

Testimony

of

Jay K. Varma, MD Deputy Commissioner, Division of Disease Control New York City Department of Health and Mental Hygiene

before the

New York City Council Committee on Health

On

Evaluating Efforts to Improve Surveillance, Testing, Treatment, Outreach and Education Relating to Hepatitis B and Hepatitis C

and

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Int 51-A: Requiring the Department of Health and Mental Hygiene to Issue an Annual Report Regarding hepatitis B and hepatitis C

> June 24, 2014 City Council Chambers New York City

Good afternoon, Chairman Johnson and members of the Health Committee. My name is Dr. Jay Varma, and I am the Deputy Commissioner for the Division of Disease Control at the New York City Department of Health and Mental Hygiene. I am joined here today by Dr. Fabienne Laraque, director of our viral hepatitis program, and Dr. Jane Zucker, Assistant Commissioner for the Bureau of Immunization at the Health Department. On behalf of Commissioner Bassett, thank you for the opportunity to testify today.

Because this is the first time I have had a chance to testify before this Committee, I will briefly describe the roles played by the Health Department with regard to infectious Disease Control. I oversee all of the infectious disease programs at the Department, which includes separate programs for HIV, sexually transmitted diseases, tuberculosis, vaccine-preventable diseases, and general communicable diseases, as well as our public health laboratory. Our programs for general communicable diseases, vaccine-preventable diseases, HIV, and the public health laboratory all play vital roles in addressing viral hepatitis.

The bill under consideration today, Int. 51-A, is intended to raise awareness about two important causes of illness and death in New York City: hepatitis B and hepatitis C. Though they share a common name, these viruses are distinct. The prevalence of each varies widely across different populations of New Yorkers, and they require different control measures. Therefore, I will talk about each of these diseases separately in my testimony today. The Department appreciates the Council's interest in these areas and the value of data reporting; however, we are concerned that the reporting mandated by this bill would place unnecessary requirements on financially-constrained programs. We are interested in working with the Council to ensure this legislation does not inadvertently pull resources from core programs that identify and treat viral hepatitis in NYC.

### Hepatitis C

Let me begin by discussing hepatitis C. Hepatitis C is a virus that is transmitted by contact with infected blood, most often from an unsafe injection. There is no vaccine to prevent infection. Therefore, the primary strategies to control hepatitis C include reducing unsafe injections to prevent new infections, and testing and treating infected people to prevent deaths. We estimate that 146,500 New Yorkers are living with hepatitis C infection. The highest infection rates occur among Hispanics and non-Hispanic blacks, and in the South Bronx and East and Central Harlem. The annual death rate from this disease has increased 46 percent in 15 years in New York City.

Until recently, very little testing and treatment has been performed for hepatitis C, because drugs to treat it were toxic and ineffective. In the past year, new drugs have become available that can cure hepatitis C by taking a few pills every day for only a few months. We estimate that only 50 percent of infected New Yorkers actually know that they are infected, and fewer than 10 percent of infected New Yorkers have ever been treated for hepatitis C. The Health Department works closely with our community partners to educate the public and doctors about testing and treatment. It is essential for more physicians to be trained to treat hepatitis C, and to develop larger-scale public health programs to help navigate patients to appropriate education and treatment services.

Despite large cuts to our disease control programs in the past 10 years, our team is working assiduously on hepatitis C. In 2013, the Department released an action plan to reduce

illness and death from hepatitis C in New York City. Major activities that the Department has taken to implement this action plan include:

- Developing educational content for the public, such as re-design of our hepatitis web pages, production of new print and video materials, and development of an app for patients;
- Developing educational content for healthcare providers and working with providers to improve testing practices and provide training in HCV;
- Continued implementation of the Check Hep C project, which involves education, testing, and linkage to care of patients in high prevalence settings;
- Working to expand services at syringe exchange programs to address increases in injection drug use and hepatitis C infections among young people;
- Building community resources and advocacy through the HCV Task Force; and
- Amending the New York City Health Code to permit more complete monitoring of testing and treatment in New York City.

### Hepatitis **B**

Now let me turn to hepatitis B. Like hepatitis C, hepatitis B can also be transmitted by contact with infected blood. Unlike hepatitis C, however, it can also be easily transmitted by contact with semen or other body fluids. Even more important, a highly effective vaccine to prevent hepatitis B infection has been available in the United States since 1981. The primary strategy to control hepatitis B in New York City, therefore, involves preventing new infections through vaccination.

An estimated 100,000 New Yorkers are currently living with the hepatitis B virus. Chronic infection is most common in Sunset Park in Brooklyn, Flushing in Queens, and Chinatown in Manhattan. Of patients with chronic hepatitis B infection, over 90 percent were born outside the United States, the majority in China.

Routine vaccination of all newborns in New York City began in 1991. Because hepatitis B vaccination is a school immunization requirement, more than 95 percent of all children less than 18 years of age in New York City are fully immunized. The Department also places a high priority on immunizing adults who are at very high risk and on preventing transmission of infection from infected mothers to children. Our sexually transmitted disease clinics offer hepatitis B vaccination to high risk populations. And our vaccine preventable diseases program case manages approximately 1,800 pregnant women with chronic hepatitis B each year, 91 percent of whom were born outside the United States. We work with these mothers and their physicians to ensure that their newborn babies receive both immunoglobulin and vaccination promptly and completely after birth to prevent acquisition of hepatitis B.

A major gap in the health system is that there are limited resources for people already infected with hepatitis B. First, there are no medications that can reliably cure hepatitis B infection. Treatment with a combination of medications can help prevent damage to the liver and prevent liver cancer, which is the most serious complication of infection. The cost of drugs alone exceeds more than \$50,000 per patient per year. Second, as noted above, most infections occur in immigrants from China, many of whom are not eligible for health insurance.

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#### Legislation

The Department shares the Council's concern about hepatitis B and hepatitis C. We are concerned, however, that this legislation imposes a work burden that extends the Department's staff beyond its current resources.

In previous years, we produced a consolidated report about viral hepatitis. We were able to produce that report, because we had a CDC grant specifically for viral hepatitis surveillance. We lost this grant in 2012, which meant that we no longer had funding for seven staff previously dedicated to viral hepatitis. Nevertheless, the Department worked to ensure that the most important and accurate data about this disease is publically available, even if it not in a printed report. The Department's EpiQuery system now includes data about hepatitis B and hepatitis C that can be easily analyzed by anyone through an interactive and user-friendly system.

We are also concerned that some of the data elements requested in Council's proposed legislation cannot be reliably measured, such as acute hepatitis B and hepatitis C infections, liver cancer deaths due to hepatitis B and hepatitis C, adult vaccinations, and the percentage of hepatitis B and hepatitis C cases referred to care or in care. The Department looks forward to working with the Council to improve this legislation, and further broaden awareness about hepatitis B and hepatitis C.

Thank you for the opportunity to testify today. Dr. Laraque, Dr. Zucker, and I are happy to answer any questions.

The Rev. Dr. W. James Favorite Chairman of the Board The Rev. Dr. Calvin O. Butts, III Chairman Emeritus

> President and CEO C. Virginia Fields



PUBLIC HEARING STATEMENT C. Virginia Fields President and CEO New York City Council Council Chambers - City Hall Tuesday, June 24, 2014 1:00 p.m.

Good Afternoon. Honorable Chairman, Corey Johnson, and distinguished members of the New York City Council Committee on Health. On behalf of the Honorable C. Virginia Fields, former Manhattan Borough President, and currently President and CEO of the National Black Leadership Commission on AIDS, Inc., I am Leatrice Wactor Affiliate Services Director. Thank you for the opportunity to speak at today's hearing.

Viral hepatitis is the leading cause of liver cancer in the United States and two out of every three people living with hepatitis are unaware they are infected. Over 245,000 New York City residents are living with hepatitis, an epidemic that remains virtually unknown to the general public and at-risk populations

Viral Hepatitis is a major systemic health disparity that disproportionately impacts several communities including African Americans, Latinos, Asian Americans, and Pacific Islanders, across all five boroughs of New York City. Among African Americans, chronic liver disease – often hepatitis C related – is a leading cause of death for persons aged 45-64 years old. Latinos experience some of the highest rates of hepatitis C infection in the U.S. Hepatitis B is the

leading cause of liver cancer for Asian Americans, and two out of every three Asian Americans living with hepatitis B are also living with hepatitis C. Of the 1.1 million people living with HIV in the United States, about 25% are co-infected with hepatitis C, and about 10% are co-infected with hepatitis B.

Fortunately, today there is now considerable hope. There is a vaccine for hepatitis B. There is no vaccine for hepatitis C, but there is now a cure. Both the Centers for Disease Control and Prevention (CDC) and the US Preventive Services Task Force (USPSTF) now recommend that all baby boomers (persons born between 1945 and 1965) receive one-time screening for hepatitis C. But the recommendations alone are not enough.

On October 23, 2013, Governor Cuomo took a significant step in addressing a major component of the epidemic when he signed the hepatitis C testing law requiring all baby boomers be tested at least once for hepatitis C.

We need both resolute leadership and sustained collaboration through funding, to create and implement a health system response at the city and community level in order to alter the trajectory of this epidemic. We need to respond to the obligations presented by the New York State law that accurately includes requiring the New York City Department of Health and Mental Hygiene to issues an annual report regarding hepatitis B and hepatitis C.

Annual Reports, issued by the Department are key to reducing these viral hepatitis disparities that will serve to

- Educate the community about the silent epidemic and its impact
- Improve awareness of how viral hepatitis is transmitted and can be prevented
- Increase vaccination coverage for hepatitis A and B

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- Get people tested if they have been exposed to hepatitis; and
- Connect those infected with chronic hepatitis to care and treatments to help them stay healthy

Funding goals of the New York City Department of Health and Mental Hygiene Hepatitis Infection Control Program citywide initiative are designed to address and eliminate health disparities in viral hepatitis as well as prevent, educate, test, treat and eradicate hepatitis C and hepatitis B in all five boroughs. The program also includes patient and community education, surveillance and evaluation. Addressing health disparities is the key component of the DOHMH Hepatitis Infection Control Program citywide initiative.

The National Black Leadership Commission on AIDS, Inc., supports efforts of The New York City Council, Committee on Health, to amend the administrative code, as well as funding to address these urgent and highly infectious diseases.

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Thank you.

C. Virginia Fields

June 24, 2014

Honorable Corey D. Johnson New York City Council Chair Committee on Health New York, NY 10007

Dear Council Member Johnson,

Thank you for your progressive leadership of the New York City Council's Committee on Health. The undersigned organizations write to urge you to expeditiously fund the New York City Department of Health and Mental Hygiene (DOHMH) proposal for the creation of a Hepatitis Infection Control Program and New York City Health and Hospitals Corporation's (HHC) Hepatitis Public Private Partnership.

Viral hepatitis is the leading cause of liver cancer in the United States and two out of every three people living with hepatitis are unaware they are infected. Over 245,000 New York City residents are living with hepatitis, an epidemic that remains virtually unknown to the general public and at-risk populations. On October 23, 2013, Governor Cuomo took a significant step in addressing a major component of the epidemic when he signed the hepatitis C testing law requiring all baby boomers be tested at least once for hepatitis C.

Viral Hepatitis is a major systemic health disparity that disproportionately impacts several communities including African Americans, Latinos, Asian Americans, and Pacific Islanders, across all five boroughs of New York City. Fortunately, today there is now considerable hope. There is a vaccine for hepatitis B but little can be done without educating the community. There is no vaccine for hepatitis C, but there is now a cure. Both the Centers for Disease Control and Prevention (CDC) and the US Preventive Services Task Force (USPSTF) now recommend that all baby boomers (persons born between 1945 and 1965) receive one-time screening for hepatitis C. But the recommendations alone are not enough. We need both resolute leadership and sustained collaboration to create and implement a health system response at the city and community level in order to alter the trajectory of this epidemic. We need to respond to the obligations presented by the New York State law and take advantage of industry's offer of support to leverage limited government resources.

The goals of the New York City Department of Health and Mental Hygiene Hepatitis Infection Control Program citywide initiative are to address and eliminate health disparities in viral hepatitis as well as prevent, educate, test, treat and eradicate hepatitis C and hepatitis B in all five boroughs. Addressing health disparities is the key component of the DOHMH Hepatitis Infection Control Program citywide initiative.

Among African Americans, chronic liver disease – often hepatitis C related – is a leading cause of death for persons aged 45-64 years old. Latinos experience some of the highest rates of hepatitis C infection in the U.S. Hepatitis B is the leading cause of liver cancer for Asian Americans, and two out of every three Asian Americans living with hepatitis B are also living with hepatitis C. Of the 1.1 million people living with HIV in the United States, about 25% are co-infected with hepatitis C, and about 10% are co-infected with hepatitis B.

The DOHMH and the HHC are both prepared to take advantage of timely advancements in vaccines, treatments and diagnostics. Each will build on and modify their service structure from what they have learned addressing the HIV epidemic. In this way, each will highly leverage limited government resources with industry support through a public private partnership that provides direct funding and delivers supplies to address these urgent and highly infectious diseases. The public private partnership will include government, voluntary agencies and industry to meet the screening and linkage to care goals established in the plan for the Prevention, Care and Treatment of Viral Hepatitis developed by the Hepatitis Infection Control Unit of the DOHMH and assist HHC to meet their identification and treatment goals established by their administrations. The programs also include patient and community education, surveillance and evaluation.

We also stand in support of an additional proposal submitted by Council Members Koo and Chin that will directly fund community based organizations. We strongly support this proposal and all of the programmatic efforts outlined. We feel the proposals emphasis on direct funding to community based organizations, focus on injection drug users and education are worthy ones. We believe that the ultimate solution may be to combine the proposals and not eliminate any. We are willing to do what we can to help accomplish this.

We are prepared to engage the full force of all the organizations we represent and work with, ranging from religious organizations to the injection drug user/harm reduction community.

Thank you for your consideration. For additional information about the topics raised in this letter, please contact Guillermo Charon, Executive Director - Latino Commission on AIDS at 212-675-3288 or email Guillermo at gchacon@latinoaids.org.

Sincerely,

**Guillermo Chacon** 

GACharon

Latino Commission on AIDS gchacon@latinoaids.org http://www.latinoaids.org

C. Virginia Fields

National Black Leadership Commission on AIDS <u>cvafields@nblca.org</u> http://www.nblca.org

**Daniel Raymond** 

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Harm Reduction Coalition <u>Raymond@harmredcution.org</u> <u>http://harmreduction.org/about-us</u>

### The New York City Council Committee on Health Hearing June 24<sup>th</sup>, 2014 Testimony of Ronni Marks

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Thank you for inviting me here today. My name is Ronni Marks. Most of you know me, as we have had many meetings regarding HCV. I am the founder of The Hepatitis C Mentor and Support Group, Inc., an organization that was formed to address the lack of supportive services for people living with Hepatitis C, including patients co-infected with other conditions such as HIV/Aids, Hepatitis B and Pre/Post liver transplant. I am also the facilitator of a Hepatitis C Patient Support Group. I am here today as a Hepatitis C patient, who is also a Baby Boomer.

The CDC now recommends an age-based screening strategy consisting of a one-time screening blood test for HCV for those at highest risk,including people who ever injected drugs(even once many years ago) and everyone born between 1945 and 1965 (Baby Boomers) Approximately 75% of HCV infections in the U.S. exist among Baby Boomers. One in thirty Baby Boomers in the U.S. has HCV. The CDC recommendation was endorsed by the U.S. Preventive Services Task Force in June 2013. And as most of you know, New York was the first state to pass a bill requiring hospitals and health care providers to offer a test for HCV. The broader testing recommendations likely will detect a substantial number of people who are unaware that they are infected.Screening for HCV should be included in all routine lab work. 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 very real potential to reduce the dramatic increases in health care costs, as well as human misery, this trend is projected to cause. The cost of a Liver Transplant is \$520,000. That is without all the medications post-transplant.

I appreciate the opportunity to talk with you about this critical need for people of my generation and many others such as, underserved communities affected by viral hepatitis, including marginalized minority patient populations, immigrant patient communities, persons with a history of substance abuse, homeless, and high risk youths. We are seeing rising rates of HCV among young people who inject drugs, as well as Liver Cancer and mortality rates rising among Afro American and Hispanic persons.

I was diagnosed with Hepatitis C in 1997. I contracted the virus from a blood transfusion. While it doesn't matter how any of us contracted the virus, before 1992 blood was not tested for HCV and many others are walking around unaware of their status. 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 information, no patient support groups, and no advocacy organizations. I had a successful career in fashion design,but after failing to respond to treatment at that time, 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 at NYU/Langone Medical Center. I'm pleased that our group has become one of the largest groups in New York City. More support groups like this one are needed 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 we can feel. Despite being four times more prevalent than HIV/AIDS, public awareness of

Hepatitis C is very low. The fact that Hepatitis C often does not cause symptoms for many years...until the disease has caused severe damage to the liver...may account for this lack of awareness and attention. Even many primary care physicians and other health care practitioners know little about Hepatitis C. This lack of public awareness and understanding fuels patients' sense of isolation and makes it more difficult...but also more important...for them to gain accurate information about Hepatitis C and its treatment.

Right now a revolution in the treatment of Hepatitis C is underway. New generation (DAA'S) directacting antivirals have recently become available and an even more promising new class of drugs are in development and testing. These drugs promise a cure for individual patients. I being one of them, as I have just completed treatment. These new drugs give the ability to stem an emerging health crisis for society. They will be easier for patients to tolerate, but come at a high cost. One pill alone is a \$1000 a pill. Many patients are not able to have access to them.

All-oral therapy for hepatitis C virus (HCV) infection creates new opportunities for preventing HCVrelated morbidity and mortality. This curative therapy will greatly expand the number of persons eligible to receive treatment. Curing HCV and eradicating this disease should be a goal of our healthcare system.

To ensure that the full benefits of these regimens are realized for individuals and communities, the partnership of New York City public health and community organizations can play an important role. We must have essential services like better testing and linkage to care. Supportive services must be made available to patients from every walk of life, regardless of race, gender, orientation or economic status.

I urge you to please help us make sure that all New York City residents have access to Hepatitis C testing, treatment, and care.

Thank you.

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# NEW YORK CITY COUNCIL COMMITTEE ON HEALTH

# OVERSIGHT HEARING: EVALUATING EFFORTS TO IMPROVE SURVEILLANCE, TESTING, TREATMENT, EDUCATION AND OUTREACH RELATING TO HEPATITIS C & HEPATITIS B.

## TESTIMONY OF

## JOSEPH MASCI, M.D., FACP DIRECTOR OF MEDICINE ELMHURST HOSPITAL CENTER

## NEW YORK CITY HEALTH AND HOSPITALS CORPORATION

June 24<sup>th</sup>, 2014

Good afternoon Chairperson Johnson and members of the Health Committee, I am Dr. Joseph Masci, Director of Medicine at Elmhurst Hospital Center, which is part of the New York City Health and Hospitals Corporation (HHC). I am also a Professor of Medicine - and also Preventive Medicine - at the Mount Sinai School of Medicine. On behalf of HHC, thank you for the opportunity to testify on efforts to increase screening, treatment and education for Hepatitis C and Hepatitis B.

As you know, Hepatitis is a disease that inhibits the proper functioning of the liver and is a leading cause of death due to liver disease. The three most common forms of Hepatitis – are Hepatitis A and Hepatitis B and Hepatitis C. Hepatitis C (HCV) is the leading cause of liver cancer in the nation with mortality rates that have now surpassed that from AIDS.

In the U.S., 3.9 million Americans are estimated to be infected with Hepatitis C and 65-75% are unaware of their infection. Unfortunately, many of these individuals are not receiving care. Hepatitis B (HBV) is 100 times more infectious than HIV and has become the most common serious liver infection in the world. Approximately 1.25 million persons are chronically infected with HBV in the US. More than 150,000 Americans are expected to die from viral hepatitis associated liver cancer or end stage liver disease in the next decade.

Hepatitis C is most efficiently transmitted through contact with blood through injection drug use. Hepatitis B can be transmitted by blood and other body fluids, through direct blood-to-blood contact, sexual contact, injection drug use, and from an infected mother to a fetus/infant. Both Hepatitis C and B disproportionately affect minorities. HCV infection is complicated by the presence of sexually transmitted infections and also disproportionately affects persons who engage in high risk unprotected sexual activity, persons living in poverty and those men who have sex with men (MSM). There is evidence too that it may disproportionately affect transgender persons. All of these groups also have less access to care. In particular, African Americans and Hispanics are affected more by Hepatitis C and Asian and African immigrants are affected more by Hepatitis B. These disparities are of particular concern to HHC given our focus on reducing disparities and eliminating barriers to care.

The Centers for Disease Control and Prevention (CDC) estimates that although Americans born between 1945 and 1965 comprise an estimated 27 percent of the population, they account for approximately 75 percent of all Hepatitis C infections in the United States, 73 percent of HCV-associated mortality, and are at the greatest risk for developing hepatocellular carcinoma and other HCV-related liver diseases. While the recommendation to offer once in a lifetime screening and follow-up to this population is of most concern to address, there is recognition that some adolescents may also be at significant risk of HCV especially those who are starting to inject drugs.

An estimated 146,500 New Yorkers are infected with HCV but less than half may be aware of their infection. People who were born between 1945 and 1965 have a higher prevalence of HCV infection. In the past, treatment for HCV infection was long, fraught with severe side effects and not very effective. In addition, individuals who tested with traditional laboratory tests often never receive or return for their results, leaving many HCV infected persons unaware that they are infected. Recent advances in rapid HCV diagnostics and HCV medications have changed the landscape of HCV treatment because current treatments have significantly higher cure rates, at 95-100% in trials, have a much shorter treatment period and have many fewer side effects.

Rapid HCV screening technology and better treatment options provide a tremendous opportunity for improving health, saving lives, and reducing health disparities. With this easy testing and better-tolerated treatment, it is anticipated that more patients will complete treatment or avoid the most pernicious aspects of HCV infection. There is also a safe and effective vaccine to protect against hepatitis B infection. It is recommended that all infants, children and adolescents up to the age of 18 receive the vaccine as well as adults who are at risk for infection.

HHC is prepared to take advantage of the recent advancements in treatment and diagnostics to build on or modify our service structure and apply what we have learned addressing the HIV epidemic to reduce the burden of Hepatitis in New York City. With additional resources, HHC could collaborate with DOHMH, community-based organizations, other stakeholders as well as pharmaceutical and diagnostic testing companies to create an infection response program that would:

1. Expand testing for persons with HCV and HBV infection, and educate and link them to care and treatment;

- 2. Educate providers and increase treatment capacity through telemedicine, expert consultation and involvement of our patients;
- 3. Monitor disease patterns and response to interventions;
- 4. Share our results with others interested in these issues and,
- 5. Design and implement a media campaign to educate the public about HCV and HBV and provide an infrastructure for coordination of care, case management and medical adherence support.

HHC is committed to improving patient outcomes by delivering comprehensive high quality medical care and supportive services to patients with Hepatitis C or Hepatitis B. With a commitment over time, new innovations in testing and treatment interventions, we are hopeful that we can make great strides in reducing the transmission and burden of these diseases in New York City.

This concludes my testimony. I would now be happy to answer any questions you have.

On behalf of the Empire Liver Foundation and the Center for the Study of Hepatitis C, we would like to thank the distinguished city council members who have invited us here today to testify at this hearing regarding the vitally important *Proposed Initiative 51-A* on viral hepatitis. We are very pleased to provide our strongest endorsement of this proposed initiative sponsored by council members to enact a local law to amend the administrative code of the city of New York, in relation to requiring the Department of Health and Mental Hygiene (DOHMH) to issue an annual report regarding hepatitis B and hepatitis C.

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Viral hepatitis B and C, the leading causes of liver disease, liver cancer, and liver-related deaths in the United States (US), are silent epidemics that affect over 6 million Americans<sup>1, 2</sup>. Many of these deaths are now preventable with early diagnosis and appropriate treatment. The tremendous public health burden of viral hepatitis in the US remains an unmet need with inadequate screening and reporting efforts. The scope of these diseases have long been underreported, which has severely hindered our nation's ability to reduce the spread of infection, identify infected persons, target treatment and generate support for vitally needed research. The City of New York is the epicenter for viral hepatitis and is well poised to implement effective policies to address the impending health and economic crisis related to hepatitis B and C. Importantly, there are new treatments for viral hepatitis that are highly effective and well tolerated that can result in disease cure for hepatitis C virus and disease control for hepatitis B virus. Active research is now being done on treatments that could cure hepatitis B as well. New York City has a large number of health care providers trained to treat viral hepatitis. Despite effective screening tests and treatments, more than half of all viral hepatitis infections in the US remain undiagnosed<sup>1</sup>. Many of these individuals will not know they are infected for years or decades until it has caused irreversible damage to their livers. There is a pressing need to uncover these cases to preserve liver function, prevent liver failure and liver cancer and thereby save millions of lives.

Hepatitis C has eclipsed HIV as a major cause of death in Americans and disproportionately affects minority and marginalized communities. The median age of death for those with hepatitis C in NYC between the years 2000-2011 was 60 years old, compared with 78 years old for those without the infection <sup>3</sup>. Among persons with hepatitis C who died, more than half died within 3 years of a hepatitis C report to the DOHMH, clearly indicating the need for earlier testing and improved access to treatment. The burden of chronic hepatitis C infection in NYC is very high. In 2010, an estimated 146,500 adult New Yorkers had chronic HCV infection<sup>4</sup>. In 2012, in NYC, there were 7,643 newly-reported cases of HCV infection. Of these, 51% were born between 1945-1965. The highest rates for newly-reported HCV infections were reported in the neighborhoods of the South Bronx, East Harlem and Central Harlem, which are characterized by health disparities including poor access to health care, high poverty, increased HIV prevalence and drug use, and low education levels<sup>4,5</sup>.

Hepatitis B is the most common predisposing factor for the development of hepatocellular carcinoma (HCC), *the third most common cause of cancer death in the world*.<sup>2,3</sup> Similar to hepatitis C, infections due to hepatitis B are often silent. Without active surveillance, many HBV infections are first diagnosed when patients present with advanced and untreated disease, highlighting the need for early detection, increased awareness, and earlier intervention. Hepatitis B is highly endemic in East Asia and Sub-Saharan Africa where over 8% of the population is infected. Approximately 18 million Asians and 1.5 million Africans live in

the US,<sup>5</sup> with many living in New York City. The highest rates for newly-reported hepatitis B infections in the City of New York were reported around the three major Chinatowns in Brooklyn, Manhattan and Queens, Harlem and the Bronx. The burden of hepatitis B infection is expected to increase in the face of immigration patterns into the US from highly endemic countries, particularly in New York City where more than 30% of the population is foreign-born.

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The public health approach to addressing viral hepatitis is rapidly evolving. In 2014, policy achievements and pharmacological advances far surpass efforts to identify, link to care, and treat those infected with hepatitis B and hepatitis C. The Centers for Disease Control and Prevention (CDC) along with US Preventive Services Task Force (USPSTF) recently endorsed a birth-cohort-based approach of routine one-time hepatitis C screening of all persons born from 1945 to 1965. On October 23, 2013, New York State's Governor Cuomo signed a new Section 2171 of the Public Health Law that went into effect Jan 1, 2014, and requires health care providers in New York State to offer a hepatitis C screening test to every individual born between 1945 and 1965, in line with the recently updated recommendations. New York is the first and only state to have this requirement. Likewise, USPSTF recently upgraded screening recommendations for hepatitis B in at-risk persons including those born in countries with a prevalence of hepatitis B in fection of 2% or greater, HIV-positive persons, injection drug users, household contacts of persons with HBV infection, men who have sex with men, and persons who are immunosuppressed or receiving hemodialysis.

Coordinated and effective strategies must be implemented to ensure that those at risk for viral hepatitis-related complications and death can benefit from these significant policy and pharmacological achievements. The Affordable Care Act is aiding efforts to combat the longterm consequences of chronic viral hepatitis infection in the US. The law prohibits health plans from denying health coverage based on preexisting conditions, those with chronic viral hepatitis who were previously uninsured will now be able to get coverage and access to treatment.

Right now, thanks to new scientific advancements and health care reform, we have the opportunity to transform how the nation and our city deal with viral hepatitis. The City of New York can be transformed from an epicenter of the epidemic to a national leader and the envy of cities around the world in saving and improving the lives of our citizens by implementing this proposal. Meeting the challenge of this major public health crisis is imperative and we cannot lose any time to make a positive and meaningful impact. By enacting the Proposed Initiative 51-A, we will together take an important step forward to address the existing gaps to identify and care for patients with viral hepatitis. The Empire Liver Foundation is a non-profit foundation comprised of viral hepatitis providers, whose stated mission is to increase community awareness of liver diseases, provide education to health care providers and patients and provide guidance to policy makers who influence the practice and science of hepatitis B and hepatitis C. Its members are expert health care professionals actively involved in the diagnosis and treatment of patients with hepatitis B and hepatitis C, and are actively involved in research aimed at curing the disease. The members of the Empire Liver Foundation hail from throughout the State of New York and include national and internationally renowned key opinion leaders from the City of New York. The Center for the Study of Hepatitis C is comprised of an internationally distinguished and dedicated group of clinicians and scientists dedicated to the care of patients with hepatitis C and advancement in scientific discovery. This policy is in

line with core mission and beliefs of both the Empire Liver Foundation and the Center for the Study of Hepatitis C and we are pleased to provide our strongest support for the proposed initiative.

- 1. Valdiserri, R.O. & Koh, H.K. (2014) Breaking the Silence on Viral Hepatitis. Ann Intern Med.PMC
- 2. IOM report

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- Pinchoff, J., Drobnik, A., Bornschlegel, K., Braunstein, S., Chan, C., Varma, J.K. & Fuld, J. (2014) Deaths among people with hepatitis C in New York City, 2000-2011. *Clin Infect Dis* 58, 1047-1054.PMC
- 4. Balter, S., Stark, J.H., Kennedy, J., Bornschlegel, K. & Konty, K. (2014) Estimating the prevalence of hepatitis C infection in New York City using surveillance data. *Epidemiology and infection* **142**, 262-269.PMC3891473
- 5. Ackelsberg, J., Laraque, L., Bornschlegel, K., Rude, E. & Varma, J.K. Hepatitis C in New York City: State of the Epidemic and Action Plan. (2013).
- 6. NYC DOH surveillance reports

Harm Reduction Coalition Testimony on Proposed Int. No. 51-A Submitted by Daniel Raymond, Policy Director, Harm Reduction Coalition June 24, 2014

The Harm Reduction Coalition strongly supports the proposal to require the Department of Health and Mental Hygiene to issue an annual report regarding hepatitis B and hepatitis C.

The burden of chronic viral hepatitis in New York City represents a major and neglected challenge to public health, health equity, and our health care system. New York City is an epicenter of hepatitis B and hepatitis C in the United States; at the same time, New York has also been a laboratory for innovation and community mobilization efforts tackling viral hepatitis. My comments will focus on hepatitis C.

We are at a pivotal moment in the history of the hepatitis C epidemic, 25 years following the identification of the virus. When I began my work on hepatitis C policy for the Harm Reduction Coalition ten years ago, through an initiative funded by the City Council, the prospects for controlling hepatitis C were bleak. At that point, there was considerable uncertainty about how to prevent new infections among people who inject drugs, and limited treatment options with at best modest success rates and significant side effects which deterred most from pursuing treatment. Moreover, as we talked to people at harm reduction programs across the city, we found a substantial lack of knowledge, confusion about hepatitis C diagnosis, indifference from health care professionals, significant stigma, and an overall sense of resignation and futility.

Today, we are on the precipice of a new era with the potential for radically transforming the response to hepatitis C. New treatment advances can cure hepatitis C in most patients with shorter, simpler

regimens. Knowledge and awareness has increased, and community-based testing programs have reached thousands of people. However, the new treatments come at a steep price, and we must ensure that our strategies and interventions leave no one behind.

The health department plays a critical role in measuring and monitoring our response to hepatitis C, and particularly in the impact on health disparities and vulnerable groups. Federal resources for the hepatitis C epidemic remain limited and inadequate; we must mobilize resources and harness the political will to rise to the challenge of hepatitis C in New York City. Monitoring and surveillance efforts by the city health department will play a critical role in evaluating successes and gaps, and guiding the City Council and other stakeholders in assessing impact, return on investment, and resource needs for the future.

Harm reduction and syringe exchange programs have been at the forefront of the hepatitis C response in New York City, with support from the City Council and the health department. They play a critical role in prevention, education, and outreach; testing, linkage to care, and patient navigation; and providing support, mentoring, and leadership to the very groups most marginalized and most severely affected by the hepatitis C epidemic. Our programs and their participants need the active engagement and greater support and partnership from the health department to succeed. We have the knowledge and tools to bring an end to the hepatitis C epidemic in New York; we must now ensure that we have the necessary leadership, commitment, coordination, and focus. The proposed law would lay a vital foundation to any future progress by bringing that focus to bear on hepatitis C; for that reason, I urge the City Council to move swiftly to secure its passage.

Daniel Raymond Policy Director Harm Reduction Coalition 22 W. 27<sup>th</sup> Street, 5<sup>th</sup> Floor New York, NY 10001 Testimony before The New York City Council Committee on Health Hep B & C Oversight Hearing

Crystal Jordan, JD, MPH Vice President, Health Services

Kimberleigh J. Smith, MPA Vice President, Policy & Advocacy

On behalf of: Harlem United Community AIDS Center



June 24, 2014

Thank you to Chair Johnson and the members of the City Council Health Committee for convening this hearing and for allowing me the opportunity to testify before you today. My name is Crystal Jordan, and I am the Vice President for Health Services at Harlem United.

Harlem United is a community-based health organization serving Central Harlem, East Harlem and the South Bronx - neighborhoods highly impacted by HIV, AIDS, Hepatitis C and sexually-transmitted infections. Rooted in the community for more than 25 years, we offer a full continuum of primary care, dental services, mental health, harm reduction and substance abuse services as well as supportive housing, community-based outreach, education and screenings for HIV, Hepatitis C and STIs. We recently expanded our target population to include homeless individuals.

Three years ago, we testified before the Council about the growing HCV epidemic in Harlem and the South Bronx. Since then, nearly miraculous HCV treatments has been developed, progressive state legislation now mandates that HCV screenings be offered to baby boomers and aggressive local, state and federal plans exist to take a public health approach to Hepatitis and curb the epidemic.

But even in the context of such progress, we are seeing an epidemic in our community that is alarming. It is estimated that 146,500 New York City residents may have chronic HCV and, of that number, approximately 50% of people living with HCV are unaware, according to the NYC DOHMH.

In 2013, Harlem United enrolled 365 clients with HCV at our two health centers and mobile units alone: 157 were co-infected with HIV/AIDS and HCV and 208 were mono-infected with HCV. This represents 60% of our clients living with HIV and 30% of HU's total client population. In addition, Harlem United conducted over 2,000 HCV tests at our health centers and mobile sites, of which nearly 297, or 15%, were positive. Furthermore, we know firsthand that Hepatitis can be a silent killer, as many do not know they are infected until they get sick. This is an urgent public health issue affecting our core target populations.

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As a frontline community based organization, we support the city's strategic efforts to reduce illness and death related to HCV in New York City. We urge the New York City Council to work with the New York City Department of Health and Mental Hygiene to confront this urgent public health issue with public dollars addressing the objectives outlined in the city's action plan issued in September 2013.

Specifically, our experience teaches us that focusing on the following will go a long way toward addressing this deadly epidemic:

<u>1.</u> Develop a seamless linkage to care system that will allow providers to navigate and patients to self-manage the many hurdles specific to the successful treatment of this illness, including specialty visits: alcohol and substance use screenings; medication adherence; and numerous, requisite laboratories as well as ancillary services. Many patients with HCV face social barriers, behavioral health and substance use issues and have co-occurring medical conditions that make it challenging for them to initiate and remain in HCV-related medical care. Fully 50% of our HCV clients are dealing with substance use and mental health issue. Furthermore, we know that few clients initiate treatment because of the tedious list of required steps prior to treatment. Most often these steps prove to be too much, especially for our clients who are dealing with survival as well as mental health and substance abuse issues.

- 2. Grow investments in provider education in order to increase the ranks of providers who are prepared to treat individuals with a multiplicity of chronic conditions, as they present. These conditions can include HIV, HCV, hypertension, diabetes, asthma. In order to address the HCV epidemic we need to ensure that our clinical providers and community-based providers are sufficiently trained and skilled not only to treat HCV, but also to manage the complicated medical and psychosocial issues that patients face and which may emerge during treatment
- 3. Finally, we urge the city to work with the state to improve access to lifesaving medications by reducing, or mitigating, the cost barriers related to paying for treatments and securing insurance coverage for treatments. With the FDA approval of Sofosbuvir, for example, much hope has been given to patients who have found previous treatment options ineffective or who have feared the intense side effects of interferon heavy treatment regimens. Now a once a day pill, has eased trepidations about HCV treatment. Physicians are ready to prescribe, but Gilead's Sofosbuvir costs close to of \$90,000 for twelve weeks of treatment. In addition, the transition to managed care and specialty care management is causing confusion between provider and patient, delaying care, and increasing out-of- pocket costs.

By strengthening the linkage to care system and retention efforts, investing in provider education and capacity, reducing barriers to lifesaving medications - we can deepen our reach and make a true impact on the HCV epidemic.

Thank you for your time and attention.

### Testimony for Public Hearing Int 0051-2014 Proposed Int. No. 51-A. A Local Law to amend the administrative code of the city of New York, in relation to requiring NYC DOHMH to issue an annual report regarding hepatitis B and hepatitis C.

June 24, 2014

### Don B. Lee

CEO, MDLand International A Healthcare Technology Company

Good Afternoon, my name is Don Lee. I am CEO of MDLand International - a New York City based Healthcare Technology Company. Thank you for the opportunity to comment on the proposed Surveillance, Testing, Treatment, Outreach, and Education reporting relating to Hepatitis B and Hepatitis C in New York City. We speak in support of Intro No. 51-A and, in particular, would also like to highlight the importance of leveraging healthcare technology to cost-effectively fulfill beyond the traditional reporting goals; where all too often, the process of reporting is a separate resource-intensive project. We believe adoption of the right technology will costeffectively improve surveillance, track treatment outcome, and support treatment implementation for the complex care of Hepatitis B and C. More importantly, with the right tool and strategy, data elements captured will be more inclusive and meaningful for populations that might otherwise be marginalized or are sometime neglected on a national basis.

As part of MDL and's larger mission to leverage health technology to support evidence-based practices and Meaningful Use for our Clinical Clients, we also look to the issue of social change in the field of health service to bring health disparity issues to the forefront of surveillance, service, and treatment.

MDLand is proud to have received the Public Health Champion recognition by the Primary Care Information Project of NYC DOHMH, ONC Certified HIT 2014 Edition Complete EHR certification towards Meaningful Use, NCQA PCMH Prevalidation, the Surescripts White Coat of Quality 2013 Award, Gold Status Recognition by nationally-recognized lab companies; in addition to being a member organization of HL7 International, as well as other gold standards.

As a corporate sponsor of the DOHMH Check Hep C project in 2012, and from our collaboration with the Hepatitis B Coalition, we know firsthand the challenges and importance of data collation and aggregation. We at MDLand developed and launched an Electronic Medical Record module to connect all multi-site programs via web access providing real-time data capture and reports. The module provided quantitative reports for each site and our team of clinical experts provided detailed reports to analyze treatment outcome and a meta-analysis of the Project in year one.

The NYC Check Hep C project also made comparisons with data and national trends recorded in the *National Health and Nutrition Examination Survey* (NHANES). Of note in the NHANES data report, classification of populations such as the homeless, those with a history of incarceration, and the transgender community were not aggregated in the data surveys. From the NYC Check Hep C project, however, one of the innovations was the capturing of samples of all three of these high-risk, marginalized populations. From our review, the data points reflected a clear need for intervention and access.

Models of health care burden propose the peak of HCV-related morbidity and mortality will occur from 2015 to 2020; and as late as 2030. Accordingly, the demands on the public health system will continue to increase to match the incidence of illness and acute disease progression with at least one million projected to die from HCV-related complications.<sup>1</sup> The need to support direct care, integrated health technology systems, and treatment surveillance cannot be understated and the success of one cannot be separated from the other.

As such, the work of the **NYC Hep C Task Force and Hep B Coalition** must be recognized and properly supported for its impact and breadth of service in engaging high-risk communities and its need to build resources from its expert knowledge of treatment barriers and success. Without their knowledge to guide actionable goals, surveillance can only provide the numbers; which, in fact, may be limited in their scope and reach for historically known disparity groups rarely counted in National surveillance reports.

As an Innovative Healthcare Technology/EMR developer with a deep interest in and commitment to improving public health, we consider it unconscionable that there are surveillance reports that continue to aggregate communities in public health data under the category of "Other." We are critically aware each person is someone's child, friend, family, partner, coworker, or neighbor; that there are birthdays, weddings, and intimate moments of hugs and wishes that are invisible when counted under "Other."

We at MDLand see the connection and value that with health, come choices and possibilities, equally for everyone, and that numbers alone do not provide the full picture; but that service is the frame of which possibilities are understood. We develop our technology to enable efficient and meaningful documentation and individualized encounters that have inclusive population health implications.

Of particular importance, is the need to understand Hepatitis B in NYC. From the **New York State Department of Health Chronic Hepatitis B Surveillance Summary 2004-2009**, Asians and Pacific Islanders make up 42% of confirmed Hepatitis B.<sup>2</sup> Chronic HBV infection leads to cirrhosis, liver failure, or hepatocelluar carcinoma (HCC) in 15%-40% of patients and to liver transplantation in roughly 25% of patients per year with decompensated cirrhosis. Disease burden and the cost to quality of life have been carefully studied by many. The 2% threshold for prevalence of chronic Hep B in the CDC and US Public Health Service screening guidelines has shown cost effectiveness.<sup>3</sup>

We welcome the possibility to support efforts for meaningful use of data, mapping population needs according to disparity, and addressing treatment efficacy.

We encourage the City to examine the possibility of making a larger impact and to continue the path of integrating health and technology and to address services for both Hepatitis B and C. As a New York City Corporate Citizen, MDLand is dedicated in supporting the work of NYC DOHMH to address public health needs for all treatment needs, particularly for health disparity groups hardest hit with chronic diseases and high barriers to treatment access.

Thank you again for the opportunity to testify today and we look forward to working with you in the future.

Retrieved from https://www.health.ny.gov/diseases/communicable/hepatitis/hepatitis b/docs/2009 chronic hepatitis b short summary.pdf.

<sup>&</sup>lt;sup>1</sup> Smith, Bryce D., Morgan, Rebecca L., Beckett, Geoff A., et al. (2012). Recommendations for the identification of Chronic Hepatitis C Virus Infection Among Persons Born During 1945-1965. *Centers for Disease Control and Prevention (CDC) Morbidity and Mortality Weekly Report, 61(4).* Retrieved from http://www.cdc.gov/mmwr/pdf/rr/rr6104.pdf

<sup>&</sup>lt;sup>2</sup> New York State Department of Health. (2009). [Graph illustration of Confirmed cHBV Statewide by Race]. Chronic Hepatitis B Virus Surveillance Summary 2004-2009.

<sup>&</sup>lt;sup>3</sup> M. H. Eckman, T. E. Kaisar, and K. E. Sherman. (2011). The Cost-effectiveness of Screening for Chronic Hepatitis B Infection in the United States. Oxford Journal, Clinical Infectious Disease, 52(11), 1294-1306.

Retrieved from http://cid.oxfordjournals.org/content/52/11/1294.full.pdf+html



Planned Parenthood of New York City

#### PLANNED PARENTHOOD OF NEW YORK CITY SUPPORTS CITY COUNCIL BILL 051: Requiring the Department of Health and Mental Hygiene to issue an annual report regarding hepatitis B and hepatitis C

Planned Parenthood of New York City thanks our strong supporter and Chair of the New York City Council Committee on Health, the Hon. Council Member Corey Johnson for convening this hearing, as well as the leadership of Hon. Council Members Margaret Chin and Peter Koo for introducing this legislation. As a leading reproductive health and advocacy organization, PPNYC urges the New York City Council to pass legislation that would strengthen tracking and evaluation methods of Hepatitis B and C programs and initiatives in New York City.

For over twenty years, PPNYC's Project Street Beat has provided street-based HIV and STIprevention and access-to-care services to underserved communities throughout the South Bronx, Northern Manhattan, and Central Brooklyn. As a provider of Hepatitis B and Hepatitis C testing and referrals to treatment in nontraditional settings, we strongly support tools to better assess and address the city's response to viral hepatitis.

The Project Street Beat program is particularly successful at reaching hard-to-reach populations, serving individuals who typically do not access services at traditional health care venues, such as hospitals and health centers. Last year alone, Project Street Beat staff engaged in close to 23,000 outreach encounters with women, men, and youth at risk of sexually transmitted infections on the streets of New York City.

High rates of Hepatitis B and C continue to exist predominantly in low-income communities of New York City; with nearly 1 in 2 New Yorkers living in poverty we know the need to improve access to care is immediate. Too few New Yorkers know their status when it comes to viral hepatitis and even fewer access the care they need - this is unacceptable in a city that leads the way in so many health respects. More can be done. PPNYC applauds steps to monitor and improve current methods of prevention, testing and linkages to care.

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Since 1916, Planned Parenthood of New York City (PPNYC) has been an advocate for and provider of reproductive health services and education for New Yorkers. Serving more than 50,000 clients annually, PPNYC's health care centers in Manhattan, Brooklyn, the Bronx and Staten Island offer reproductive health services, including gynecological care, life-saving cancer screenings, male reproductive health services, contraception, pregnancy testing, abortion, testing and treatment for sexually transmitted infections, and HIV testing and counseling. Through a threefold mission of clinical services, education, and advocacy, PPNYC is bringing better health and more fulfilling lives to each new generation of New Yorkers. As a voice for sexual and reproductive health equity, PPNYC supports legislation and policies to ensure that all New Yorkers—and, in fact, people around the world—will have access to the full range of reproductive health care services and information.

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THE CITY OF NEW YORK         MOD       Appendix Ce Card         I intend to appear and speak on Ian No. 5 - A Res. No.         I intend to appear and speak on Ian No. 5 - A Res. No.         Harris State         I intend to appear and speak on Ian No. 5 - A Res. No.         I represent:         I represent:         Employed Liver         Full Address:         I represent:         Employed Liver         Employed Liver         Formulation + Center         Address:         I represent:         Employed Liver         Formulation + Center         Address:         I represent:         Employed Liver         Employed Hamalian + Center         Address:         I intend to appear and speak on Int. No.         I in favor         I in favor         I in favor         I in favor         I in opposition         Date:         Madress:         MATLES WALLEND         Address:         MATLES WALLEND         I represent:         Address:         I State         I represent:         Address: </td <td></td>	
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I intend to appear and speak on Int. No. 5 - A Res. No. Hard to appear and speak on Int. No. 5 - A Res. No. Date: 624/14 Date: 624/14 Date: 624/14 Name: 6000 (PLEASE PRINT) Name: 6000 (PLEASE PRINT) Address: 62 (PLEASE PRINT) THE COUNCIL THE COUNCIL THE CITY OF NEW YORK Appearance Card I intend to appear and speak on Int. No. Res. No. I in favor I in opposition Date: 6000 (PLEASE PRINT) Name: 64 THEE WALTON Address: 00 DN ATOS I represent: 215 W 13524 ST Address: 215 W 13524 ST	
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I represent: EMPINE Liver Foundation + Center Address: English Control of Heghthy Contro	Name: MANNI PERUMAISUAMI
Address: <u>Friday of Heylichic The Council</u> The Council The CITY OF NEW YORK <i>Appearance Card</i> I intend to appear and speak on Int. No. <u>Res. No.</u> in favor in opposition <i>Date:</i> Name: <u>EATHEE WACTOM</u> Address: <u>NATIMAL BIACKLEADERSED</u> WARTS WO DN AFDS I represent: Address: <u>215 W 135 DM ST</u>	
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in favor in opposition Date: (PLEASE PRINT) Name: <u>EATHEE WACTON</u> Address: <u>NATIONAL BIACKLEACERENCE</u> WARDISSING ON AFDS I represent: Address: <u>215 N 135 DA ST</u>	Appearance Card
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(PLEASE PRINT) Name: <u>EATHLEE WARTON</u> Address: <u>NATIONAL BIACKLEADERSHED</u> WARPISSING DN AFDS. I represent: Address: <u>215 N 1350 ST</u>	🗋 in favor 📋 in opposition
Address: NATIONAL BIACKLEADERSHED WARISSING ON AFDS I represent: Address: 215 W 13504 ST NIC	N GATURE A DATON
I represent: Address: $215 \text{ IV} 135 \text{ DV} \text{ ST}$	Address: NATIONAL BLACKLEADERSHED
N/(	I represent:
Please complete this card and return to the Sergeant-at-Arms	Address:

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