CITY COUNCIL
CITY OF NEW YORK

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TRANSCRIPT OF THE MINUTES

Of the

COMMITTEE ON HEALTH

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HELD AT: Council Chambers – City Hall

B E F O R E: MARK LEVINE
Chairperson

COUNCIL MEMBERS:
Alicka Ampry-Samuel
Inez D. Barron
Andrew Cohen
Mathieu Eugene
Robert F. Holden
Keith Powers

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

Dr. Winfred Wu, Medical Officer
Division of Prevention and Primary Care New York
City Department of Health and Mental Hygiene

Dr. Cheryl Lawrence, Medical Director
Office of School Health

Alicia Hyndman, New York Assembly Member
29th Assembly District, Southeast Queens

Jacqueline Baker, Parent Advocate for Sickle Cell
Disease

Charlene Jacobs, Nurse Practitioner,
Mount Sinai Hospital

Tom Milton, Pediatric Hematologist Treating
Sickle Cell Disease

Linda Vallone, Research Nurse, New York City
Health and Hospitals, Queens

Pandora Burns, Sickle Cell Patient

Geneva Marie Farrow, Sickle Cell mom, Advocate
and Educator

Gloria Rochester, Gloria, President and CEO of
the Queens Sickle Cell Advocates Network and
National Sickle Cell Disease Association

Sarah Santiago, Adult living with Sickle Cell
Disease

Ginger Davis, Adult living with Sickle Cell Beta Thalassemia

Ken Cohen, Regional Director, NAACP New York State Conference Metropolitan Council

Jeremy Griffin, Member of New York State Blood Disorders Coalition, Executive Director of the New York City Hemophilia Chapter

Brendan Faye, Advocate for Sickle Cell Treatment

Anthony Donovan, Hospice Nurse

Doris Polanco, Sickle Cell Patient

ADA Gonzalez, White Hispanic female with Sickle Cell Disease, Creator of Sickle Cell 101 Espanol

Marlene Smith Sotillo, President, Sickle Cell Awareness Foundation Co-op International

Molino Sotero, Vice President of the Sickle Cell Awareness Foundation

Nadine Baker, Sickle Cell Funding Advocate

Epiphany Samuels, Sickle Cell Patient

[sound check] [background comments/pause] [gavel]

CHAIRPERSON LEVINE: Good morning everyone. I am Mark Levine, Chair of the City Council’s Health Committee. I want to welcome you to today’s hearing. For those of you who have been unable to find an open seat in the Chamber, there will be an overflow of seating available downstairs with a video link. We do have an extremely important topic today. It’s a busy day around City Hall and my colleagues will be hopping in and out I’m sure. I want to welcome for their debut testimony Drs. Wu and Lawrence from the Health Department. We look forward to hearing from them on our topic today, which is chronic disease. We’re going to be hearing a package of eleven pieces of legislation including three bills and eight resolutions that focus on chronic disease in New York City including heart disease, stroke, tick-borne illness, and Sickle Cell disease. New York City has logged many public health victories in recent years, but significant challenges remain including for the chronic diseases we are focusing on today, most of which have trend lines moving in the wrong direction. These diseases have something else in common: Education, awareness and outreach are critical to their prevention, timely diagnosis and/or successful treatment. First up, we'll be looking at coronary artery disease and strokes, which are a leading cause of death in the United States and New York City. One of the biggest underlying causes of cardiovascular disease is high blood pressure, and over the past two decades the trend lines on this measure are moving in the wrong direction. In 1996, 22% of New Yorkers reported high blood pressure. By 2018 despite major advances in medicine along the way that percentage had risen to 29%. High blood pressure and cardiovascular disease also disproportionately affect communities of color and uninsured and under-insured individuals, and treatment is complicated by the fact that many people are unaware that they even have high blood pressure because there are usually no warning signs or symptoms. Next up, we'll be looking at Sickle Cell Disease an inherited blood disorder that can cause intense pain, anemia, stroke and premature death. About 100,000 people in the United States are living with Sickle Cell Disease, approximately 10% of which are right here in New York City, but only 2.5% of the national population that's has it. Sickle Cell Disease disproportionately affects African-Americans, and Hispanic Americans. Patients with Sickle Cell Disease often report feeling ignored or judged by medical professionals and thus can feel hesitant to seek medical attention. Research on Sickle Cell has been consistently under-funded, and today we still do not have enough safe, effective treatment or cure for this disease. And finally ticks-borne diseases, which are also on the rise in New York City and nationally likely due to climate change. The number of reported cases of lime disease in the United States for example has tripled since the late 1990s, and the location and geographic range of ticks that spread germs continues to increase. Because of this trend, the Northeast including New York City is now considered s a high risk region for tick-borne illnesses. These diseases often go undiagnosed and without awareness early treatment—or without awareness or early treatment, there can be dangerous results including swelling of the brain and even death. Today's bills aim to raise awareness about these chronic diseases to increase education, encourage prevention and early intervention, and to provide resources to those in need of care. We look forward to hearing from DOHMH and from various advocates and health organizations on how we can partner together in this fight. We thank you for being here today and look forward to a robust discourse. I look forward to hearing from the Administration now. I think Dr. Yoo—Dr. Wu, will you be kicking us off? Alright please. We have a customary affirmation that will be administered for both of you by our committee counsel Sarah Lyst.

LEGAL COUNSEL: Do you affirm to tell the truth, the whole truth and nothing but the truth in your testimony before this committee and to respond to honestly to Council Member questions?

PANEL MEMBERS: [in unison] I do. [off mic]

LEGAL COUNSEL: Thank you. You can begin. [background comments/pause]

DR. WINFRED WU: Good afternoon Chair Levine and members of the Committee. I am Dr. Winfred Wu, Medical Officer in the Division of Prevention and Primary Care at the New York City Department of Health and Mental Hygiene. I am joined today by my colleague Dr. Cheryl Lawrence, Medical Director in the Office of School Health. On behalf of

Commissioner Barbot, thank you for the opportunity to testify today on the proposed legislation, which would require the Health Department to provide a list of the organizations the department regularly consults with regarding the prevention and management of chronic diseases, place automated self-administered blood pressure machines in certain public places and establish standardized procedures for treating students with tick bites. The mission of the Health Department is to protect and promote the health of all New Yorkers. A primary component of our work is therefore aimed at reducing the burden of chronic disease by addressing the underlying risk factors that lead to obesity, heart disease, cancer, diabetes and stroke. In recent years the Health Department has expanded our work specifically to address hypertension control. We engage with a variety of stakeholders to inform and improve our approaches to reducing the burden of chronic disease. These organizations include, but are not limited to academic institutions, community based organizations and non-profit organizations that aim to prevent and reduce chronic disease or more broadly address the social determinants of health that impact chronic diseases. I will now turn to the legislation under consideration today. Intro 643 would require the department to provide automated blood pressure machines for self-testing use in public space such as parks. Hypertension is a leader respecter for heart disease and stroke, two conditions that contribute to more than 1 in 5 premature deaths in the city, making community based blood pressure kiosks as accessible as possible is a Health Department priority as they serve three main purposes. (1) Enhancing awareness of blood pressure among the general public; (2) serving as an engagement tool in early detection of hypertension following a high blood pressure reading, which is then confirmed by a clinician; and (3) offering a free accessible way of monitoring blood pressure between visits with a healthcare provider when other preferable methods are not available. The Health Department supports increasing access to blood pressure measurement including through automated machines. One type of blood pressure machine is a kiosk and the Health Department currently maintains 60 blood pressure kiosks throughout the city. This includes 55 kiosks at community pharmacies and five kiosks in partnership with other city agencies.

Community pharmacies are a strategic location for the placement of the blood pressure kiosks as they offer kiosk uses access to pharmacy staff who can answer questions and offer educational materials on blood pressure. Between June 2017 and June 2019, close to 200,000 readings have been reported from these kiosks with a monthly average of 7,955 readings. A 2019 field survey found that the kiosks were beneficial to users and nearly half reported using a kiosk weekly to track their blood pressure. As a result of using the kiosk machines, users indicated they intended to report their blood pressure results with their doctor and some planned on making changes to their diet and physical activity. Location information for these kiosks and other sites that offer free blood pressure checks are available online via the NYC Health Map. The NYC Health Map is promoted on agency, social media channels and agency staff have previously distributed educational materials to primary care provider offices, and pharmacies about the importance of getting your blood pressure checked. The department supports the Council’s interest in improving hypertension control efforts through the placement of blood pressure monitors in public spaces. We look forward to working with the Council to discuss the best ways to reduce hypertension amongst New Yorkers. Next, Intro 4 would require the Health Department to provide a list of non-governmental organizations that we routinely consult with on the prevention and management of chronic diseases. We currently work with hundreds of community partners and other organizations on many aspects of this work. We support providing this information and look forward to discussing the details of the legislation further with the Council. Lastly, Intro 1243 would require the Health Department to promulgate rules that establish a procedure for school nurses to respond if a student appears to have a suspect tick bite. As part of the standard procedure for school nurses for students presenting with health issues in the rare occurrence that a student presents at a school nurse’s office with a tick bite the nurse would assess the area, provide first aid and inform parents to refer the child to the student’s medical providers for any treatment needed. This is part of an established mechanism that emphasizes the importance of seeking care from primary care providers for health issues.

We are confident that school nurses are well equipped to handle any students that present with a suspected tick bite, and would like to further discuss the proposed legislation with the Council. Thank you for the opportunity to testify. We are happy to answer any questions.

CHAIRPERSON LEVINE: Thank you so much, Dr. Wu. I'm pleased that we have been joined by Health Committee Member, Council Member Bob Holden and a very special guest the Chair of our Finance Committee who is the lead sponsor of our resolution today related to Sickle Cell and I'm going to que him, Council Member Danny Dromm to say a few words.

COUNCIL MEMBER DROMM: Thank you very much, Chair Levine for holding this hearing to give attention to more of the issues the Sickle Cell related conditions that impact so many members of our communities. I will let the health professionals describe the science behind Sickle Cell related conditions, but what is clear is that Sickle Cell disease is a public health crisis. With so many individuals in New York who either have Sickle Cell trait or Sickle Cell Disease, a large effort is needed to meet this issue head on, and to address the new added concerns that arrive. Recognizing the need for the state to launch a more coordinated effort to tackle this health challenge, Senator James Sanders and Assembly Woman Alicia Hyndman introduced A-06493 and S2281 with the goals of decreasing morbidity and overall cost, the increasing quality of life, this legislation would create demonstration programs to coordinate service delivery, provide genetic counseling, conduct community outreach, promote mental health services and train professionals. In addition, the bills would establish a statewide coordinating center to provide resources and monitor progress. Since nearly all of the individuals impact are of African descent, the diagnosis and treatment of Sickle Cell Disease is a bellwether or how well our society is dealing with race-based health disparities. With top notch medical professionals dedicated community based organizations and government backing, New York is poised to address one condition that is so prevalent in communities of color and move toward closing the healthcare gap. I look forward to hearing the testimony of all the witnesses, but especially want to recognize the work of Dr. Tom Moulton a dear friend and zealous advocate for individuals and their families dealing with Sickle Cell Disease. Without him, we would not be here today. Thank you very much.

CHAIRPERSON LEVINE: Thank you so much Chair Dromm for your leadership on this issue. I—I want to welcome you again, and I often remark that I hold the city's public health—the city's Health Department in extremely high esteem. I consider it to be the best big city health department in not just America, but the world and this is my first time working with all of you in this forum, but we welcome you here to the committee. I…I want to understand your exact stance on the bills that are being heard today starting with Intro 643, um, which would require placement of blood pressure monitors in public spaces. To the extent that you have objections or concerns, could you articulate them?

DR. WINFRED WU: So thank you, Chair Levine for that opportunity to comment. So that agency is supportive of the Council's intent through Intro 643 to increase the awareness and availability of a blood pressure and opportunities to measure blood pressure within the community. This is, you know, we recognize this an important strategy as part of addressing the hypertension issue within New York City and we look forward to speaking further with the Council with respect to the bill.

CHAIRPERSON LEVINE: I want to acknowledge we've been joined by our colleague Council Member Daneek Miller who is also one of the leaders on the issue of Sickle Cell Disease, and I want to cue him if he has an opening statement to make.

COUNCIL MEMBER MILLER: Thank you, Council Member and Chair, no, I—I just simply want to say that—I want to thank my colleague Council Member Dromm for his resolution and the resolution, which I had calling on Jim Knife (sic) It would be a national day and…and with the city's dreadful disease, which I myself have a trait and—and it's—it's—it's just so disheartening that we have perceived that we have digressed, um, in treatment and in research, and because of that, the cost has—has really increased and will continue to increase because of people are often misdiagnosed. They're not treated in-in—in the same way, and we want our health services to be done in an equitable way just as everything else and this is a disease that is obviously disproportionately impacting the African-American community, and we want to ensure that those resources are there. One of the other things I just want to say here, and this is a commitment that I have made and the Caucus has made and I'm hoping that our—our colleagues here while we call on the state to do their part for $5 million, certainly the city, which has now 70% of the Sickle Cell patients in the Greater New York Area should do their part as well. So, certainly within HHC that there is somewhere that we can provide comprehensive Sickle Cell services as well, and—and do our part as well. So, I'm really excited about the work that is being done here in these chambers today. I want to thank you, and I want to thank Council Member Dromm as well. Thank you.

CHAIRPERSON LEVINE: Thank…thank you, Council Member, and you're absolutely right about how disproportionately is impacted by this. The national figure is that 10% of all the cases in the whole country are right here in the five boroughs of New York City. So, we have to address this as a city and a state, and I thank you, both of you for bringing this to the Council's attention today, and we're going to be hearing from advocates shortly to go in depth on this issue. But doctor, I just want to understand a little bit better about your stance on the high blood pressure testing. We know that many people with high blood pressure actually don’t know that they have this condition. You don’t necessarily have symptoms though it can be a very severe underlying health problem that can lead to cardiovascular disease. So, it’s clear we have to get people teste, and we have to go to where they are to make it easy and convenient, and I think that’s the intent behind wanting to place these devices in public settings where our folks are going. Why not do that? What’s wrong with the—with that strategy?

DR. WINFRED WU: So, Chair Levine, we agree that it’s an important health issue—health issue with respect to helping New Yorkers understand the issues that related to hypertension particularly amongst those who may have hypertension and are unaware of it. The Health Department has, um, performed and implemented various programs to raise awareness amongst New Yorkers about the dangers of hypertension and the fact that it’s, you know, coming as clinical silent killer. There was a recent campaign called Know Your Numbers, which encouraged

New Yorkers get their blood pressure checked so that they could understand, um, where their blood pressure stands and to, you know, follow up with their care providers if it was elevated. We agree that, um, making available increased opportunities for measurement of blood pressure in the community is an important one. Place blood pressure kiosks is one of several different strategies, um, to make the measurement in the community feasible. As—as mentioned in the testimony earlier, the Health Department support the New York City Health Map, um, where New Yorkers can look to identify areas in the community where they can obtain a fully measured blood pressure. To date there are about 1,300 sites citywide that New Yorkers can go to get their blood pressure checked in the public, and we continue to seek out opportunities to promote NYC Health Map through direct engagement with the public as well as detailing, um, amongst healthcare providers and—and other invested stakeholders.

CHAIRPERSON LEVINE: Are you concerned about the cost or the logistics or some of other aspect of placing kiosks in public locations.

DR. WINFRED WU: So, Chair Levine, there are a number if legislative issues as it relates, um, placement of blood pressure kiosks. I can share with you the department's focus on placing the 55 aforementioned kiosks in the community. We had—we focused on pharmacies really for three main reasons. One being that these are generally entities within the community. There's a real trust, you know, given, you know, focused on health. The second is based on the fact that we understand many New Yorkers with hypertension are on medication, and so pharmacies are locations in which they are very comfortable and routinely visiting to, you know, get their medications. But I think--I think there third and most importantly is that access to a clinical pharmacist who can really help individuals understand any readings that they get a kiosk or from a pharmacist obtained pressure. Help them contextualize and understand what that number means as it relates to, um, you know, their health and perhaps their medical treatment. So, again that is why we focused on placing blood pressure kiosks in the community and again we—we view making access to community-based blood pressure measurement with kiosks being just one of several different approaches. Others include, um, promoting individuals to, obtain home blood, you know, obtain home blood pressure monitors such that they are able to measure those—their blood pressures at home, and share that information back with their healthcare providers.

CHAIRPERSON LEVINE: I want to acknowledge that we've been joined by fellow Health Committee members, Council Member Andy Cohen and Council Member Keith Powers. Doctor, do you keep track of the communities with the highest incidents of hypertension and is that where you are focusing your efforts to secure more testing?

DR. WINFRED WU: So, um, so, Chairman, yes we—in terms of the blood pressure kiosks that we did place, we—we sought to focus on communities, um, where we understood the hyper—the prevalence of hypertension was greatest, and so that was, you know, what informed our decision making as far as place—instruction of pharmacies for placement.

CHAIRPERSON LEVINE: Very good. Regarding Intro 2043, which—excuse me, 1243, um, this might be a question for Dr. Lawrence, which seeks to, um, solidify our response to rising rates of tick-borne diseases among children in our public schools. Could you clarify again your stance or the Administration's stance on this legislation?

DR. LAWRENCE: We'd like to continue discussions on this bill. Our concern, as mentioned before that our nurses are well equipped to handle the needs of New York City kids. So this is a—we would like to be able to continue the discussion further.

CHAIRPERSON LEVINE: Okay, but are you concerned that it's redundant that it would be difficult to implement? Why not secure that all nurses are—are well equipped and following a uniform protocol in testing:

DR. LAWRENCE: So, thank you for that question. So, school nurses work within their scope of practice, and in accordance with applicable laws and regulations and guidelines. Specific authorized activities such as tick-borne—tick illnesses are not individually identified in applicable requirements for regulated professionals.

CHAIRPERSON LEVINE: Okay, I do want to turn to some questions on Sickle Cell, which is the third major disease category that we're covering today. Your know there's—there's a disease which disproportionately afflicts the Ashkenazi Jewish community. It's called Tay-Sachs, and as—as an expectant parent I had the experience that all Ashkenazi Jewish parents now have at least in this country of an intense battery of tests screening and counseling when we were—my wife and I were expecting our first child to determine whether we were facing Tay-Sachs in—in our offspring, and there is a menu of responses that the health system is now mobilized to take in such cases including things like I-V-F, and other strategies, and these methods while a little bit scary for—for folks like me and my wife have served to dramatically reduce the incidents of Tay-Sachs in this country, and I wonder why we don't have similar mobilization of effort to take on another disease, which disproportionately targets one group in this county and that is Sickle Cell, which if I had my stats right is 200 times more likely to be found in—in African-American children relative to white children. It also disproportionately although at lesser incidents impacts Hispanic-American children. Why don't we have a similar mobilization of screening and education and early intervention so that we can win the battle against this disease?

DR. WINFRED WU: So, Chair Levine, you know, we recognize the burden, the tremendous burden that Sickle Cell disease presents to many New Yorkers, um, and we would look forward to the opportunity to speak with the Council further on potential opportunities to further many of the points that you had just articulated. I can tell you with respect to the city, much of our—our programmatic work around Sickle Cell disease is driven through New York City Health and Hospitals where they have many program staffed with amongst other folks board certified Hematologists, who, you know really are well versed in, um, you know the management of Sickle Cell disease.

CHAIRPERSON LEVINE: I got you. Like it’s on the hospitals once someone contracts the disease, but we’re focusing here on the kind of education, the screening, the outreach that does fall into the bailiwick of the Health Department, right. This is a broader public health imperative that needs to take place not just in public hospitals, but in doctor’s offices, everywhere and even outside of doctors’ offices. What is the Health Department's strategy for this?

DR. WINFRED WU: So, Chair Levine, again, most of the--most of the focus from the city has been through New York City Health and Hospitals. Um, many of the programs do have community engagement activities, um to—to, um, speak—that speak to many of the points you had, um, raised and, um, but nevertheless, you know, we as the Health Department would look forward to the opportunity to speak with you and other members or the Council to think further about strategies to, you know, address awareness and—and screening and—and-and the like.

CHAIRPERSON LEVINE: Okay. I'm going to pause and—and ask my colleague Council Member Dromm—I believe he has questions.

COUNCIL MEMBER DROMM: Thank you very much Chair. I'm wondering if you know how many people in New York City have Sickle Cell disease.

DR. WINFRED WU: So, thank you for that question, Council Member Dromm. The Health Department itself doesn't have specific numbers as far as the total number of New Yorkers who have Sickle Cell Disease. Um, you know, we look to date from the Center for Disease Control Intervention, which estimate one in approximately 365 African-Americans have Sickle Cell Disease, and so, you know, again we recognize that, you know, that equates to a large number of New Yorkers who, you know are suffering from the condition.

COUNCIL MEMBER DROMM: So, you don't collect the number yourself then?

DR. WINFRED WU: We do not collect that data primarily. No.

COUNCIL MEMBER DROMM: Okay, um, what does DOHMH do to ensure that those with Sickle Cell disease receive the best care?

DR. WINFRED WU: Yeah, so thank you for that question, Council Member Dromm. Again, the city—the city is primary response around the Sickle Cell Disease, um, is driven through New York City Health and Hospitals. There are three programs in particular based out of Harlem Hospital, Kings County and Queens Hospital Center where they have, you know, programs specifically geared towards Sickle Cell Disease, which includes both, you know, the diagnosis and management, but again they also have community engagement efforts that seek to, you know, work with members of the community to address many of the issues and concerns already spoken to earlier.

COUNCIL MEMBER DROMM: So does, um, DOHMH do anything to educate the communities about Sickle Cell?

DR. WINFRED WU: So, the city—I—I—so the Health Department, um, does not have any of those primary programs, but we would look forward to the opportunity to speak with you and other members of the Council on ideas on how to, um, you know, further advance that messaging.

COUNCIL MEMBER DROMM: Does DOHMH screen new borns for Sickle Cell?

DR. WINFRED WU: So, it’s a good question, Council Member Dromm. The Health Department itself does not perform any primary screening. That is left to, the care providers for which the parents and, you know, children and mothers who are at risk for Sickle Cell Disease. That is primarily managed clinically.

COUNCIL MEMBER DROMM: And are those numbers reported to you or are they reported to CBC?

DR. WINFRED WU: Okay. So, those numbers are not reported to the Health Department and they are neither reported to the CDC.

COUNCIL MEMBER DROMM: Does DOHMH provide any type of mental health services to those dealing with Sickle Cell Disease?

DR. WINFRED WU: So, I'd have to defer to—defer to, um, colleagues at New York City Health and Hospitals again, who, you know, have a lot of the programming around Sickle Cell disease. My understanding is that they do, you know, offer comprehensive services to address, you know, the larger needs beyond just Sickle Cell Disease, you know, within their clinics.

COUNCIL MEMBER DROMM: Does DOHMH coordinate with Health and Hospitals on or have discussions with Health and Hospitals about Sickle Cell Disease?

DR. WINFRED WU: So, I can—I can say that at least from my purview under the chronic diseases I work with, you know, the Health Department does regularly engage with NYC Health and Hospitals. I can't speak specifically to our engagement with H&H as far as Sickle Cell Disease, but we would be happy to follow up with you and-and the Council as far as, you know, kind of our collaboration with H&H on Sickle Cell Disease.

COUNCIL MEMBER DROMM: Okay, it seems like this is one area where a lot more really needs to be done, and it seems to be an area to me that has been very overlooked by DOHMH, and, um, I—I hope that that doesn't continue to be the case moving forward. So, hopefully with this resolution and with Council input we'll be able to discuss this in more depth the next time with the Department of Health and Maybe with Health and Hospitals as well. So think you very much.

CHAIRPERSON LEVINE: Thank you, Council Member Dromm, and I see that we've been joined by some of the activists and leaders and—and some of the patients who have come to talk about the issue of Sickle Cell, and we look forward to hearing from you in our public testimony coming up shortly, and, um, I do want to thank the Administration. We're going wrap up this portion because we have another elected official who is waiting to speak. So, I thank you again for your testimony this morning, and I would like to call up a very special guest here, Assembly Member Alicia Hyndman (applause) and again, we—we welcome all our—our friends from the advocacy community. We have a tradition here in the Council that we show gratitude or cheers is through waving our hands like this, which you're free to do at any moment, and folks probably know this but if you'd like to testify, we'll ask you to approach the sergeant and you can fill out a slip to make sure that we get your name in the cue. Welcome Assembly Member Hydan—Hyndman. It's very nice to have you here.

ALICIA HYNDMAN: Thank you, Chair Levine. It's my first time so--

CHAIRPERSON LEVINE: Alright, well--

ALICIA HYNDMAN: We are honored.

CHAIRPERSON LEVINE: We're going to be extra nice to you.

ALICIA HYNDMAN: Okay, (laughs)

CHAIRPERSON LEVINE: But please, we—we welcome your testimony.

ALICIA HYNDMAN: Well, good morning. Thank you. So, my name is Alicia Hyndman. I'm the Assembly Member for the 29th Assembly District, which is in Southeast Queens and I am now in my fourth year in New York State Assembly, but I did not carry the

Sickle Cell Bill until I believe the—my second year in because the bill used to belong to Assembly Member Shelley Mayer, but she felt that it would be more apropos in the Assembly if I carried the bill and being that I do have a daughter with Sickle Cell trait, I was quite happy to do so. So, I've been carrying this bill for approximately two years with State Senator James Sanders, and some of the things that you highlighted in your questions to the Chronic Diseases Department of the New York City Department of Health is that this disease is very much overlooked. There is children that are screened at—when they're born. If they're born in a New York City hospital obviously and in New York State, and then that's really the end of it. There is no, um, it is—it is pressed upon the—the advocacy groups who are in—some of them—some of who are in this room to really do the education and outreach to those parents who now realize they have children with Sickle Cell. So, if you are not born in—in New York City, and you come from elsewhere you could have Sickle Cell, but not know it until you go to see a pediatrician if you—if you have a pediatrician or you present crises in a hospital and then you have to go get treatment, and there was a young—there was a family here earlier whose daughter every three months she—I think she's less than four years old. Every three months she has to—she presents, um, crises to Sickle Cell by I just really want to thank the advocacy and the resolution that's going to be passed that will highlight June 19th as Sickle Cell Day in the city of New York. You have an advocate robust community in here. We are really underserved. We have more states like Texas and I think Florida and California who have bigger budgets for Sickle Cell treatment and education. So, that's really what we're doing and I always say this: If there are more of us working on one accord we can do more pushing the State to get the money. We do have a Democratic Senate now So, we are optimistic that we'll get more money in the budget. My first year we were only able to get $170,000. The second year $200,000 in the budget, and then some of the hospital systems that you mentioned earlier the hospitals where—where it goes to we have to do more work. I know Dr. Molton is in here somewhere, but one of the things we're looking at doing is making sure that we work to get money into the CBOs through the New York State Department of Health to make sure that the CBOs who do most of the leg work, most of the heaving lifting to get information out to families receive that. The NAACP has also added this to one of their health initiatives, and they were in Albany lobbying last year. I know they'll probably do the same again this year, but this is—this is not about us. Obviously, it's about constituents that we serve, and I will—I'm not—I'm not a long talker. So, I'm definitely going to let the advocates talk about their issues facing Sickle Cell, but one of the things that Chair Levine you said about all the screenings you went through when your children were born because of Tay Sachs. We have to make sure that the same effort is put into a disease that predominantly affects African-Americans and Latinos. We had some really great testimony in Albany this year, and I really hope we do the same next year to make sure the budget is that much more robust. So, I thank you for your advocacy. I thank you for this hearing today. It just goes to show me that this not an issue that we're just tackling alone in—in the State Legislature, which we're tackling here, too, in New York City. So, I thank you for that.

CHAIRPERSON LEVINE: Thank you, Assembly Member for your leadership on this and for testifying. Nothing makes a New Yorker's blood boil more than hearing that Texas is beating us. [laughter] We can't let that happen. We're going to have to up the budget for that reason alone. On a more serious note, what—what do you suggest that we do to really improve our outreach?

ALICIA HYNDMAN: Well, one of the things that when you were asking the gentleman from DOH, one of them is—is—is you hit several items, which was they know nothing. They don't—they rely on Health and Hospitals. Health and Hospitals is as we know it faces severe cuts. So, how are we going to—we can't just let—give them the information and expect them to carry it. They're not teaching their—their residents about this disease. They're not learning this in medical school. If they are they're just touching on it. So we need to make sure the outreach is done. Back in the '70s, there used to—there used to be PSAs on the television about Sickle Cell. I remember the commercials. It's—it didn't go anywhere. Instead, more and more people are affected with it. So I would say the same way you put him to task is that he should—he has to follow up with you and they have to give you a plan of what they're doing in New York City to address Sickle Cell and educate schools. A lot of children present crises while in school. They miss a lot of days of school. That's not fair, and a lot of teachers don't know what Sickle Cell is. So, the education that these advocates talk about is-and the Department of Health has to work in tandem to make sure that our teachers and our administrators know what Sickle Cell is, and how it affects their students and why their students are sometimes missing class.

CHAIRPERSON LEVINE: Okay, I'm going to pass it off to Council Member Dromm for a question.

ALICIA HYNDMAN: Thank you.

COUNCIL MEMBER DROMM: Thank you Assemblywoman Hyndman. It's good to see you here in City Hall.

ALICIA HYNDMAN: Thank you.

COUNCIL MEMBER DROMM: I have seen you active in all different prats of the Borough of Queens. So, um, thank you. I'm just wondering if your legislation I think it—it calls for the opening of eight centers. Am I correct on that--

ALICIA HYNDMAN: It does

COUNCIL MEMBER DROMM: --and is that statewide?

ALICIA HYNDMAN: It does because we have to remember that we—we often neglect areas like Syracuse, Albany and Buffalo, Rochester and parts of Long island have a large African-American and Latino population and a lot of those individuals, too, are affected by Sickle Cell. So, that's why we wanted to make sure we spread it around the state. I was able to do some outreach, some interviews with advocates around the state that work on Sickle Cell because it's not just a New York City issue, but obviously w that we're addressing today, but it has to be statewide.

COUNCIL MEMBER DROMM: And the purpose of the centers would be what? What would it—what would they do?

ALICIA HYNDMAN: Well, to—once someone is—is screened, and has Sickle Cell because sometimes it's not just the newborns. It's people that are coming in from other countries who are—who present symptoms—symptoms. Once they're screened and the education, we know as far and they will tell you having a healthy diet has everything to do with fighting a crisis. There are—sometimes there are drug trial programs that Novartis has been able to have some patients enter, but the important is the—the health and development of the children and adults because if—I—I met a young—I met a mother who lost her son in his 30s because he presented crisis with Sickle Cell. So, once you get to a certain age doesn't mean you still—you still have to be active in your—and you're proactive in your treatment when it comes to Sickle Cell. So that's why it's seeded around the state.

COUNCIL MEMBER DROMM: So, I was a little bit surprised to be honest with you that DOHMH is not really collecting numbers or data or statistics on any of this information that we were asking them about prior, and I just am concerned also that they're pushing the responsibility for it over to Health and Hospitals and do you know what Health and Hospitals is doing on this at all?

ALICIA HYNDMAN: No, I don't. I know the specific hospitals that are working more than others. So, um that bothered me also. One of the things that when we met with Chairman Godfried about this bill when he said that we should probably divide up the bills we make sure that it—it—we're not leaving any area, we're not overlooking any area. So, that was one of the things we might have do some tweaking with the bill--

COUNCIL MEMBER DROMM: Uh-hm.

ALICIA HYNDMAN: --but—but the bottom line is to get the funding.

COUNCIL MEMBER DROMM: Uh-hm.

ALICIA HYNDMAN: If we don't have the money then we really can't ask any of the hospital areas to do anything as they're face cuts they do every day.

COUNCIL MEMBER DROMM: Uh-hm. Okay, thank you. very much Assemblywoman.

ALICIA HYNDMAN: Thank you Councilman Dromm.

CHAIRPERSON LEVINE: Thank you very much Assembly Member. I want to acknowledge that we've joined by Council Member Inez Barron and Council Member Alicka Ampry-Samuel, and we're now going to pass on to our first panel of public witnesses and I thank you very much.

ALICIA HYNDMAN: Thank you. [background comments/pause]

CHAIRPERSON LEVINE: Could you just give me on moment.

ALICIA HYNDMAN: No problem.

CHAIRPERSON LEVINE: Okay, yes, yes, we're-sorry. We are going to move to the nest pane.

ALICIA HYNDMAN: Okay.

CHAIRPERSON LEVINE: I apologize for the confusion.

ALICIA HYNDMAN: It's okay.

CHAIRPERSON LEVINE: You're welcome back here any time Assembly Member.

ALICIA HYNDMAN: Thank you very much.

CHAIRPERSON LEVINE: Thank you and I'm going to call up the panel and while they're making their way, I'm going to cue one of the sponsors of our legislation today, Council Member Barron, but first let me read off the names of our first panel of witnesses. They include Charlene Jacobs, Tartania Brown, Jacqeline Baker, Tom Bolton and I apologize for not being able to read the handwriting here. Linda Vallone. So, if the five of you could make your way up to our front table, and while you do that, we're going to turn it to you, our sponsor of one of the bills today, Council Member Barron.

COUNCIL MEMBER BARRON: Thank you to the Chair and thank you to the panels and the public that is here on these various issues. I'm pleased to say that I am the sponsor of Intro 4. Yes that is 4. It's been a while getting here, but we're so pleased that now under this leadership it is here to be discussed and Intro 4 is a very simple basic bill and what it says is that the Department of Health should coordinate and generate a list of all the organizations that are functioning in the city that are doing work on alerting people and advocating on behalf of those that have chronic diseases, and often time the organizations are going great work but they may not be acknowledged or known, and the work that they do may not be coordinated with other efforts that are going on. So, the gill simply says that we want DOH to generate a list of all the organizations with whom they have an affiliation so that we would have a composite comprehensive list of those groups that are working against chronic diseases. Thank you very much, Mr. Chair.

CHAIRPERSON LEVINE: Thank you very much, Council Member and I'm going to cue now our panel and, um, why don't we start with you on the end, ma'am.

JACQUELINE BAKER: [off mic] My name is Jacqueline Baker.

CHAIRPERSON LEVINE: And if you could make sure your mic is on.

JACQUELINE BAKER: Oh, Sorry.

CHAIRPERSON LEVINE: Thank you.

JACQUELINE BAKER: My name is Jacqueline Baker. I'm a parent advocate for Sickle Cell Disease and I work—I support the community based organizations. I am from Northern Westchester and a retired teacher. I have two adult sons with Sickle Cell Disease who have struggled with the disease. My youngest son lost his job. He was—made it through college at an extra year of costs as a civil engineer, but he lost a job due to many days that he had to stay in the hospital. My older son he had to go on a transfusion program for more than 20 years so that he can be able to work with Sickle Cell, but again, he still just got—recently he was sick again and hospitalized. So, I'm here to say that Sickle

Cell Disease for some reason it just doesn't get the attention it deserves. It's—it's not looked to me as a priority and it should be. It needs to get the funding like other chronic illnesses get like HIV, Parkinson's. They get a lot more money and Sickle Cell disease is just really hardly no funding or adequate funding in order to help the patients care for themselves. As my children were in school I had to talk to the teacher so to make sure that they could move onto the next grade when they sick. So, there was that constant communication, but it was a struggle and I had to keep working, you know, talking to them because they didn't understand what it was. When you even go to the hospital a lot of medical professions then didn't know how to treat Sickle Cell patients. So it was a lot you had to learn as a parent, and I did, and—and now we—you know, we see that Sickle Cell disease just needs the support and it needs the funding. It-it—a lot of things could be done better for Sickle Cell if they had the money. We're here—we're here fighting with, you know, to advocate for Sickle Cell. We are working with the legislators. We're happy that we did have a little bit of funding, but we need a lot more to make a difference so that they can live a better life. Sickle Cell patients deserve that human right, and they deserve the healthcare that they need so they go onto be if they want to become a doctor or a lawyer instead of staying in the hospital. With this money they could save—it could save them from being in the hospital for long periods of time. Thank you.

CHAIRPERSON LEVINE: Thank you very much, Ms. Baker, Correct.

JACQUELINE BAKER: Yes.

CHAIRPERSON LEVINE: Um, and I do want to acknowledge that we've been joined by our colleague on the Health Committee Dr. Mathieu Eugene, Council Member. There is also the lead sponsor of a number of our pieces of legislation that we are considering today, and we'll be hearing more from him shortly, and we'll pass it off to you please.

CHARLENE JACOBS: Good morning. My name is Charlene Jacobs. I work for Mount Sinai Hospital. I'm a nurse practitioner there. I've been working there for about two years now and I've been working with patients with Sickle Cell Disease for about four years at this time. I work with a three-person group, which is a small grouping. We care for about nearly 400 patients, adults with Sickle Cell Disease, and one thing I must say is that our team in general in our healthcare system is really struggling with keeping patients our of the hospital and decreasing their length of stay. Care in general for Sickle Cell Disease is inequitable Sickle Cell Disease is inequitable, and it’s also undermined by many other illnesses. So, for instance as we’ve been mentioning before H-I-V gets a lot more funding though it costs less that Sickle Cell. So we do need more resources in the hospital. We do need hospitals to support Sickle Cell programs like our own. As we mentioned earlier today we have patient who do not have access to us as healthcare providers. So, therefore, they are not getting the care that they need, and their health—t their health and their lives are shortened because of this. Patients are living until 36 years old, which is lower than it used to be. It used to be in their 40s. Therefore, we—we need funding for programs to support Sickle Cell, support Sickle Cell community based organizations, hospitals and to provide resources for patients and their families so they can live healthy, active and productive lives. Thank you.

CHAIRPERSON LEVINE: Thank you very much and apologize that we have to use the two-minute clock. We have a very long list of people who want to speak and we just want everyone to be heard today those of you who want to testify. We thank you very much and Mr. Milton.

DR. TOM MILTON: Hi. I'm Dr. Tom Milton. I'm a Pediatric Hematologist working with Sickle Cell Disease for over 30 years and I want to clarify something in terms for the bills and some facts is that New York State has 10% of the Sickle Cell population in the nation. Yet in 2017, New York State spent specifically for Sickle Cell Disease $170,000. That is a 66% decrease in funding from the early 2000s. So, despite this being health disparity, the government has consistently whittled away funding for Sickle Cell inadequate as it is. Eighty percent of the Sickle Cell Disease patients live in the New York City area not just New York City, New York City area. That is why the bill—out of the eight programs five are in the New York City area and three are upstate. In addition, patients get care not only at the tertiary hospitals that get at community hospitals as well. So, in that bill and amongst those five in New

York City area two must come from community hospitals so that we can collect the data. Part of the reason for this bill is to collect data on Sickle Cell Disease patients, which is sorely lacking. How much does it cost? Are they being cared for? Most adult patients do not get the specialize care, and that is part of the reason why there is such a disparity in terms of mortality. If you look at England, mortality is much higher in terms for age than it is in for the United States. So, you know, the bill will be specific—it has very—much more specifics in it, but there are so many complications and it is proven that comprehensive care not only decreases the cost of Sickle Cell Disease, but improves the quality of life, and with just a 3.3% decrease in cost per patient New York State Medicaid could save anywhere from $4 to $5 million, which more than funds the $3 million that's been asked in the bill. [bell]

CHAIRPERSON LEVINE: Impeccable timing, Dr. Milton. [laughter] You must have practiced in front of the mirror. Thank you very for your leadership on this and for speaking out today.

DR. TOM MILTON: Thank you.

CHAIRPERSON LEVINE: Please.

LINDA VALLONE: Hi. I’m Linda Vallone, I’m a Research Nurse at New York City Health and Hospitals, Queens. I’m here actually to talk about our program on Sickle Cell Disease, and the progression of our program. In 2012, we had a big problem. Our readmission rate was 64% meaning that our patients were living the majority of the life out-inside of the hospital as opposed to outside of the hospital. We had to make changes so we invested in collated (sic) investment a program at New York City Health and Hospitals where we hired a nurse practitioner and we designated a doctor to be in charge for this Sickle Cell program exclusively and, um, hiring these people had made changes in our E.R. in our on In-Patient Unit, in our Infusion Centers and in our Psycho-Social Services. The results of these programs even just after two years showed that we decreased the readmission rate from 64% to 34%, which is a 45% decrease, and that actually equates to $1.7 million savings, cost savings for our one little hospital, and so I’m here because I—I really do believe that if we invest—invest again that word investment, a little money in these very—these patients to live outside of the hospital and to live a life that ill actually be able to also have a cost savings along that line and—and that we're really not sacrificing much by doing that.

DR. TOM MILTON: If I may, Queens Hospital is the Health and Hospitals Corporation Hospital.

LINDA VALLONE: Right.

DR. TOM MILTON: What would be nice is that we could spread the word of the cost savings from there to the rest of Health and Hospitals Corporation Hospitals.

LINDA VALLONE: Yes.

CHAIRPERSON LEVINE: Okay, with that point, thank you very much. Please.

DR. SARKANIA BROWN: Good morning Council people and fellow advocates. [bell] Oh, that's not for me.

CHAIRPERSON LEVINE: Thank you for your remarks.

DR. SARKANIA BROWN: [laughter] That's not for me.

CHAIRPERSON LEVINE: Desperately.

DR. SARKANIA BROWN: I have it down to two minutes. Give me two minutes [laughter] Good morning. My name is Dr. Sarkania Brown, and both my brother and I have Sickle Cell Anemia. So, I became a physician with a—with a specialty in pain and palliative care actually due to the hardship that my brother and I have gone through and my desire to make a difference by being a voice at this table. My brother had multiple strokes at the age of four years old, and which took away his physical ability and his speech. Since the age of four, my brother has been wheelchair bound and he talks with a voice box. His strokes were due to Sickle Cell Disease which is the number one reason for strokes in children. Unfortunately, this disease causes more than just debilitating pain. It affects every organ in the body and everywhere that blood goes. So, from the brain to the lungs, to the heart and even the skin. All parts of the body are touched. Being a working physician I have to care for my patients, but I also have to care for myself. I have multi-joint damage. I have liver damage. I had multiple surgeries including one earlier this year where they had to place a stint in my failing liver. I've had double responsibilities to not just to my brother, but to my fellow persons living with this disease to inform people that without knowledge and support from our wonderful government that we are dying young and suffering in silence. I just turned 40 but that is considered geriatrics in the world of Sickle Cell. I hope, pray to live to 60, which is the average lifespan—lifespan. At this point it's gone down. By supporting this bill New York State will not only be aligned with the other states as we've stated, but we can also provide the desperately needed funds for this disease where 10% of the nation's lives in New York State as stated. Part of the bill's money will go to patient navigators and advocates who can help people like my brother and myself go to attend [bell] and maintain appointments. Again, I implore you to please accept this resolution in the New York State Budget and approve the $3 million to go to Sickle Cell Disease advocacy, treatment and research. Thank you.

CHAIRPERSON LEVINE: My goodness, Dr. Brown, thank you so much for speaking out today and for your leadership in the face of these challenges. It's really heart breaking to hear the challenges of your family, but it's really inspiring--

DR. SARKANIA BROWN: Thank you.

CHAIRPERSON LEVINE: --the way you've turned this into a cause that you're clearly a very important leader for. You're such an important panel. I want to repeat something that I had said earlier as someone who's an Ashkenazi Jew, I'm very familiar with another disease which is Tay-Sachs, which disproportionately affects Ashkenazi of Ashkenazi Jewish descent, and when my wife and I had kids we had—the doc just put us through a whole battery of screenings an counseling to prepare for the possibility that—that our—our offspring could have this disease and it's very stressful to go through, but collectively the efforts to combat Tay-Sachs has lead to a dramatic drop in the incidents of this disease in America, and there is simply no excuse that we haven't done the same thing in Sickle Cell. There's no excuse that we haven't recreated that kind of success in adequately allocating resources to outreach, education, screening and most importantly the continuum of care not only in childhood, but into adulthood. We're hoping that the resolutions that Council Members Dromm and Miller put forward today will help call attention to that. We are strongly supportive of the legislation in Albany and I'm not sure if she's still here, but we're very grateful that Assembly Member Hyndman was here in person who is one of the lead sponsors, but you certainly have my support in this fight and we'll do everything we can to make sure that resources and attention are adequately allocated to this.

DR. SARKANIA BROWN: Thank you.

CHAIRPERSON LEVINE: Thank you very much to this panel. We're going to continue to hear from others, but we appreciate you very much. [applause] [background comments/pause] We have what looks like it's going to be another very good panel. Leading off with, um, a young person. We're happy about that, Abigail Jean Regon (sp?) We have Geneva Farrow. I might not be reading this correctly but Gloria Rochette. Okay so got it. We have Mary Sarah Santiago, Ginger Davis, and finally I think that's Pandora Burns. We may be a chair or two short, but we'll—we'll make sure everyone gets to speak on this panel. Okay. I think we have everyone. Great. And we—we may need an extra chair. [background comments/ pause] Okay, sorry for the musical chairs, but we're happy to get everyone up to the table and if it's okay I would love to start off with Ms. Abigail

ABIGAIL JEAN REGON: [off mic]

CHAIRPERSON LEVINE: Can you turn your mic on?

ABIGAIL JEAN REGON: Is it on? I doubt it. Hello, I'm Abigail Jean and I'm 10 years old. My baby 2 years old and she has Sickle Cell Disease. I have already lost count of how many times she's been in and out of the hospital, which hurts me a lot because I know that my family is suffering with Sickle Cell Disease. We need to do something to help pass from the Sickle Cell Bill, which would change hundreds of family's lives for the better. We need our elected state officials including Governor Cuomo to increase funding for treatment and awareness. I am so very proud of Senator Kevin S. Parker and Assembly Person Rodneyse Bichotte for their continued support of this bill. I now ask them to make sure that the Sickle Cell Bill is passed and fully funded. In addition, we need to provide more financial and medical support for these families as well as increase education for our communities to learn about testing and finding resources. Thank you for your attention. [applause]

CHAIRPERSON LEVINE: Abigail, that was wonderful testimony. You do better than some of my colleagues in the City Council. [laughter] I hope you will run for City Council one day. How old are you?

ABIGAIL JEAN REGON: Ten.

CHAIRPERSON LEVINE: Okay and what grade are you in?

ABIGAIL JEAN REGON: Fifth.

CHAIRPERSON LEVINE: Okay, have you ever testified in the City Council before?

ABIGAIL JEAN REGON: No. Okay, well, [laughter] I hope you will come back. It I so important to hear your voice and the words that you said are very important. We really appreciate you sharing your family's personal challenge here because it does make it real, and gives a human face to this disease and we appreciate your courage in speaking our and calling for support of this very important state legislation. So, it really has an impact that you've come here today, and all these cameras here are going to—are currently broadcasting live on—on the web. So, you'll have people who will be—who have already heard your hearing today, and it's going to be on the City’s television station later in the week, and archived online. So, you’re going to go far and wide with these very, very important comments, and I do thank you again for speaking out. Would you mind introducing the person who’s behind you?

ABIGAIL JEAN REGON: Oh, this is my Nanny Rosie.

CHAIRPERSON LEVINE: Okay, we thank you for Rosie as well. [laughter] Okay and ma’am. I’m going to ask you on the end, it’s a very tough act to follow, but we’re going to ask you to go next and if you can make sure that your microphone is on. There’s a button there.

PANDORA BURNS: Hello. My name is Pandora Burns. I’m a Sickle Cell patient at Greens Hospital Center, and I’m very grateful to the Council persons in pushing this bill because it is very vital. Sickle Cell might not be as popular as some of the other critical diseases, but it is a disease that is life threatening that people live with day after day. Some people never really go into remission with Sickle Cell. You know, this is something that they live with, and so this is very vital. I think the outreach should even be not only at hospitals, but in pharmacies and institutions of education and faith-based institutions because you'd be surprised even some people in the medical field are not abreast about Sickle Cell, and with more and more people being diagnosed now, it is very important that people have follow-up. Our hospital have a dynamic follow-up team, practitioner, Artura Cassia and the staff there. We have our own private emergency, but a lot of places don't have these things, and they can have these things if they had more financial input. It is a critical disease, and unfortunately at the slow rate of research, it's going to be here for a while. So, appreciate you addressing this, and we do hope this bill goes through. Thank you.

CHAIRPERSON LEVINE: Well, thank you very much, Ms. Burns, and we're so sorry to hear about your personal struggles, but it means a lot to have your voice added to this debate today, and we're glad that you're here. Thank you. Ma'am.

GENEVA MARIE FARROW: Good morning. My name Geneva Marie Farrow, Healthy Warrior mom. I'm a s Sickle Cell mom, advocate and educator. 5:10 a.m. Tylenol with Codeine in the E.R. It didn't kick in until 6:00 a.m. 7:15 a.m. Toradol; 9:15 a.m. Tylenol; 10:25 a.m. Oxycodone. 12:30 p.m. Morphine. 1:22 p.m. Toradol. 4:00 p.m. Oxycodone. 5:15 p.m. Tylenol. 5:44 p.m. screaming in pain at five-minute intervals. 6:00 p.m. Morphine. 6:20 finally asleep. 7:00 p.m. Toradol and on and on. This was the first 24 hours of my son's last hospital stay. He was hospitalized due to a pain crisis in his feet after a trip to the beach. Dylan is five years old and only 42 pounds with Sickle Cell Anemia S.S. Prior to this hospital stay, Dylan had not visited the E.R. or had a hospital stay in 20 months and 29 days. Prior to his long stretch of being healthy, we were hospitalized regularly from everything including Pneumonia, RSD, and the flu until I figured out a holistic approach to treating his Sickle Cell. We changed his diet and now we take a whole host—he takes a whole host of vitamins and herbal supplements to keep him out of the hospital. Tomorrow we celebrate two months since his last hospital stay. No one educated us about anything else [bell] in terms of Sickle Cell other than folic acid, Penicillan and hydration. More funding is needed to educate parents on alternatives to what the status quo is now. Thank you. [applause]

CHAIRPERSON LEVINE: Thank—thank you very much, and I know we're all very enthusiastic. I just want to remind folks that our convention here is—is to share support by waving, and my goodness, hearing about the pain that seems to be one of the really defining symptoms of this disease it's really—it's really upsetting, and I'm so sorry that you have suffered through that--

GENEVA MARIE FARROW: Thank you.

CHAIRPERSON LEVINE: --and you are focusing like a laser on the need to educate and—and offer outreach to people who are suffering, and those who might be at risk and—and we definitely share that priority and thank you so much for speaking out.

GENEVA MARIE FARROW: You're welcome.

CHAIRPERSON LEVINE: Okay, please.

GLORIA ROCHESTER: Yes, I—I guess it's my turn, you know. Good morning—good morning Chair Levine. I'm a fellow member of the Health Committee. My name is Gloria Rochester, and I'm the President and CEO of the Queens Sickle Cell Advocates Network. I heard this come about in the early '70s. I have one child that was born here in the United States. I came to the hospital three days with my daughter. No one indicated to me about Sickle Cell or either that I have the trait. So, I went on with my daughter and about the age of 18 months I find her limping and then I took her to the doctor. They said nothing is wrong with her. Take her home and for compress and everything will be okay. Later on, I find my daughter again is limping a couple month later, and when I took back to the hospital, they said she has Sickle Cell S.S. and children like that don't pass their 20th birthday. I did not get a genetic counselor. I did not get a support group. All I was told to come the next day to do some tests for my daughter and I did, and right after that I went to the library to get some books on Sickle Cell. During my journey with my daughter what I did I start a journal to write everything down that I was going to show the journey of taking care of her. So, on that I started an organization called the Queens Sickle Cell Advocates Network that we based in Queens, New York. Our mission is to empower those affected with Sickle Cell Disease by providing them with the knowledge and skills needed to better and advocate the healthcare system so they can move effectively advocates for their personal care and promote accessibility to services and meet the Sickle Cell community needs. We've been doing that for 40 some odd years and doing a beautiful job, and a matter of fact we've become the National Sickle Cell Disease Association here in New York because that's the excellent work that we do. We're asking the City Council to support Resolution 335 and we just had Council Member Daniel Dromm, which called the New York State Legislature to pass fully funded and the Governor to sign the bill now known as A-6493S2281. Legislation that will establish eight demonstration programs throughout New York State and one coordinating center to be improve the life and care of the Sickle Cell Disease patient, education about Sickle Cell, the trait and other—and—and other disparities. We are also calling into support Resolution 980 through my Council Member I. Daneek Miller to declare June 19th of each year Sickle Cell Awareness Day in the City of New York that we proposed to him in joint to pass that resolution. Mobility increased sharply, and you could see the poster that I have over there with a few from the

Queens Sickle Cell Advocates Network the patient that have passed on, and there is just a few, but every single day we have patients all over the country that are dying, and we need to do something about that. The cost of treating Sickle Cell Disease is estimated at $1.1 billion per year. The average cost of patient per month is $2,000. Please, we are asking the city and the state to invest in these families. Sickle Cell Disease is a disease that needs to be taken care of. Seventy percent of the births is in New York State, were born in New York City and nearly [bell]- Thank you ever so much for New York State top put in the funding for Sickle Cell. We're looking for $5 million in the State of New York and what the City Council can adopt in their initiative coming up. Thank you ever so much for having us here to testify today.

CHAIRPERSON LEVINE: We thank you very much for speaking. We really do. Thank you.

SARAH SANTIAGO: I'm a little nervous speaking in front to the Council, but I'll try the best I can. I'm not much of a public speaker, but I will speak. My name is Sarah Santiago. I am outreach worker for SETP and Sickle Cell trying to see new patients at work, and also I am diagnosed with Sickle Cell Disease. My parents came here in 1984. I was born in 1987. I'm about to be 32 years old in October, but through the years the little bit of English my parents know, they, you know, when I was born the doctors told them that I have Sickle Cell Disease. They told me—the told my parents that I would not live long with Sickle Cell, and a little bit of English my parents know, they keep educating me go to the doctors, learn more about Sickle Cell and ask my old pediatrician Dr. Wong a lot of questions. Also with school it was difficult for me to go to school because, you know, with the Sickle Cell and some of the teachers are not educated, and it was hard for me to make friends and everything because of the Sickle Cell Disease. They put me in Special Education classes because of my Sickle Cell. They almost kicked me out of school because I missed so many days of school and absence. We don't want the same for these children. We want these children to have an education. I have two college degrees, Associates and a Bachelors and I made the Dean's List 3.7 when I was in college and with Sickle Cell I could be anything that I want to be, and we're asking you to please fund this because you know what? A lot of students that are going through what I'm going through need the services that they need. Thank you so much.

CHAIRPERSON LEVINE: Well for someone who was nervous, you—you have amazing poise, and it's really inspiring to hear about your success in academia, and professionally against this challenge. I hope other young people learn about your story because-

SARAH SANTIAGO: Yes, sir.

CHAIRPERSON LEVINE: --it is inspiring, and thank you for speaking today. You were great.

GINGER DAVIS: Good afternoon. Thank you very much to the Council to the Health Committee and Chairman Levine who happens to be my Council representative. This is a big, huge issue that has been silent for too long. I'm sorry. My name is Ginger Davis. I'm an adult living with Sickle Cell Beta Thalassemia. It's the third most common type of Sickle Cell Disease in prevalence, the first one being Hemoglobin SS known as Sickle Cell Anemia, and the second one is SC Disease. I became and advocate at the age of 8 because of the stories that my mom told me about my brother Mark Anthony who was the first of five children, the classic 205 born with the disease, but he was not diagnosed, and died from a complication that was very treatable. I got diagnosed at the age of 2 and was fortunate to be put into comprehensive care at Long Island Hospital, which was torn down for its property value. So we have moved to New York Methodist Hospital, the Presbyterian at Methodist, which has become so insanely over-crowded that people are languishing in the E.R. for days before they get a bed and sometimes are being discharged from the emergency room never having been admitted to the hospital. We've lost our Adult Comprehensive Treatment Programs. When Dr. Rita at Bellevue retired last year, they closed the last one stand-alone program that was here in New York City. Montefiore Hospital does a great job, and they have a great team that's doing things, but it's not enough, and even they had a—a national model of a Day Mott Hospital specifically for Sickle Cell Disease that was shut down for a treatment clinic even though they were saving Montefiore Hospital hundreds of thousands of dollars annually for having this comprehensive care. This bill that has been languishing in the State Legislator—Legislature since 2011 is egregious, [bell] and we need to have the Assembly and the Senate take this to the floor, vote on it, pass it and for the Governor to allocate the $3 million in the Budget for 2020.

CHAIRPERSON LEVINE: Thank you, thank—thank you very much. We have a question or comment now from our colleague, one of the sponsors of this legislation, Council Member Miller.

COUNCIL MEMBER MILLER: Thank you so much Chair Levine. So, I want to talk about education and, and I'm going to give you this kind of shared benefit of my experience in having the trait and experiencing what my experience was as an adolescent and—and joint pains and other things that we went through that never not got identified until two years later, and I want to say that I grew out of it. Hopefully that—that is the case, but and—and a lot of the education that I had around Sickle Cell, um, came from advocates and—and so, um, which is very important. It's more important that we fully fund this and so that our local healthcare providers and facilities are—are fully serviced, and so that folks who are going to be impacted have all the tools and resources so that it was just articulated they can have the quality of life that they deserve, that they're not misdiagnosed that—that children aren't put in situations that aren't conducive to learning that both and—and the quality of life that they deserve. That being said, is there currently a program whether with HHC or some other hospital network here in the city? I'm focusing specifically here that has the type of resources that we feel comfortable that could provide not just information, but the healthcare that—that is deserved, and if not, what would that model look like?

GINGER DAVIS: We have the resources and no, the programs don't exist. The new one screening program and was with laboratory. We get our pamphlets for Sickle Cell traits, Sickle Cell Disease and the various hemoglobin types from them, but for the hospitals that provide comprehensive pediatric care, and do have adults in their population, you cannot go anywhere in any one of these hospitals in New York City and find a pamphlet on Sickle Cell Disease. The resource is there. It's not being distributed, and it's not being even requested by the hospitals. The 1990s was the last time we had a public—a free public trait testing program and when that grant was lost, no one from HHC stepped up and said we need to continue this, and primarily for people who are migrating to New York City, they're the ones who are not being tested and they're being identified when they get sick come into the hospital, and then they're tested and—and told that they have Sickle Cell Disease. And still in the various languages that the information existing is not available and distributed. So there's a lot of work and the community organizations we do we do what we can, and with the Sickle Cell Thalassemia Patients Network and we're forming Angels, Sickle Cell Foundation from Rockland County, and we struggle hard for the simplest resources like education materials and to be able to distribute that as far as we can.

COUNCIL MEMBER MILLER: So, if there was a an ask for this committee, this Council--

GINGER DAVIS: Uh-hm.

COUNCIL MEMBER MILLER: --what would that be?

GINGER DAVIS: It would be to set policy. We need policy in New York City that things are done in a certain way. In terms of we have the school-based clinics, us being able to go to the Director of School Health Education and meeting with them, and being able to educate all of the nurses that are in all of the schools in the five boroughs to be able for our community based organizations to go into the schools throughout our boroughs to educate the principal and their staff particularly in schools that have children with Sickle Cell Disease and other hemoglobin disorders. We need to be able to pass that education on, and most of importantly, we need to get into the colleges that are teaching future doctors and nurses, therapists, nurse practitioners because when we walk into the hospital and are asked by a nurse practitioner or a resident when did you get Sickle Cell Disease, it's infuriating. This should be basic knowledge that this is a genetically inherited disorder and they don't know that, but what they do know is to repeat that we are drug seekers, drug addicts, frequent flyers, fakers. They know those things, but they don't know what it is that they need to do to care for us when we're coming into the E.R.

COUNCIL MEMBER MILLER: Okay, thank you very much. Obviously and Ms. Rochester, I certainly want to hear from you because just a quite a bit of my education comes from—from Queens Sickle Cell Network, but also I hear stories when I talk to principals and administrators and—and other in schools about problem children, and I don't think that they are being properly, not necessarily diagnosed, but—but—but treated and given placing in—in—in an environment where—where-where they can learn because they are not necessarily misdiagnosed, but because they don't have the tools--

GINGER DAVIS: Yes.

COUNCIL MEMBER MILLER: --and the knowledge to—to—to properly, um, provide an environment for them to learn in the way that they should and—and so what I'm—what I'm seeing is that there is a lot of unintended consequences that—that occur by virtue of—of this. We don't understand this thing.

GINGER DAVIS: Yes

COUNCIL MEMBER MILLER: And—and that's the simplest part of it and even how we, um, the—the cost associated is because we're not investing and we don't understand the lack of knowledge and—and this unknown factor is—is causing real problems. So, I—I can really appreciate, um, but again, I—I just, you know, what can we do beyond that and I—and I think that simply what the resolution is called for and—and Council Member Dromm has absolutely been on—so on top of this. This committee has been on top of it, but certainly we could do more, and calling on the state is fine, but we have to do more here. What can we do?

GINGER DAVIS: Well, all of us are here and we'll be coming into your offices [laughter] and we'll work together to see what we can really do, and, um, you, this time for talk is over. We need action, and we're going to be here to help you help us with that. [background comments/pause]

CHAIRPERSON LEVINE: I have three other Council Members and Dromm has a quick comment,

COUNCIL MEMBER DROMM: Yeah, just a quick comment because I know that a lot of the folks that were out on the steps with the press conference before might not have been here. But when I did question the Department of Health and Mental Hygiene, they didn't have any statistics or numbers or count or whatever. They said that they rely really on Health and Hospitals to do it. So, you know, what I would say is I think we should, you know, work together with DOH and Health and Hospitals to find out if there's any discussion going on between the two agencies and being that education process. My education was at the dinner by speaking to people most affected by it and Dr. Brown was one of those people that I had the opportunity to sit with, and-and that's why, you know, I said—I committed at the dinner that this is, you know, we wanted to move this forward. So, yeah, we need to do that very, very much.

CHAIRPERSON LEVINE: Absolutely and we're not going to let the Department of Health off the hook on this. They have the key role in any public health challenge where we have the community outreach, community education. We need clinicians to be up to speed. We need reporting centrally We do this with many, many, many diseases in this city. That is the mission of the Health Department, and while obviously the public hospitals have a key role here, much of what we're talking about here has to be driven by the Department of Health, and we're going to hold them accountable for that. Thank you to this excellent panel. We're going to move onto the next group of witnesses. We have Ken Cohen, Dr. Rit Bellevue, Dr. Cassandra Dobson, Jeremy Griffin, and Brendan Fay. [background comments/pause] Okay, sir, would you like to lead us off?

KEN COHEN: Yes. Good morning. My name is Ken Cohen. I am the Regional Director of the NAACP New York State Conference Metropolitan Council with 14 branches of New York City, just a small portion of the 53 branches in New York State. The NAACP has taken this issue very seriously. Dr. Hazelton-Dukes has written the Governor. We have walked the halls of Albany to support this bill, and we ask knowing that the City Council and this committee has to support this bill as well. We have come here today in support of all the advocates to make sure that their voices are heard, and that people understand how important it is to fund to fight this illness. We ask you today to throw your full support behind them in not just words, but in dollars. Thank you.

CHAIRPERSON LEVINE: Thank you. Succinctly and powerfully stated, and we do stand with you in this fight. Thank you. Please, ma’am.

DR. RITA BELLEVUE: [heavy accent] Good morning. My name is (sp?) Dr. Rita Bellevue. I am a retired hematologist, and today, I am on behalf of SCAC, the Sickle Cell Advisory Council City of New York, and I am an advocate today for the Resolution being Number 335 and Resolution Number 980. Recently the Sickle Cell Advisory Council City of New York was organized by Dr. Douglas Wethers (sic) 40 years ago with a group of professionals, patients and families. Presently, it's a—it's an organization for physicians, patients, for cell workers, health professionals, all of the community-based organizations, and we work together, you know, for—for—for something better for our patients. So, what I'm going to say now I'm going to say it from my heart. I worked 40 years in Brooklyn (sic) Medical Center and Methodist Hospital, and what I would like to do I would like to do as I can to provide comprehensive care, and as a leader of the service, I make—I make sure that everything run well for the babies, adults and where various services went into. Adult—operation on adults. So, you know, I saw so many things in my 40 years working with patients. I, you know, I saw them graduating. I saw the—I saw the wedding, I get the pictures of the babies, but I saw—I also got to know news of the funerals. Sickle Cell is really a very unpredictable disease, and very—we have very, very places for patients in New Yorker as well as I'd say in New York State because as a physician and as I was working with the sisters and advising association, I make sure that I knew what was going on in New York, and I'm going to take one second to say that I was there when we $750,000 for individuals of New York State. I was there when it became $500,000 and when I left four years ago, it was $250,000, but we cannot do anything with that. We cannot take care of the patient and there are places in New York City that they are not seeing for patients with Sickle Cell. So, we need. I'm standing here and being and you know in front of you, you know, really to do—please do something for our patients with Sickle Cell Disease. Thank you.

CHAIRPERSON LEVINE: Thank you so much. Thank you. [background comments] Ma'am.

FEMALE SPEAKER: Good morning. Thank you for having me, the Council. It is my honor just to tell you who I am. I'm a nurse with Sickle Cell Disease. I also have a doctoral degree because I had to go back to learn about this disease so that I could help what I saw in the hospital. The care that a patient gets in the hospital is unbelievable because there's a lack of adult hematologists to care for patients. Often times when a pediatric patient leaves their hematology, they are thrust into the wild and there is no hematologist to care for them as adults, and this is about the age of 18 to 21, and so we need comprehensive centers because I have worked in a comprehensive center and I see the progression. I see the care that these patients gets, and it was amazing. Like Doctor—like the doctor says, they graduated, they went to school, they get educated. There was a continuity of care. Now, there's a—an inappropriateness of care. Many doctors now are not interested in caring for patients with Sickle Cell Disease, and so we need to regroup. We need to educate doctors, nurse and, healthcare workers to support patients with Sickle Cell Disease so that they can get the care that they believe that they should get, and so that they can live a healthy quality of life. Thank you.

CHAIRPERSON LEVINE: Thank you very much.

JEREMY GRIFFIN: Hi, my name is Jeremy Griffin and I am, um, and advocate for patients with rare blood disorders. I'm here as a member of the New York State Blood Disorders Coalition, and also as the Executive Director of the New York City Hemophilia Chapter. Our organization exists to build community, to improve health outcomes for people with bleeding disorders, and, um, people with Hemophilia they are missing a protein in their blood that causes their blood not to clot, and they end up not being—it's not like they're going to cut and they're going to bleed to death, but the end up having joint pain and bleeds internally, and those joint issues are very similar, the pain. The experience is very similar. Our patient population also seeks treatment at hematologists just like the Sickle Cell community. So, I'm here as a partner. We believe strongly that, um, that partnership has a power to help patients with chronic and rare conditions, and we have been very fortunate to work with the Sickle Cell community over the last few years. We worked with Assembly Woman Victoria Joiner to pass March's Bleeding Shores Awareness Month a few years ago, and then we also worked on Assembly Woman Collins Rare Disease

Advisory Council Bill. Very excited about the work that's being done, and that's why we're here to support what they did. Also, I'm here to share with you that partnerships matter. Comprehensive care is a partnership. It's multiple physicians and treatment people coming together. Since 1974, the Hemophilia Treatment Centers were set up to be federally funded. It has made a huge difference for people with Hemophilia to have these federally funded centers for people to go for excellence. It helped us build a community to improve health outcomes. New York State needs to do the same thing for folks with Sickle Cell. For—since 2011, a community has been coming to New York State in pain, and what the state has done is turned its back. It is time for that to end, and it is time to bring the funding that is necessary to get the resources and awareness for the Sickle Cell community.

CHAIRPERSON LEVINE: And—and thank you, doctor, and you're confident that the—I think it's a $5 million ask. Is that correct?

JEREMY GRIFFIN: Yeah.

CHAIRPERSON LEVINE: That that going to have a meaningful impact?

JEREMY GRIFFIN: Yeah. I—the ask was $3 million. I think for next year it's going to be $5 million. That's correct.

CHAIRPERSON LEVINE: Well, we'll raising the stakes, and I think there's a consensus that $5 million is the target, and that's against the current level of funding of what? Currently it's—it's a paltry sum, is that correct?

JEREMY GRIFFIN: I—I would have to default to someone else here that knows. Maybe it is a paltry sum. [background comments]

CHAIRPERSON LEVINE: So, um, it was only $117,000 in 2017, which is shameful.

JEREMY GRIFFIN: Yes.

CHAIRPERSON LEVINE: Absolutely shameful. We must do better.

JEREMY GRIFFIN: Yes. Thank you to the Council for all the support on this.

CHAIRPERSON LEVINE: Of course,

BRENDAN FAYE: My name is Brendan Faye. I'm a New York resident, and I am here today as an ally and advocate for the Sickle Cell community because of my relationship. I'm married to Dr. Thomas Molton. I knew nothing about Sickle Cell until we met. I arrived in New York City in the middle of the AIDS crisis and I'm well aware of what advocacy and activism has achieved in raising awareness and ensure care for people with AIDS. I'm here today angry at my city and state at the appalling lack of care for New Yorkers living with Sickle Cell. It is absolutely appalling and shameful that other states like North Carolina could provide $4.25 million specifically in their budget for the care of Sickle Cell patients or Pennsylvania $1.26 million. California in their most recent budget assigned $15 million for five treatment centers, and yet New York I hope in the next budget because of the advocacy from this New York City Council Chamber will provide $5 million to care for the 10% of the U.S. nation's patients with Sickle Cell who live here in the state and 18% in the city. We can do a lot, the city can do a lot. Many of us are aware for instance on the buses and on trains where we see awareness programs, and why can't we have an awareness program in our city transport system around Sickle Cell? [background comment] You know, the Mayor's Office in this city recently put out a call who should be honoring New York City women who have impacted the lives of people in the city. How about honoring and telling the story of pioneer women like Dr. Doris Wethers who just died at the age of 91. We're all in this together, you know, and I want to thank you, Council Member Dromm for taking up this initiative and the committee for this historic hearing today.

CHAIRPERSON LEVINE: Thank you so much for your outspokenness on this issue, and so many other causes of social justice. It's not surprising to see you active in this fight, but welcome to have your voice. Another incredible panel. Thank you very, very much, and we're going to continue now. I will call up Anthony Donovan, Doris Palonco, Ada Gonzalez, Marlene Smith, Sotilla or Sotia, and Mo—sorry, Molino Sophio. It's hard to read the handwriting. The someone to whom I was referring to there the last name I think is-- [background comments] Okay, I apologize. Couldn't read that. [background comments/pause]

COUNCIL MEMBER DROMM: Why don't we start right over here?

ANTHONY DONOVAN: [off mic] How do I turn it on. Thank you very much for this opportunity. It's a—it's a great honor to be listening to everyone today. I, um, my name is Anthony Donovan, Hospice Nurse, and I just want to recall 1974, 45 years ago working at Columbia Presbyterian, and walking into a room meeting a beautiful, intelligent young man who was going through an episode of something I had never heard of before, Sickle Cell, and I recall his courage today, and all of your courage. I have never seen such bravery and such courage with so much pain, and what was really tough for me, but nothing compared to with you all was I couldn't do a thing for him, and I pleaded with the doctors in 1974 to help me help this young man with his pain, and I got a story yes, about drug addiction. You know, how like we couldn't give morphine at that time. Well, he survived that episode. I got to know this man, a beautiful person, and his next episode he did not survive, but I'll never forget him, and I hope you who are struggling so long, it's-to me your ask is so small. $5 million. Are you kidding me. So, thank you very much for taking this on. Like I said, it's an honor and I greatly respect each and every one of you. Thanks.

COUNCIL MEMBER DROMM: Thank you very much, and thank you for your advocacy.

DORIS POLANCO: Good morning. My name is Doris Polanco. I'm a mom of two daughters and I'm—I was diagnosed when I was about three months with Sickle Cell S-C. When I wake up in the morning getting my two daughters ready for school. Most of the time I wake up with pain. Sometimes I can't even do their hair because my hands are swollen and I'm in so much pain that I have to just somehow just—sometimes I even knock on my neighbor's door and say hey can you please help me out. Like I can't even move my finger, but I'm sorry. I'm really not [laughter] but I just want to say that when we get that pain, it feels like someone is taking a hammer and is just whacking away at your limbs. In my crisis are usually in my arms and legs. For different people different places, but I just want to say I'm tired of waking up and waking up in the middle of the night and wondering if I'm the next one to die. In the past nine months I've lost three friends that had Sickle Cell and I'm tired. I'm tired of like waking up and just, you know, I even written letters to my two daughters just in case that which I—if I pass away, you know to explain to them the struggles that I went through trying—while trying to raise them. About three months ago I almost lost my life. It was my most—longest hospital stay. I was there for 42 days, and there were so many complications. One of them was my bone marrow just shut down and it was not producing any blood. So, the doctors had literally about 20 days to try and get back up and running before it was too late. Like numerous things happened throughout my hospitalization, but, um, [bell] Yeah, I almost gave up and I'm glad I didn't because my daughters need me, and I just want to say, please like why is it taking so long for us to get put in the budget? Like I feel that we don't matter to the city. You know, there are so many other states that gets so much more funding, and have less population of Sickle Cell, and New York City, which is one of the most concentrated places where Sickle Cell patients are, are getting what? $110,000. Like are you kidding me, you know. Like please just—I wish sometimes that someone would just pity us and just help. I though they were going to help me, (sic) It's been a long journey and I'm just—I'm just tired of waking up to someone else dying from this disease. So, please, please if you even—like help us out.

CHAIRPERSON LEVINE: Thank you.

ADA GONZALEZ: [off mic] Good morning. Hello. Hi, my name is ADA Gonzalez, and, um, I'm a White Hispanic female with Sickle Cell Disease, and I emphasize White Hispanic because in the Hispanic community there's not a lot of information about the disease, and it's stigmatized as an African-Americans disease when, in fact, there's many Hispanics, many Europeans with the disease. I am member of the Sickle Cell Patient Senior Network and I run a social media page called Sickle Cell 101 Espanol, and my purpose is to educate the Spanish community. I get a lot of requests from all over the world asking for donations, and they don't have those resources. So, the only thing I can do is give whatever information that I have received from the organizations here, the advocates here. I want to tell you a little bit about myself. When I was one years old—I was diagnosed at birth. I was a premie and diagnosed at birth. I'm 54 and when I was born, a year later I needed emergency colectomy surgery, because my spleen stopped working, and since then, I've had multiple blood transfusions. I've had multiple pneumonia, multiple bone implants. I've had gallbladder surgery.

I’ve had two hip replacements. Every milestone in my life my parents were told I would not live to see that milestone. I almost died three times when I was 1, when I was 20 and most recently now in April. I have been very fortunate, and I call myself fortunate because unfortunately hydroxyurea, which is the only drug [bell] that really helps people now, does not work for everybody, but I was part of the studies back in 1990, and it works for me. So, I went from being sick every three weeks in the hospital from being sick every three years, but still, you get sick and you still have complications. So, we need funding so that we can help the providers. We can help the hospitals give us the care that we need, and to help the advocates, to help families for those who are not as fortunate as I am to be able to move around to have care, to have somebody go to their homes and—and buy their food. Like she said, sometimes she’s so sick she can’t take care of her children to help her within things like that, and we don’t have the fundings for that. We don’t even have fundings for research. We are very blessed for those of us that that this one drug helped, but a lot of them here this drug does not help. So, we need something so that—we need research so that we can find the one specific drug that can help all of us not just one person. Oh, I'm sorry. Not just some people. Thank you.

CHAIRPERSON LEVINE: Thank you, Ms. Gonzalez, and your perseverance is—is truly all inspiring--

ADA GONZALEZ: Thank you.

CHAIRPERSON LEVINE: --and we're happy that you're here today to share your very important perspective. Thank you.

ADA GONZALEZ: Thank you.

CHAIRPERSON LEVINE: Ma'am. [background comments/pause]

MERLENE SMITH SOTILLO: Good morning. Thanks to the Health Committee for having us here this morning. My name is Marlene Smith Sotillo, and I am the President of the Sickle Cell Awareness Foundation Co-op International. I am originally from Trinidad and Tobago. I came here with two children that had Sickle Cell my son and my daughter. That picture described my son that passed away. Now, it's been a major struggle taking care of children with Sickle Cell, and having two children with Sickle Cell

I can tell you I had endless sleepless nights, but my love for kids for education and for information keeps me going forward every day. I am thankful that we are able to meet here again today. I've been running from state to state to try to get information and to get the help, and to get whatever is needed to come to New York to see if they could implement some of the changes or some of the things that's happening in other states that can be implemented here that we would have better treatment for our patients and for our children with Sickle Cell when my son go—he had – he died at 30 years old. He had gotten one crisis. He never had a crisis in his life before that time he passed away. That was his very first crisis. I took him to the hospital, and the doctor telling me he does not have Sickle Cell. He had not symptoms of Sickle Cell. When did he—when did he inherit this? Sickle Cell is something that you are born with, and if you don't understand what is wrong with someone, how are you going to be able to treat them, and they kept him there. Apparently they did not quite understand what to do for him and I lost my son. My daughter still struggles every day. You know, there's no funding for the things that we need.

There's no—you cannot do the electrophoresis testing because there is no funding. The patients when you get to a certain age, and you're not under your parents you don't have anywhere to go to get the funding or to get the care that you need. You go to the hospital and you have to wait like it seems forever to get care, and this—these things shouldn't be. I mean we have to go to through this for too long to get care for our families. It is heartbreaking, and I don't mean to, um, to be critical, but it's about time that something is done to help us We're suffering here. I have the Sickle Cell trait. I'm in and out of the hospital all the time for pain. My—my kidneys, my hear, my eyes. I mean we—we definitely have to do something, and I mean I implore you guys to, you know, take the time to invest in us because we really do deserve it. Thank you so much for your time. It's just a happy/sad day for me today just being here today. Thank you.

CHAIRPERSON LEVINE: Well, thank you, Ms. Smith. Your pain is really palpalble and we feel it. We share your pain for your loss. It must take a lot of strength to come here and speak out. I can't imagine what it took even to come here today, but it’s so important that you did because we need to hear your story and the story of your wonderful son and your other child so that we don’t allow this date to forget them, and the thousands of others who are suffering here. So, think you again for your strength, and you really are an inspiration.

MERLENE SMITH SOTILLO: Thank you.

CHAIRPERSON LEVINE: And it’s an honor to have you here.

MERLENE SMITH SOTILLO: Thank you.

CHAIRPERSON LEVINE: Okay. Sir.

MOLINO SOTERO: [heavy accent] Good morning, good morning. My name is Molino Sotero. I am the Vice President of the Sickle Cell Awareness Foundation also the other half of the President, and we do share this young man that who we lost in—in common. Eleven years ago this organization started and within that time while you are seeing this morning that it takes courage to come here, it’s elven years that we have been running back and forth and trying in Jamaica Queens with all the other organizations to try to put this fine property. (sic) Another thing I would like to say, I would like to applaud and acknowledge the Dr. Bellevue here this morning, Dr. Milton and all the other people here who is part of the Sickle Cell Organization that is here together this morning in support of these bills. We need funding. Sickle Cell needs funding and at this point in time still there are providers who don't understand the meaning of Sickle Cell. They still don't understand because recently where I am sill employed at the hospital we had a patient here there would remain for over 45 minutes in pain and they don't understand pain it with Sickle Cell. There are providers who still believe that pain with Sickle Cell is 1 to 10, 1 to 10 with pain with Sickle Cell doesn't make it—it doesn't work. So, here we are. We're here this morning. We are applaud that everyone is here this morning who is in the fight. We are glad that you will be able to acknowledge every one here today, and see what we are pushing for. We have been bac and forth with the legislators over the years to try to get funding to provide more for Sickle Cell patients. They are dying. We are losing them, and nothing is being done. So, we're here this morning one more time asking. I'm beseeching you guys try and help the Sickle Cell community that they at least live a better life. While they are still living a little longer, we would still ask that they go further in life. They would like to provide because when patients who have Sickle Cell in the community it's on everybody. It's on the community, it's on the family, it's on neighbors and everyone in the community. So we ask you this morning to please help us push it forward. Dr. Morgan is here. We have Ginger here, we have Dr. Bellevue here, and all the other folks that are here this morning we would like you again once more reach out to us. We are running for the past 11 years and we still intend to keep running it. Thank you very much.

CHAIRPERSON LEVINE: Thank you, sir, thank you, and again, the deepest sympathies for your loss and admiration for your strength in speaking out. It's—it's important to know that we have leaders like you, and your wife to serve as resources and a source of knowledge for the Council as we work on this. I'm very happy that we've connected with you and all of the great advocates in the room today, and I thank this outstanding panel and we do have one additional and final panel. Thank you again and I'll call up their names. It’s Gary Rissman, Epiphany Samuels and Nadine Baker, and I—I know it might feel liked the, um, the deas is a little bit sparse up here, but all this testimony is being filmed is being broadcast currently on the Council’s webpage. That video is going to be archived, and everything that you’re saying today is going to be transcribed, and the transcripts will be available online as well. So, your statements really will be seen and read far and wide. It really does have an impact, and we’re very glad that you’ve been part of this hearing today, and it looks like we have just two final witnesses. Would—would you be Ms. Samuels? Is that right? Okay, and then the other one is Ms. Barker.

NADINE BAKER: Yes.

CHAIRPERSON LEVINE: Okay, you want to kick us off, Ms. Baker.

NADINE BAKER: [off mic] Sure, my name is--

CHAIRPERSON LEVINE: [interposing] And if you can turn your microphone on. There’s a light.

NADINE BAKER: [on mic] Oh, okay. My name is Nadine Baker. I am the aunt of two young men who have Sickle Cell Anemia. I am also the sister of

Jacqueline Davis who is also an advocate, and I just want to say that this bill needs to be--Sickle Cell Anemia needs the funding that we'll be able to—that will help Sickle Cell patients live a quality—live a quality life. When you think about all the other diseases in this country that get millions and millions of dollars like cancer, like diabetes, Lou Gehrig's Disease, I mean the—the list goes on, and Sickle Cell I all the way down at the bottom when so many people are affected by it particularly, and it is true African-Americans and Hispanics, and there are also other groups in there, but that is the group that it mainly affects, and I can't help but ask the obvious. If millions of White people were dying from this disease, something would be done. This is one of the richest most powerful—well, it is the richest most powerful country in—on this planet. New York City is one of the richest cities. Well, it--New York City may be the richest city in, um, in America, okay, and in the world, and it just doesn't make sense with all the money that passes through this city, okay, all the money and the resources that are here for everything else that it can't be here for people who suffer from Sickle Cell. And it really is a disgrace and it’s also insulting and like I said, I can’t ignore the obvious When you think about who and what groups of people Sickle Cell affects. All lives matter, all lives matter, and the lack of funding what message is that sending? That people with Sickle Cell their lives don’t? Something’s really got to be done about that, and I say—and again, one of the richest countries in this world, the richest city in this world, that is unacceptable, and I hope that something will be done about it.

CHAIRPERSON LEVINE: Well, thank you Ms. Baker and—and as I think we mentioned earlier, this horrible disease is-is approximately 200 times more likely to strike a person of African descent which--

NADINE BAKER: Right.

CHAIRPERSON LEVINE: --is a person of European descent, and so it’s just simply disgraceful that we haven’t given this disease the adequate resources, the attention, the research, the education and outreach that’s needed. It’s indefensible, and the sad reality here is right. If this were a disease--

NADINE BAKER: [interposing] Yes, that’s right.

CHAIRPERSON LEVINE: --that affected millions of white people it would have been funded along time ago.

NADINE BAKER: A long time ago.

CHAIRPERSON LEVINE: It pains me to say that. It really does.

NADINE BAKER: And—and it still—and—and I really do feel that affects—it makes African-Americans and Hispanic people who have the disease, I think that makes them feel ashamed by the lack of awareness, by lack of care--

CHAIRPERSON LEVINE: No, no.

NADINE BAKER: --that a lack of funding for treatment.

CHAIRPERSON LEVINE: No patient should be-absolutely.

NADINE BAKER: [interposing] And I think we should make it a lot more proactive for their own cause my nephews included.

CHAIRPERSON LEVINE: The only-the only ones who should be ashamed are the ones who are not funding this adequately.

NADINE BAKER: Yes.

CHAIRPERSON LEVINE: Not the patients. Thank you, Ms. Baker--

NADINE BAKER: [interposing] Thank you.

CHAIRPERSON LEVINE: --and our final witness is Epiphany Samuels—Samuels. Please.

EPIPHANY SAMUELS: Hello. Thank you for having me here. My name is Epiphany Samuels, and I have Sickle Cell SS, and I am a Sickle Cell advocate and an adult with Sickle Cell. Where do I start. [laughter] I want—I want to ask you all to please invest in my life, an the--

NADINE BAKER: Yes.

EPIPHANY SAMUELS: --thousands of others lives. I, um, and thousands of other lives by passing this bill. I am 28 years old today. Well not today,

NADINE BAKER: Oh, well, thank God.

EPIPHANY SAMUELS: But [laughter] I am 38 years old, and I'm living today with Sickle Cell. Thank God, but my brother who had Sickle Cell wasn't as fortunate. When I was 15 he was 16 and he got Sickle Cell complications and due to lack of knowledge and—he was sent home in a hospital after not even being in the hospital and then returned back to the hospital, and died a couple of days after that. Because of Sickle Cell I am more susceptible for gaining other diseases and illnesses. So, I also have Rheumatoid Arthritis. I also have Lupus, Scoliosis, Brain aneurisms. There's a longer list, Asthma and with being an adult with Sickle Cell and not having the funding, am losing my—I'm losing my team of doctors to go—for them to go to other doctor—you know, for them to go to other hospitals to go take care of people with other diseases that have funding, and there should be no reason why I'm not getting treated because doctors don't want to stay where there is no money and--

NADINE BAKER: Uh-hm.

EPIPHANY SAMUELS: --I just ask you also--

NADINE BAKER: [interposing] Yep.

EPIPHANY SAMUELS: --to invest [bell] in our lives.

NADINE BAKER: In your life.

EPIPHANY SAMUELS: I my life. Yes. Thank you.

NADINE BAKER: Yes.

CHAIRPERSON LEVINE: What a powerful note to end on. You are amazing. This has been such an extraordinary hearing today. I want to thank everyone who came out to testify. To have this on the record is going to do a lot to elevate this disease here at the City Council, and—and statewide, and this is an important step in the process. We, hopefully will move soon to vote on the resolution in support of the legislation that's been spoke about today. And then to have a full vote in the City Council. So, this is the first step in the process, but an important one and I thank you all and this concludes our hearing. [gavel] [background comments/pause]

CERTIFICATE

World Wide Dictation certifies that the foregoing transcript is a true and accurate record of the proceedings. We further certify that there is no relation to any of the parties to this action by blood or marriage, and that there is interest in the outcome of this matter.

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Date September 14, 2019