON ARROYO: I'm just asking for cooperation. [time bell] That's all.

BRIAN EDLIN: The Department of Health and Mental Hygiene convened and expert panel of 30 community leaders and experts last year. We met with the commissioner, conveyed our findings to him about the state of the viral

hepatitis epidemics. We told him that accelerated efforts are need now, for surveillance, for prevention, for testing, for care, for treatment. You heard from Jules and I will reiterate that what we need now is a program to respond to viral hepatitis. A comprehensive program to test New Yorkers for viral hepatitis, and to link those who test positive to care and services; and to link those at risk who test negative to prevention services. And we believe that the best way to get started, the best time to get started on this is now, when we can have the biggest impact, and the best way to do it is through a program such as we, I described in the, in the testimony. We think $3 million is a small amount of money, and we think it's something that's probably, can be readily accomplished through the efforts of City Council or this, or the City of New York, with its resources. And we ask for that amount because we think that it's an amount that could be readily put to use. And using the infrastructures and strategies that we have now in place. And I've included in my testimony a breakdown from that, and I think the advocacy community is fairly

united, and as you learned, the Health Department, also, about, about the way that this could be put to use. We need to build public awareness so that people understand about the importance of testing. We need to provide testing so that we can screen people. You know, and Dr. Masci, you know, discussed a little bit about recommendations for screening the population, but recommendations are based in part on the assess--the assessment of the prevalence of a condition in the population. But we know that viral hepatitis in the first place, there's a cycle of invisibility. We don't test because we don't have recommendations to test. We don't have recommendations to test because the surveillance system we have is inadequate to capture the infections that exist. We don't have an adequate surveillance system, because we haven't provided the funding to do that. And so we have this sort of cycle of invisibility. This is an infection that we know disproportionately affects disadvantaged populations, it disproportionately affects ethnic minorities, it disproportionately affects undocumented immigrants and immigrants from high prevalence countries, it

disproportionately affects impoverished people who have a nine times higher prevalence of hepatitis-C than the rest of the population. 14 percent of African-Americans in the United States, let alone New York City, in the United States, have hepatitis-C virus antibody. 14 percent of African-American men, aged 40 to 49. It's lunacy that we have a policy of not testing everyone, in a situation where these are infections that we know many of them can be cured. So, these are our recommendations. I have lots of information on the, on the questions that you asked about, about screening, about treatment, about prevention, and about surveillance. And I look forward to the discussion.

DEBORAH LEVINE: Good afternoon. I want to thank the Council for holding this hearing this afternoon. I will be giving testimony on behalf of the Hon. C. Virginia Fields, who's been called to D.C. to work on federal issues. So, I will be stepping in this afternoon. The National Black Leadership Commission on AIDS has been a long champion around the conversation about HIV and AIDS, and its co-infections, in particular

hepatitis. Several years ago, under the leadership of Councilwoman Dickens and also Councilman Vann, who raised the issue with us, around our New York City Council faith based initiative, to include the conversation about hepatitis, and bringing more awareness to the communities that we currently work and function in, which shouldn't really surprise anybody, tends to be the zip codes with the highest rates of infection. So it only makes sense that our conversation about hepatitis and prevention, so that people are aware of one, how hepatitis is contracted, and also what those symptoms are. And so the reason why we are here today is to one, support the advocacy community around the notion that testing needs to be something that is a larger conversation, but to also talk about those structural interventions that are currently in the communities, like the counseling, testing and referral projects that you have the final report for, that that funding not be cut, so that we can continue those educations. Part of the work that we do is working with faith communities, training clergy, training those folks who are working with

people in the community, who generally don't go to community based organizations, who are not getting the messaging, but who are just as much at risk because of not only some of the behaviors that they may engage in, because they don't know, but because they live in zip codes that have very high viral loads around HIV and AIDS. And so our plea today is simply to you, to also look at those existing structures that are currently working, and that you look at not cutting the funding so that we can continue to ramp up and expand. Although for us, under this counseling, testing, referral project, hepatitis is not something that is mentioned or is a requirement for us; but under the leadership of C. Virginia Fields and our board, we made it a part of a requirement that our testing organizations not only test and, and talk about HIV and AIDS, but also provide screening for those folks who may be at risk and recommendations for them to follow up with their physicians, but to also do testing on site. [time bell]

[applause]

KEVIN LO: Hello, my name is Kevin Lo, I'm speaking on behalf of the Charles B. Wang

Community Health Center, down here in Chinatown. I think what I'll, I'd like to discuss today is the "other" category. And I'd like to ask to be removed from the "other" category, let us out of that category. A lot of, a lot of reporting you see today ropes in Asian-Americans into this abyss of the "other" category. And yet, with chronic hepatitis-B, it is disproportionately higher in Asian-Americans. When we run a hepatitis-B screening program, 20 to 30 percent of our patients screened test positive for hepatitis-B. Two-thirds of chronically infected Asian-Americans are completely unaware of their status, because they have yet to be tested, or there's confusion on whether they have been tested at all. So there's definitely a potential for underreporting. In 2008, the New York City Council discontinued to, specifically to the Charles B. Wang Community Health Center, as part of the Asian-American hepatitis-B program, $1.5 million in funding. And since then, we've really had to scramble to figure out how to screen and how to treat all of our patients. We have about, currently 2,000 active patients in our hepatitis-B registry, and 100

priority patients on our waiting lists who need treatment, who do not fit into the funding that we have for treatment, for uninsured patients. So we definitely need a sustainable solution for these patients. Also, on top of that, we do work with the perinatal hepatitis unit, at the DOH, and they refer household contacts of the mothers that they test, to our health center. And recently the DOH had discontinued free testing through their laboratories, actually without our knowledge, and so we continued sending specimens to the DOH lab, unknowingly that the, that funding had been ended. They continued to refer patients to us, and we've created, we now absorb the testing cost, so this is an added burden, definitely, on our health center. You know, we have, we deal with a very highly transient community, low English proficient, and you know, screening and regular care is already a huge challenge. And to add this additional burden of costs and cost effectiveness, is even a bigger challenge, it just gets us into an even deeper hole. It's a very difficult community to work with. You know, we have to be culturally and linguistically sensitive to our

community to get the right care to our patients. So, so I join my fellow speakers today in requesting for the funding of surveillance treatment, you know, and make [time bell] make our community count, make us, get us out of that "other" category, and really get surveillance into our community, to figure out how many people are under served and underrepresented. [applause]

CHAIRPERSON ARROYO: Kevin, I'm, I'm not clear what you mean, "get us out of that "other" category." I'm, I don't want to misunderstand what you're saying. What--

KEVIN LO: Okay, I think historically, you know, Asian-Americans have been lumped into this "other" category. I mean the categories--

CHAIRPERSON ARROYO: "other" category? That's--

KEVIN LO: It's, it's literally called other. So--

CHAIRPERSON ARROYO: Ahhh!

KEVIN LO: Right [laughs] Sorry.

CHAIRPERSON ARROYO: Got it, got it. Okay.

KEVIN LO: I don't, yeah, I mean, in the sense that, you know, we're, we're kind of in this abyss of, of just, we are, we're not a high enough percentage, so they lump us together with, with other people that don't have a high percentage. In comparison to larger groups, whereas if they look within our community, they'll find a higher, a disproportionately higher infection rate.

CHAIRPERSON ARROYO: Understood.

KEVIN LO: And you know, I think that's true for many--

CHAIRPERSON ARROYO: Understood. I did not understand that at all.

KEVIN LO: --[laughs] sorry.

CHAIRPERSON ARROYO: So I'm glad I asked the questions, 'cause I, I didn't know what you meant. I was like, what do you mean other? You know, 'cause I get very defensive, sometimes about stuff. [laughter] But thank you for clarifying that, it's a very, very important point, and one that I think we should, as we look at surveillance systems that our City should have, that we absolutely take that into consideration.

Eric, okay. [laughs] Okay. Thank you for your testimony. I do look forward to ongoing conversation. I see that there is agreement on the proposal, so that's important, and critical to, to somehow having a larger conversation about making it possible. Thank you for your testimony. Daniel Raymond, Tom Marino and Daniel Tietz. And last but not least, is Joseph Akima, APICHA, and Henry Pollack, NYU School of Medicine. If you can be ready to bat up, that would be cool, thank you. Welcome. I think you've sat here long enough to get the gist of how to do this, right? And you've obviously done it before. So, if you can begin identify yourself for the record, speak in the, to the mic; otherwise, Nic will yell at you. Right, Nic?

TOM MARINO: Good afternoon. My name is Tom Marino, I'm the Director of Clinic Operations and the Administrator for our Hepatitis-C Clinic at Harlem United Community AIDS Center in Harlem. And I'm joined by Kimberly Smith who is our State and Local Policy Director at Harlem United. Thank you to the Committee for having this hearing, and also want to say hi to

Councilwoman Dickens, who is our Councilwoman.

COUNCIL PERSON DICKENS: - - hi. [laughs]

TOM MARINO: Harlem United, as you may know, is a community based organization serving Central Harlem, East Harlem and the South Bronx. And from that community comes a high population of HIV/AIDS, hepatitis-C and sexually transmitted infections. We offer a full continuum of primary care dental services, mental health services, harm reduction, substance abuse services, supportive housing, community based outreach, education and screenings for hepatitis-C, HIV and STIs. Of our 817 HIV positive clients who came through our health centers last year, a third of those individuals are co-infected with hepatitis-C. From our experience, what we've done at Harlem United is approach it as a medical home. So what we've done is establish a hepatitis-C clinic that's championed by a nurse practitioner with a long experience in hepatitis-C and liver disease, and we're working on the support services that are needed to get these individuals into treatment. Everyone is talking about different

funding, knowing who they are and all of that, but there's so much more about what is needed to support the co-infected client to get them onto treatment. Treatment is only as good as the support we can give them, to get to that point. We need to provide mental health screening, we need to provide depression screening especially, because with the medications that are available, especially Peginterferon, depression is highly prevalent as a side effect. We need to look at their nutritional needs, look at their, where they're getting their next meals from, what is affecting their liver disease as a whole. We approach everything in terms of a medical home model. We have a lot, 94 percent of our clients are active, or former drug using individuals; most, 20 percent of whom are injection users. So, we know that our harm reduction, and our needle exchange program have been very effective in helping us to improve the quality of life of those living with chronic liver disease and HIV. In addition to helping people learn about their hepatitis-C status, we understand that the treatment options, better education is going to be

needed around those treatment options, better support services, support groups, we hold a lot of support groups for individuals to get them ready to become treatment eligible, so that when treatment is available, they can prosper and do very well under treatment. [time bell] We also need more help getting people to the clinic. Patient navigation services are key to improving the continuity of care, the outcomes in care, and we need funding for those resources to be available to us, so that the people--because we're talking about a very high no-show population. These are people who don't understand the value, necessarily, of coming to a clinic to get a continuum of care, to get continuity in care. And without the ability to send out someone to bring them into the clinic, we can't have good outcomes. So, in specifically around hepatitis-C, we are using patient navigation services to get those people in, for their mental screening, for their nutrition needs, and for their primary care that they need to get good treatment. Thank you.

[applause]

DANIEL RAYMOND: Good afternoon,

I'm Daniel Raymond from the Harm Reduction Coalition. And thank you for the opportunity to testify on this issue. I'll speak briefly, you have my testimony in front of you, and I'd like to address some of the things that we heard earlier today. From our perspective, HIV/hepatitis co-infection is a crisis in New York, and it's only going to become worse if we don't act. I think some of us here share our frustration that we did not always hear that sense of urgency and that sense of crisis from the City earlier in the afternoon. That this is going to be what makes or breaks us in the HIV epidemic over the coming years, if we want to continue to reduce mortality, if we want to keep people healthy, and if we want to keep people alive, we've got to come to terms with hepatitis co-infection. And we haven't done enough yet. Again, though, we do have hope, and I think this is a message that I'd really like to reinforce, because we've heard it a few times today, but it's, we really need to be shouting this from the rooftops. Hepatitis-C is curable. It doesn't work for everybody, but the treatments are becoming better every year, and we can get rid

of hepatitis-C in people if we can get them into care, if we can get them diagnosed, and if we can get them proper coordinated services. That's something that's doable, that's a hope that we've never had for HIV so far. And it's a hope that we'd like to bring out to all of the communities, especially the most marginalized, who are affected by HIV/hepatitis co-infection. I do want to, to say, though, that this is, we're on a cusp. Right? We have some new treatments coming out, hopefully a rapid oral test coming out later this year, and it's a fork in the road. We have a decision to make: we can mobilize the services and resources that we need to make this truly accessible to benefit the most vulnerable New Yorkers with HIV, or we can continue in the fragmented path that we've been on all along. And if we continue on that path, we'll see mortality increase because this is a condition that's affecting an aging population. The people who have had hepatitis-C, who are HIV positive, many have had it for 20-30 years. Over that time, slowly but surely, the liver damage increases until we get to a point of serious liver damage,

possibly liver cancer. So, this is that moment in time where we need to make a commitment to act. And I fully support the recommendation that my colleague Jules brought to the table for a concerted push from the Health Department of $3 million in resources for screening and linkage to care. I do also want to briefly mention a few other initiatives that are important. I circulated a letter that a group of us have sent to Senator Schumer to protect syringe exchange in the federal budget that Congress is currently negotiating. If we don't have access to federal funding for syringe exchange, we'll never get ahead on the prevention side. We've won some significant battles over the past couple of years, but that's all in jeopardy and we could [time bell] really use support from the City Council on that. We also work in coalition with Harlem United and other groups, as members of the Injection Drug User Health Alliance. Part of our work and part of the funding of the initiative that's been supported by the City Council is hepatitis-C care coordination. That's been really invaluable for getting people with histories of

addiction linked to testing and linked to medical care. While we've lost over half of our funding under that initiative from the City Council over the past couple of years, we do feel like the need is growing and we'd like to keep in mind the restoration of $1.5 million this year. And finally, my organization is working in partnership with both the City and State Health Departments, and the State Primary Care Association, to really explore bringing hepatitis-C care and treatment into community health centers and federal qualified health centers across New York. We feel like they're at the front lines of meeting the needs of our communities, and they're ready to partner with us in order to make their services accessible and responsive to the needs of people with hepatitis/HIV co-infection. So, again, I do want to support my fellow advocates out in the room, and thank you again for shining a light on this important issue.

[applause]

CHAIRPERSON ARROYO: And you do support each other, that's for sure. [laughs] That's good to see. Daniel?

DANIEL TIETZ: Hi, my name is Dan Tietz, I'm the Executive Director of AIDS Community Research Initiative of America. I'm going to, you got my, my testimony, and I just want to, you know, second what others have said here. I especially appreciated Dr. Edlin's remarks and, and testimony. And so I won't go over some of that. I'm going to focus instead on one of the things that we've been doing for more than a decade, and that is so much needed here, which is education. So, education for providers in particular, but also people at risk or living with HIV. You know, 30 years into the HIV epidemic, I mean, this is really a new crisis, and it's, and I think as others here have well noted, so little known. So little known out there, so little done about it. It's shocking to me that there could be literally almost no money for this, in the community, to do anything about prevention, care, treatment. And so I think that's, that's where the work is now. HIV service providers at this point are very familiar with discussing prevention, behavioral counseling and referrals to clients, about HIV, but they're shockingly ill-

informed and completely unprepared to do that with HCV, and that's even noting that here in the City, we count some 68 contracts, HIV related contracts, that require them to talk about HCV. I don't think it's for a lack of interest, I think it's for a lack of resource. So, no one's paying for someone to develop those materials, to develop those messages, and to get them to those organizations. As I said, we've got curriculum on this, we've been training on this for a long time. It is one of our most requested topics, is HCV. We get this request endlessly. The reality is, we can only give away so much, in terms of like our time and sending staff out to do that; somebody at some point has to provide some resource to make that training more standardized, more available to all providers, not just HIV providers, but certainly HIV providers, but other primary care providers. Those materials have to be developed and distributed, and that training has to happen. Let me just poke through this. One I think very overlooked population is incarcerated individuals, which actually hasn't come up much here today. The various facilities at Riker's Island run by

the New York City Department of Correction, house over 15,000 inmates at any given time. Approximately 70 percent of those have histories of substance use, including injection drug use, which places them in a high risk group. And they're, we should note here, in close proximity, we all know that sex happens in prisons often without condoms, yet Riker's and the DOC provide, as best I can gather, no hepatitis prevention treatment or care. Another group that frequently expresses a need for more and more current information is primary care personnel. As I said, just across the City, there is, there is so little known, and [time bell] the requests for that information are overwhelming, and yet no one provides support to meet those requests. Lastly, I just want to really join with others in noting that this requires comprehensive services. This is, I think, like HIV in some respects, in terms of the need for comprehensive services, but maybe even more so really with regard to the mental health services. And, and, you know, right now, cure rates are low. I mean, it could be as low as 20-25 percent. And with the current treatment,

and as people have noted, there are in fact a couple of protease inhibitors probably likely to be approved before year's end. There's a couple of others that are in clinical trials, we have one right now at ACRIA in clinical trials. Those, those will improve cure rates but you have to appreciate how, how difficult it can be if you're a provider to persuade someone to stay with the drug, that's from their perspective ruining their life, when you can only promise them that, well, maybe one in three chance, you know, one in, one in five chance that they're going to be cured. So, I think with improving cure rates, we have a real obligation to help people get through that treatment and stick with it.

[applause

CHAIRPERSON ARROYO: Thank you. I think you're the only panelist that did not speak to the recommendation for the $3 million to prepare New York to respond to the viral hepatitis.

DANIEL TIETZ: Yeah, at least that much.

CHAIRPERSON ARROYO: [laughter]

Okay. Thank you so much for your testimony and thank you for hanging out here the whole afternoon, basically. Our last panel--Oh, I dropped somebody on the floor. Joseph Akima, APICHA; and Henry Pollack. And I want to thank Council Member Dickens for hanging out here with me all afternoon. [laughs] This is the last panel, yes. We saved the best for last, would that help? [laughs]

JOSEPH AKIMA: Oh, yeah. Okay, so, my name is Joseph Akima, and I'm the Counseling, Testing and Referrals Project Manager at the Asian and Pacific Islander Coalition on HIV and AIDS, also known as APICHA. I'm here today on behalf of our Chief Medical Officer who couldn't make it, and so like a deer in the headlights, he said, "Joey, you got to go." So, I'm going to do my best here. APICHA's a health center located in Chinatown, and our primary target populations are Asians, people living with HIV and AIDS, and LGBT individuals. In view of the populations we serve, we integrate STD and hepatitis services into our medical practice. We aggressively screen our patients for STIs, regardless of HIV status, and

have routinized HIV testing for our HIV negative patients. When we test for STIs, we have implemented a protocol which calls for routine screening for the presence of pharyngeal, anal and urethral gonorrhea and chlamydia, and we also aggressively test our patients for syphilis. In addition, we screen for hepatitis-A, B and C, and provide vaccinations against hepatitis-A and B, when we find patients are susceptible, regardless of their risk. We have taken an aggressive approach to treating hepatitis-B and C. We attempt to cure people with hepatitis-B whenever possible using interferon, the same medication used to treat our hepatitis-C co-infected patients. An injection medication, interferon can be cured, curative as opposed to suppress, the suppressive approach commonly used by the medical community. In some countries, China for example, people became infected with hepatitis-C and HIV through blood transfusions. This is often on top of hepatitis-B and tuberculosis, which is also endemic there. We started treating with interferon ourselves because we had experience in suing the medication, dealing with the side

effects, and prescribing growth factors when necessary, to stimulate production of red and white blood cells. Our target has proven, protocol has proven to be on target. In 2010, was ten percent of our 200 HIV positive patients were co-infected with hepatitis-B, a reflection of the hepatitis-B prevalence among Asians and gay men; six percent were co-infected with hepatitis-C; and one percent were triply infected with hepatitis-B and C and HIV. Our HIV clinic also had high rates of STDs, in which ten percent were diagnosed with syphilis, 12 percent with chlamydia and ten percent with gonorrhea. We believe these high rates reflect the effectiveness with which we approach STI screening. We have also found that our HIV negative patients are also highly susceptible to acquiring hepatitis and STDs. In 2010, two percent of our 250 HIV negative client patients were co-infected with hepatitis-B. Four percent were diagnosed with syphilis, seven percent screened positive for chlamydia and eight percent tested positive for gonorrhea. In addition, five percent of our negative patients came in for treatment of urethritis. So whatever

our recommendations, we want to encourage the community health centers providing medical care for Asians and Pacific Islanders, gay men and people living with HIV and AIDS, to integrate hepatitis services into primary care [time bell] provide these providers with the necessary training and support, and encourage them to adopt a more aggressive screening protocol for hepatitis-B and C infections. We also want to expand immunization programs, and intensify prevention activities targeting Asian and Pacific Islanders, LGBT and other populations at high risk for hepatitis-B and C. And in funding for STD and hepatitis is needed for people who are uninsured, and for community health centers to provide prevention education and outreach. Just to add to what my colleagues over, Asian and Pacific Islanders speak over 100 different languages, and we're all lumped into this Asian umbrella. APICHA years ago at the beginning stages of, you know, when they founded the agency, went to the CDC and demanded that Asian and Pacific Islanders be removed from the "other" category. And if there's any other, you know, surveillance data still doing

that, we still need to be removed from the "other" category. Thank you.

[pause]

HENRY POLLACK: Now? [background voice] Okay, I got it. My name is Dr. Henry Pollack, I'm from NYU School of Medicine, I'm an Associate Professor of Pediatrics in the Division of Pediatric Infectious Diseases. And I've been involved with both hepatitis-C and hepatitis-B and HIV for probably more than 20 years. I currently am the scientific director of the Center of Excellence for the Elimination of Hepatitis-B Disparities, which is funded by the CDC at NYU. And also, the Center for the Study of Asian-American Health in the, direct the hepatitis studies. So, there's been a lot of, I've given my testimony, but the, there's been a lot of talk about hepatitis-C, so I'm going to talk mostly about hepatitis-B right now, although some of the issues are somewhat the same. Like hepatitis-B, the, the prevalence, the estimates of the amount of infection I think are grossly underestimated. And that's been shown on the national level, and also I think locally, I think the DOH estimates

are underestimates, and our estimates are, are based on a large number of screenings we've done in the community, including a large study that was funded by the City Council several years ago, where we found one in five Chinese were infected chronically with hepatitis-B, and overall about twelve percent of Asian-Americans. It's also very prevalent within the African immigrants, in Eastern European immigrants, in Haitian and certain Caribbean islands. So it's quite prevalent. We, the, for instance, in Chinese, the, the rate of infection is probably like 100 times higher than it is in the Caucasians in the United States. It's a huge health disparity. And our feeling is that the number of persons who are infected in New York City is between 100,000 and 250,000. And that puts New York City in the epicenter, once again, of hepatitis-B infection, hepatitis-C, and HIV infection, probably accounting for ten percent of the number of persons who are chronically infected in the United States. So what are the consequences of hepatitis-B infection, a chronic infection? The studies show that up to 25 percent will die of

their infection if they're not treated. And the major cause of death is from hepatocellular carcinoma, liver cancer, and also from liver failure. And I've seen, and this affects primarily men, in their, it takes a long time to have this effect, and it, primarily in their 40s and 50s, in sort of the height for their, when they have families, when they're the major caregivers and, not caregivers, but bringing in money, and this has a devastating effect on the family. And I've seen many, many kids, and I'm, I direct the Children's Hepatitis Clinic at Belleview and at Charles B. Wang, whose parents did not get tested because they did not have access to resources, who then the kids come back a year later, two years later, and I ask them, and their father has died. And it's, you know, [time bell] it puts a family in poverty. So, there's a huge problem there. It's all, it's something that's under the, underdiagnosed, under aware. They were, talk sort of about the HHC. We did a study that was funded by the CDC and HHC where we looked in primary care doctors and their, and their diagnosis and management of hepatitis-B, and

the rates were quite appalling. They were grossly under diagnosing them, less than 50 percent, and the management was really poor in terms of what would be standard management. And also on the same point, they were over di--over testing people who did not need the test, so there was actually a lot of cost savings that one could get if you focus on who you really needed to get. Treatment, in terms of people being aware of it, it's less than 50 percent of persons chronically infected in hepatitis-B in New York City, in at least in the Asian populations that are aware of their infection, that have been tested. And primary caregivers are, there is a large problem in terms of their also testing these people. Treatments are become extraordinarily effective, in terms of suppressing long term suppression. We don't talk about cure, mostly for hepatitis-B, it's a chronic infection like HIV. Some people can get off medicine, but most will stay on medicine for a long, long time. We've, so the costs are large. We, the average cost for hepatitis-B, I think, we think the costs in New York City is several hundred million dollars. And that's based on the

costs of care, but also the costs of related to disease and the costs that is related to HHC and other hospitals that have to take up these persons who appear late. And most of them with hepatocellular carcinoma appear very late, so if you appear early, 70 percent can be cured; but if you appear late, which is in most cases, less than five percent are alive after five years. So, it is something that we have just done a study that just came out in Health Affairs, last month, showing that it's highly cost effective to treat, early treatment of hepatitis-B. And it can, it would lead to great savings. The estimates for hepatitis-B and hepatitis-C, hepatocellular carcinoma overall for the U.S., is showing that those rates are increasing tremendously in the future. And there's going to be a huge burden on New York City. And so, early treatment will potentially save huge amounts in New York City, in the future. The, if I can just talk one or two more moments more, the, we obviously agree that there should be additional funding for, for viral hepatitis, both B and C. I would disagree somewhat with my colleagues, 'cause I don't think

that the most appropriate place to put that money is in Department of Health, and that might shock some people here, but some of the people have said that there is a lack of urgency, and I think there is a lack of urgency in, not in the persons who have talked over here, Eric Rude and his colleagues, but in the, the leadership of the Department of Health, and that's been long historically that they don't see viral hepatitis as a major problem that they want to address. And I think if you look on the ten diseases that are preventable and should be treated, it's not among those. And also from the CDC, there's a similar lack of urgency of what that, of treating it. So, I think it would be a mistake, because I think that those, those funds would not necessarily go where they needed to go. A lot of those funds, especially for the Asian, for hepatitis-B, need to go in the communities where they need to get funding to do the kinds of screening that they, that they can do best at. And in the, our Asian-American hepatitis-B program, which you guys funded for four years, and did a great job, we were very, very effective in getting that

community screening done, and done effectively. And, and I think also HHC needs to be a large part of that, 'cause they have, they are swamped with cases and they need a lot of guidance and, and support to be able to diagnose and treat effectively those persons. So, I think that there, the funding needs to be, you know, divvied out in a lot of different agencies, I think there needs to be some kind of taskforce that has to come up with a strategic plan for how to address viral hepatitis in New York City, 'cause it involves all these different agencies, from HHC, DOH, immigration, corrections, homeless services. So it's a very complex disease, and the only way to really effectively address that is by, you know, getting everyone together. And I think that way you can also make a lot of synergies, and you can probably cut costs in certain areas that are duplications. So I think that would be most effective. I thought, I think education is really primary, is crucial that the amount of understanding and awareness in the community is really low and that is, really needs to be addressed. And the CDC is also working in that

direction, but they're not going to be targeting New York City. So anything that can go towards New York City would be really worthwhile, especially because with healthcare reform, which hopefully will go into effect in a few years, a lot of people who now do not have the resources, will be able to have those resources. Most of the people, a large number of the persons with hepatitis-B are immigrants, without health insurance, and so that would be one way that one could diagnose these persons, and prepare for being able to treat them in the future. Thank you very much.

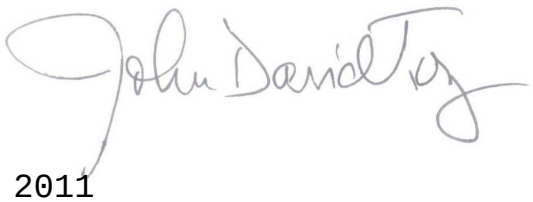
CHAIRPERSON ARROYO: Thank you. Thank you for your candid approach to [laughs] the recommendation. I want to thank you all for being here, and for staying the course, through the afternoon, it really sends a very strong message about how interested and concerned you are about this issue. And I look forward to an ongoing conversation. $3 million is not a lot of money, and I think that we can certainly put some effort behind partnerships that can make that happen. Right, Eric? Also, Council Member Dickens, thank

you so much for staying for the whole hearing. This hearing is adjourned.

[gavel]

C E R T I F I C A T E

I, JOHN DAVID TONG certify that the foregoing transcript is a true and accurate record of the proceedings. I further certify that I am not related to any of the parties to this action by blood or marriage, and that I am in no way interested in the outcome of this matter.



Signature

Date April 22, 2011