CITY COUNCIL
CITY OF NEW YORK

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TRANSCRIPT OF THE MINUTES

Of the

COMMITTEE ON HOSPITALS JOINTLY
WITH THE COMMITTEE ON HEALTH

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HELD AT: COUNCIL CHAMBERS – CITY HALL

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Hospitals

Lynn Schulman,
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SERGEANT AT ARMS: Good morning. This is a microphone test for the Committee on Health joint with the Committee on Hospitals. Today's date is September 20, 2023. It is being recorded by Michael Leonardo in the Council Chambers.

SERGEANT AT ARMS: Test one, two. Test one, two. This is a prerecorded sound test for the Committee on Hospitals jointly with Health. Today's date is September 20, 2023. It is being recorded by Michael Leonardo in the Council Chambers.

SERGEANT AT ARMS: Good morning and welcome to today's New York City Council joint hearing for the Committees on Health and the Committee on Hospitals. At this time, we ask that you silence all cell phones and electronic devices to minimize disruptions throughout the hearing. If you have testimony you wish to submit for the record, you may do so via email at testimony@council.nyc.gov. Once again, that is testimony@council.nyc.gov. We thank you for your cooperation and at any time throughout the hearing, please do not approach the dais. Thank you. Chairs we are ready to begin.

CHAIRPERSON NARCISSE: Good morning everyone. We are about to start. [GAVEL] Alright, thank you for

coming in. Good morning. I am Council Member Mercedes Narcisse, Chair of the New York City Council Committee on Hospitals. In honor of National Sickle Cell Awareness month, my colleague Lynn Schulman, Chair of the Committee on Health and I are holding this hearing to discuss the state of sickle cell care in New York City.

Thank you all for joining us today to discuss a very important issue that effects over 3 million Americans and 100,000 New Yorkers. Our hearing today and the legislation being discussed are very personal to me since I am a carrier of the sickle cell trait and so is my daughter. My sister has the sickle cell trait and married someone who was unaware he had the sickle cell trait. So, they end up with two out of four children have sickle cell disease. Sickle cell disease commonly abbreviated as SCD, is a genetic disorder that affects the red blood cells causing them to become deformed and rupture.

This leads to a host of chronic and life-threatening complications including chronic pain, stroke, vulnerability to infections, pulmonary hypertension, vision loss, organ damage, and a significantly reduced life expectancy.

In New York City alone, over 1,000 individuals are living with SCD. While thousands more carry the sickle cell traits like myself, which is a carrier state of the disease. Often asymptomatic but still having the potential to be passed on to the future generations. Importantly, when both parents have the sickle cell trait, there is a one out of four chance with each pregnancy that the child will be born with SCD, making early detection and education vital. A 2008 report that CDC revealed that in New York State, SCD occurs in approximately one out of every 1,259 births, with staggering disparities among racial and ethnic groups.

For example, it affects one out of every 260 Black or African American births, compared to one out of every 10,209 White births and one out of every 2,714 Hispanic American births. Furthermore, further report approximately 80 percent of individuals diagnosed with SCD in New York State live in New York City while 76 percent of newborns with SCD were born right here in our city.

In New York State, the rate of SCD among Black residents is nearly ten times higher than the rate among White residents. And in New York City, the

rate of SCD among Black residents is nearly 15 times higher than the rate among White residents. Given the complexity of the disease, cost and specialized care tragically. Many who suffer from SCD do not live to see an age that most of us would consider the prime life, prime of life. In New York State, only 14 percent of individuals diagnosed with SCD life pass the age of 51 years. Underscoring the urgent need for intervention and support.

Despite this alarming statistics, sickle cell research and support services remain disproportionately underfunded compared to other chronic diseases. The National Heart, Lung and Blood Institute spend only $77 million annually on sickle cell research. Meanwhile rare disease such as cystic fibrosis receive 11 times more per person funding from the National Institute of Health. The national spending of cystic fibrosis was 440 times that of SCD. And cystic fibrosis has more than twice as many peer reviewed publications than SCD.

This is a blatant injustice. Sickle cell patients face extra pain, unbearable, frequent hospitalization and a shortened life expectancy, yet they continue to be overlooked when it comes to

research funding and resources. Access to quality healthcare, early diagnosis and specialized care for SCD is often limited for marginalized communities.

This result in delayed interventions, unnecessary suffering and a diminished quality of life for our residents. These racial disparities are unacceptable. The reflect longstanding inequities in our healthcare system that have denied people of color access to quality care. In fact, hospitals have only begun testing for sickle cell trait and SCD in 2006.

I want to share this story with you. I was born in Haiti and they tested me for sickle cell trait and I knew I was sickle cell trait because we talk about that in school as a little kid. When I came to America before I got married, I had to — the first question I asked my husband is, are you sickle cell trait? But in 2006, many, entire generations born before this time, may be unaware of their carrier status.

The statistics are suffering. With one in 13 Black or African American babies born with sickle cell trait and deciding the immediate need for early detection and education. SCD is not just a health

issue. It is a grave public health concern. It is our solemn duty to act promptly and decisively. Individuals and family grabbling with SCD deserve more than our sympathy. They deserve access to specialized comprehensive, uninterrupted care to achieve the best possible outcomes. Newborn, prenatal and preconception screening, genetic counseling, and education of patients, families, schools, and healthcare providers are not just preventive measure. They are lifelines.

To address these pressing issues, I am proud to introduce Intro. 968A which would establish sickle cell education and screening program with culturally sensitive and competent care along with a Resolution supporting two New York State bills, which is S1890/A2661, the Sickle Cell Treatment Act and S1839A/A2609 would seek to establish a sickle cell disease detection and education program with the NYS Department of Health and create sickle cell centers of excellence and outpatient treatment centers.

Together, this initiative could be game changing in increasing awareness about SCD and improving access to quality prevention care and treatment.

Ultimately, reduce health disparities, complications and mortality associated with SCD.

I look forward to hearing the testimony of all the witnesses who are joining us today, and we will take everyone's perspective into consideration as we continue our work on Intro. 968-A and Preconsidered Resolution. Before I conclude, I want to extend my thanks to Hospital Committee Staff including Policy Analyst Mahnoor Butt and Rie Ogasawara. My staff as well as data and Finance Analyst Julia Fredenburg, James Wu and Alicia Miranda for their continued work on this important issue.

With that, I will turn to Health Committee Chair Schulman for her remarks on today's proceeding. Thank you.

CHAIRPERSON SCHULMAN: Thank you Chair Narcisse. Good morning everyone. I am Council Member Lynn Schulman, Chair of the New York City Council Committee on Health. I want to especially thank my colleague Chair Narcisse for her opening remarks and for sharing her life experience. Because I think that's very important and I just want to make — I want to digress for a minute and say that the majority of the members of the Council have life

experiences that they bring to the table and that's why this Council is very influential in what goes on in the city. So, I want to thank you Chair Narcisse for that.

I also want to thank my colleagues in the Administration for joining us today for this important discussion on sickle cell disease. I want to acknowledge the members we're joined by, Council Member Ariola, Council Member Menin, Council Member — remotely Council Member Moya, Council Member Barron. Okay, before I begin — oh I said that.

Sickle cell disease is an inherited blood disorder caused by a mutation in the protein of red blood cells, which are responsible for carrying oxygen throughout the entire body. Because it is a disease of the blood, there can be numerous complications such as strokes, organ failures, infections and severe pain.

Pain with sickle cell disease is not only common but also excruciating and tends to worsen as patients get older. The disease is also the most expensive to New York State Medicaid. Data from the New York State Department of Health and compiled by NYU Langone shows that in 2021, majority of patients

admitted to hospitals for sickle cell complications were on Medicaid with an average cost of $18,000 per admission. The financial burden for those suffering as well as the burden on our healthcare system is undeniable. The most recently available data shows that the total hospitalization course associated with sickle cell disease were estimated in almost $500 million in 2004 and is likely up to at least $1 billion in 2023, yet New York State has cut funding for sickle cell care by about 66 percent over the last 20 years. Those suffering from the disease deserve high-quality and cost-effective care.

The emotional, physical and financial burden that sickle cell puts on individuals and families is significant, from the cost of ongoing medical care to the challenges of navigating insurance coverage and hospital visits.

I look forward to hearing from members of the public on this issue, as well from the Administration on how the city is supporting New Yorkers with sickle cell disease and how the Council can help support these efforts. I want to conclude by again thanking Chair Narcisse as well as the Committee Staff for their work on this hearing.

Committee Counsel Chris Pepe and Sara Sucher and Policy Analyst Mahnoor Butt as well as Danielle Glants who is the Finance Analyst. I also want to thank my team Jonathan Boucher, Seth Urbana(SP?) and Kevin McAleer and I'll turn it back over to Chair Narcisse.

CHAIRPERSON NARCISSE: Thank you Chair. Like we just said today before it's personal. So, we're going to hear from Dr. Rivlin for being here and thank you and I will pass it on to anyone, no nobody else online. So, I'll pass it on. Thank you.

COMMITTEE COUNSEL: Hi, we will now hear testimony from the Administration Dr. Kenneth Rivlin and Dr. Toni Eyssallenne. I apologize if I mispronounced your name. Before we begin, I will administer the affirmation. Panelists, please raise your right hand. I will read the affirmation once and then call on each of you individually to respond. Do you affirm to tell the truth, the whole truth, and nothing but the truth before this Committee and to respond honestly to Council Member questions? Dr. Rivlin?

DR. KENNETH RIVLIN: Yes.

COMMITTEE COUNSEL: Dr. Eyssallenne?

DR. TONI EYSSALLENNE: Yes.

COMMITTEE COUNSEL: Thank you. You may begin when ready Dr. Rivlin.

DR. KENNETH RIVLIN: Thank you. Good afternoon Chairpersons Narcisse and Schulman and the members of the Committees on Health and Hospitals. My name is Kenneth Rivlin and I am the Director of the Division of Pediatric Hematology and Oncology at New York City Health and Hospitals Jacobi.

I am joined by Dr. Toni —

DR. TONI EYSSALLENNE: Eyssallenne.

DR. KENNETH RIVLIN: Eyssallenne, thank you. Deputy Chief Medical Officer at New York City Department of Health and Mental Hygiene. Thank you for the opportunity to testify regarding access to sickle cell care in New York City. Health + Hospitals is proud to provide high-quality care to all New Yorkers, including those affected by sickle cell disease. Historically, with support from the City Council to the first comprehensive sickle cell centers in the nation were established at Health + Hospitals in the 1980's.

To start, I would like to commend the Committee for prioritizing sickle cell disease. As highlighted

in the National Academy of Science, Engineering, and Medicine's 2019 Report, addressing sickle cell disease, a strategic plan and blueprint for action. Sickle cell disease is a microcosm of how issues of race, ethnicity, and identity come into conflict with issues of healthcare.

Despite being recognized by the federal government as a disparity disease, sickle cell disease receives limited resources and attention compared to other healthcare priorities. Health and hospitals is committed to improving the lives of those affected by sickle cell disease. As frontline providers, we see the inequities in patients experience, quality of care and health outcomes for sickle cell patients and are actively working to change this.

Today, I will share information on our current services — on the current services Health + Hospitals provides in regards to sickle cell disease and the work we are doing to improve the caring outcomes from those living with sickle cell disease. We are proud to share that our system is a national leader in sickle cell disease, tackling patient and provider education, research and quality improvement to ensure

those with sickle cell disease can get the best possible care.

Health + Hospitals is one of the largest providers of sickle cell care in the nation. We have six New York State designated hemoglobinopathy centers that provide services for children identified with sickle cell disease and trait by newborn screening. This is at Lincoln Hospital Jacobi, Metropolitan, Elmhurst and Kings County and two comprehensive lifespan centers at Kings and Queens.

In addition, our 11 hospitals provide state of the art acute care and ambulatory centers across our network can ensure prenatal testing, genetic counseling and social services. Approximately one-fourth of the 10,000 individuals living with sickle cell disease in New York State touch our system each year. Additionally, Health + Hospitals partners with community-based organizations to offer patient support groups through New York Hospital Jacobi, Queens and Kings County. These meetings are held over Zoom and extended to those with sickle cell disease across our entire system.

Our community health workers partner with local organizations to provide community outreach, to

provide education outreach to the community, and sickle cell disease services. Systemwide, Health + Hospitals has implemented procedural changes to better serve those with sickle cell disease. These include developing a sickle cell navigator in our electronic medical records to guide best practices. Early stigma training for ED staff and partnership with community-based organizations, a sickle cell advocacy tool. Hydroxyurea training for medical staff and providers and establishing the use of individualized pain plans, all pain protocols for all our emergency departments.

In addition, Health + Hospitals Office of Population Health has created a quality improvement learning collaborative using Project ECHO, Extensions for Community Health Outcomes model. Project ECHO is an internationally recognized tele mentoring innovation that leverages telecommunication technologies to move knowledge. The collaboration supports efforts to improve health outcomes and experience with patients with sickle cell disease. Focusing on the goal such as standardizing emergency room pain protocols and stigma with production.

Health + Hospitals is also a member of various procedures, initial networks working to advance the treatment and care for sickle cell disease. We are a designated member of the National Alliance of Sickle Cell Centers, an organization that recognizes systems that provide high-quality comprehensive care. H+H is also a member of the American Society of Hematology Sickle Cell Disease Clinical Trial Network, whose goal is to accelerate progress in the development of new treatments. Out of the 20 member consortiums, we are the only public hospital system. Being a member allows us to provide patients with the opportunity to participate in clinical research and provide our patients a voice in how this research is being done.

Health + Hospitals is part of the health resources and service administrations, Northeast Region Sickle Cell Treatment Demonstration Project. As the New York State lead, we are working to eliminate inequities in sickle cell care through quality improvement initiatives, such as increasing the use of disease modifying drugs, improving sickle cell trait counseling, establishing pediatric to adult transition programs and connecting unaffiliate

patients to our medical home using community health workers.

Other initiatives include decreasing the stigma of sickle cell disease in the emergency department through collective impact with our community sickle cell community-based organizations and utilizing individualized pain plans in emergency departments.

I am also happy to share that Health + Hospitals was the only center in the country to receive a prestigious grant from Health and Human Services Office of Minority Health for the years 2020 through 2023, to increase the use of a disease modifying drug hydroxyurea, through a shared mental model and valued based payments. Hydroxyurea has been shown to decrease the chronic vascular damage that occurs in sickle cell disease, increase the quality of life and decrease mortality.

But less than 50 percent of eligible patients use this medication. The goal of this grant was to increase its use by ten percent, by having all clinicians, ED primary care and hematologists help support patients hydroxyurea clinical decisions. Health + Hospitals is appreciative of the attention

being given to education, treatment and outreach towards sickle cell disease in New York City.

Thank you to the Committee for the opportunity to testify and your continued support for Health + Hospitals. I'm happy to answer any questions that you have.

CHAIRPERSON NARCISSE: Thank you doctor for being here and thank you for the work that H + H is doing. I appreciate that. Uhm, sickle cell patients in New York, right? We know is a lot. How many patients receive treatment for sickle cell disease or sickle cell anemia last year? Can you disaggregate this data to reflect race, age, uhm, borough, neighborhood and commodity? Comorbidity, sorry? Comorbidity, sorry that word got my tongue twisted. Okay.

DR. KENNETH RIVLIN: I can tell you about what's happening at Health + Hospitals. We follow approximately 1,200 patients with sickle cell disease within our system. And by following, I mean to see twice in a period of 18-months.

Uhm, we uhm, the majority of those patients are African Americans.

CHAIRPERSON NARCISSE: What's the number? Can you break it down?

DR. KENNETH RIVLIN: Yes. Between 85 percent and 90, in that range. I don't have the exact number. It's like 88, 86 percent are Black Americans and about 15 percent are Hispanic Americans.

Nationwide the number is about 90 percent Black Americans about ten percent Hispanic. The difference is we see a large — in our center, we see a larger Hispanic population.

Uhm, age-wise, it's about uhm 60 percent are adults and about 40 percent are children. The numbers in our system, we follow about 700 adults and about 500 children. Uhm, I'm sorry —

CHAIRPERSON NARCISSE: Borough-wide, like borough and neighborhood?

DR. KENNETH RIVLIN: So, the majority of patients are in Brooklyn, then followed by the Bronx.

CHAIRPERSON NARCISSE: Not surprising because that's where Black people mostly and Hispanic live right?

DR. KENNETH RIVLIN: Yes.

CHAIRPERSON NARCISSE: How many newborn babies were diagnosed with sickle cell disease, sickle cell anemia or sickle cell trait when tested last year?

DR. KENNETH RIVLIN: All infants born in New York State are tested for sickle cell disease and as a biproduct of that, sickle cell trait. About, I don't know the number for last year, about 250 individuals are born with sickle cell disease in New York State in a year.

CHAIRPERSON NARCISSE: Can you repeat the number again?

DR. KENNETH RIVLIN: About 250. It's about one in 1,100 births in New York State have sickle cell disease.

CHAIRPERSON NARCISSE: How many patients overall were diagnosed with sickle cell disease, sickle cell anemia or sickle cell trait? You said you don't have the number last year?

DR. KENNETH RIVLIN: I don't have the exact number for New York State for last year.

CHAIRPERSON NARCISSE: Okay.

DR. KENNETH RIVLIN: Okay, the number over the past uhm —

CHAIRPERSON NARCISSE: You know that was one of the problems for us because the last data that we had uhm was 2008.

DR. KENNETH RIVLIN: The data for sickle cell disease is a problem, right? We have no national system tracking this. We, as part of the sickle cell National Alliance of Sickle Cells, are creating databases to be able to track sickle cell disease across the nation. So, we have a database called Granddad that centers the part of the National Alliance of Sickle Cell Centers used.

We are also part of the ASH Clinical Trial Network and we submit the identified data from our system to be able to understand nationally what's going on with sickle cell disease. Information about the births for New York State for sickle cell trait and disease can be gotten from the New York State Department of Health, and that number can be gotten per year. That number is tracked.

CHAIRPERSON NARCISSE: Uhm, I use my words wisely. I feel like if it was a disease that is uhm kind of another race, it would have been — numbers would have been there because we see the statistic. Folks don't even get to live up to the age if they're lucky to age 50 right here in New York City and New York State. And uhm, we're talking about $1 billion of dollars budget, $200— you know and yet uhm we have

so many Black folks and Hispanic living among us. And yet the diseases that are affecting them, it seems like irrelevant in when it comes to investing in addressing inequities in our healthcare system.

So, me as the Chair of the Hospital Committee, affected by it. I have the trait, so you know how I am looking at the statistic as well and it's not pleasant.

DR. KENNETH RIVLIN: So, everything you're saying is correct and it's historically correct. Back in the 70's, the Black panthers used to say that if sickle cell disease was a Caucasian disease, we would have a cure by now. I'm not sure I agree with the cure by now. It's a difficult thing, disease to cure but the priority has always been level.

So, in the 1970's there was a classic paper called, "Sickle Cell Disease High Prevalence, Low Priority." And that has not changed, so that's why I'm so happy to be here before your Committee because you're prioritizing Sickle Cell Disease.

Historically, in the 1980's, the Sickle Cell, the prioritization of sickle cell disease helped the creation of two comprehensive sickle cell centers.

So, it's something that working together, we can make a huge impact.

CHAIRPERSON NARCISSE: Hmm, hmm, I really truly believe we came a long way because right now I'm sitting here as the Chair of Hospital Committee in the City Council and I have you willing to say what it is, so that means we're making progress. That's why I still believe that New York City is a great city. So, we can talk about things that uhm, nobody going to kill us when we get out, so we're making progress and we're going to make sure that we address the inequities.

And I have my partner here sitting next to me, you know to address the inequities and seeing the progress we made, that give me hope and I hope we don't go backward, we go forward. So, that's what I have to add to this.

Sickle Cell trait in New York City — I mean, what is the current prevalence of sickle cell disease and sickle cell trait in New York City? And how it evolved over the past decade? Can you provide an overview of newborn screening program for SCD and SCT in New York City? Are there any recent developments and improvements in the screening process?

DR. KENNETH RIVLIN: All infants born in New York State are tested for the disease and trait. Uhm, what we do with that information for disease is well defined. Uhm, New York State has developed the very comprehensive system to identify and get into care, all children identified with disease. What we do with trait has not been standardized and one of the quality improvement initiatives that we are just beginning to implement, just beginning to test, is how we provide trait information.

So, we're working to ensure that all patients get standardized education about sickle cell trait within the Health + Hospital system. We're also, New York State has just created a system whereby if you were born in New York State and you're a teenager, you can reach out to your doctor or to New York State directly and get your trait identity, okay? So, we're trying to through quality improvement, trying to establish that as part of the program. We're only testing it in one of our institutions and we're going to try to learn how it works and what the problems are and how to do it. Does that answer your question?

CHAIRPERSON NARCISSE: Close because we still have a lot of investment to do and I'm counting on you to push for New York State in general to address this.

Uhm, how does DOHMH and H + H support individuals living with SCD in terms of managing their condition, accessing medication and addressing complications? Can you provide details on specialized treatment centers and/or clinics within the H + H and DOHMH Network for SCD patients?

DR. KENNETH RIVLIN: I'll start with Health + Hospital systems. We have six state of the art designated hemoglobin —

CHAIRPERSON NARCISSE: Six?

DR. KENNETH RIVLIN: Six New York State designated hemoglobinopathy centers that provide comprehensive care to children identified with — that have sickle cell disease. We have two lifespan sickle cell centers across our system that provide comprehensive care to adults. All 11 of our hospitals can provide acute care for people with sickle cell disease and all our ambulatory centers can provide genetic counseling testing etc. for people that want the information.

And uhm, patients with sickle cell disease get good primary care within our ambulatory centers.

CHAIRPERSON NARCISSE: Thank you. What are the current management options that are offered to sickle cell patients who present with acute or chronic pain? What factors are used to determine whether a patient will be prescribed pain management medication? Can you actually give me some data to this to reflect race, age, and borough neighborhood? And I have a follow-up question too at once. How opioid medications prescribed or used in hospital setting? Are none opioid options offered to patients? What are the current guidelines that inform the use of prescription of opioid base medication? Are there guardrails in place to prevent the exacerbation of the opioid crisis?

DR. KENNETH RIVLIN: Uhm, complicated question. I can break it down into a couple pieces that I can answer and if you have further questions, I'll get back to you. Uhm, we have established the use of individualized pain plans in our center. Can I say that all our patients have that individualized pain plan right this second? No. This is what we're working to do. This is our Quality Improvement

Initiative and uhm, the individualized pain plan that we've designed here is consistent with the national objectives for pain management.

I can also say that as part of the National Alliance of Sickle Cell Centers, Health + Hospitals created something that's going to be used nationally and that is, the patients preferred profile. So, how does a patient in the Pain Plan, there's a comment to reduce the stigma of sickle cell disease of how the patient wants the doctor — what the patient wants the doctor to know about them.

So, that originated Health + Hospitals and is now going to be part of the future national pain plan that's coming out in 2024. That's one part. So, ideally we'd like to have every patient with an individualized pain plan. If they do not have an individualized pain plan, there should be a good quality protocol used in our EEd's and we just through our quality improvement efforts, established that all 11 of our hospitals are using a national state of the art pain protocol in EED's. Using opioids and other disease pain relieving drugs in the system.

So, we have with regards to uhm, other types of pain management, it varies by the skills of the doctors providing the care.

CHAIRPERSON NARCISSE: Uhm, when I asked for the data, like in race and age and stuff because it's very important because I used to be an ER nurse and I did not have all the training we talk, so we came a long way. So, thank you again if that is what's going on right now because uhm, one other thing in the ER I used to do triage and you have to really actually take it out of the person that comes with unbearable pain to tell you that it's sickle cell. Sometimes it takes a long conversation to get to the sickle cell and many of them seen by others that they're a drug addict. And meanwhile it's a disease the person is dealing with.

DR. KENNETH RIVLIN: So, I can imagine nothing worse than being an African American male coming to the ED in a pain crisis. We are working through that. Are we perfect at that? No but we're working to educate our providers with partnership with the community-based organizations that are behind me to train physicians about the stigma of sickle cell disease and to train them that uhm, it's a horrible

disease and the patients are coming. And if you make a mistake with regards to over medicating, it's not your role. It's role to believe the patients, so.

CHAIRPERSON NARCISSE: So, the education is very important for all parties involved of treating patient of access to anyone with sickle cell or sickle cell trait.

DR. KENNETH RIVLIN: Coming from the moment they hit EED from the unit assistant to the triage nurse to the providers, hospital staff, environmental health, all need that type of education not to perceive sickle cell patients as drug seeking. I wish it was perfect but the education that uhm, the education is being standardized part of our EED's is just beginning and should be improved. It also is being used as the model. So, if we're successful within our system, it will be used as the model for the sickle cell treatment demonstration project in the northeast.

CHAIRPERSON NARCISSE: Yeah, what are the most common complications that are observed in sickle cell patients in New York City? Sickle cell patient susceptive to episode of pain, frequent infections, acute chest syndrome, pulmonary hypertension, organ

damage and other various type of painful complication. Do hospital records distinguish between sickle cell patients and non-sickle cell patients when individual report experiencing these symptoms.

DR. KENNETH RIVLIN: Uhm, yes, we do our best to separate out. There are different types of sickle cell disease. We are collecting that type of data on the patients and we're trying to decrease these complications. So, hydroxyurea decreases the complications, decreases acute chest. We're trying to ensure that all our patients get transcranial doctors that decrease stroke. Hydroxyurea also decreases stroke, so we're trying to make the changes necessary and ensure that this is the standard of care we're providing.

CHAIRPERSON NARCISSE: You know I was waiting for hydroxyurea to talk about it if the patient in especially Kings County and the underserved community have access to that because that can help.

DR. KENNETH RIVLIN: The answer is it's the as you mentioned the National Heart, Lung, Blood Institute. It's the recommendation that all patients with hemoglobin SS or S beta thal Zero receive this

medication. As part of this Office of Minority Health Grant, we have created educational tools and are ensuring that our hospitals for pediatrics that all our physicians in the ED, in primary care pediatrics and hematologists of course know and utilize this medication, and that the hematologist monitor the complications.

CHAIRPERSON NARCISSE: Uhm, before I continue with the question I want to recognize Council Member Brooks-Powers that's with us. Anybody else? Okay online. Okay, uhm, so blood transfusion is one of the most critical treatment for patient with SCD. How has the ongoing blood shortage has impacted care for the people with SCD?

DR. KENNETH RIVLIN: We have been lucky that we prioritize sickle cell disease and our patients on chronic transfusions for sickle cell disease. I have not noticed any problem with the New York Blood Center behind me.

We also have worked to do blood drawings within our hospital system or highlighting sickle cell disease in the New York Blood Center, which is somewhere behind me can attest to that.

CHAIRPERSON NARCISSE: Uh, I'm going to go backward a little bit. Can you list the centers again?

DR. KENNETH RIVLIN: So, the Pediatric State Designated Sickle Cell Centers; let me pull my papers so I don't misspeak. Uhm, Lincoln and Jacobi, which are in the Bronx. Harlem and Metropolitan in Manhattan, Elmhurst in Queens and Kings in Brooklyn. Those are the pediatric centers and the uhm true comprehensive adult centers or lifespan centers are at Kings County and at Queens. Kings County has been since the 1980's and Queens since it became a true comprehensive center around 2016, 2017.

CHAIRPERSON NARCISSE: Are there out of pocket costs of hydroxyurea at H + H facilities?

DR. KENNETH RIVLIN: No, the cost for hydroxyurea should be provided by the insurance companies etc.. So, Medicaid should provide it without any problems. I haven't noticed any specific out-of-pocket costs.

CHAIRPERSON NARCISSE: Healthcare access and disparities. What are the specific challenges faced by individuals and families affected by SCD in terms of accessing healthcare, specialized treatment and support services within H + H network.

How is DOHMH collaborating with the healthcare providers and community organization to reduce racial disparities in SCD diagnosis and care?

DR. KENNETH RIVLIN: Uhm, can you just quickly, the title of the question?

CHAIRPERSON NARCISSE: Oh, what are the specific challenges faced by individuals and families affected by SCD in terms of accessing healthcare, specialized treatment and support services within the H + H network?

DR. KENNETH RIVLIN: H + H, we do a wonderful job for pediatrics and we are working very hard on a national problem with sickle cell disease and that is the transition and transfer to adult care. So, for pediatrics, I think we do an excellent job. I think we do a pretty good job. We built into our system transition education. The problem both within New York City, within the Health + Hospital Corporation and nationally is providers providing uhm to sickle cell patients.

Patients will get care at comprehensive centers that is state of the art. They will get good care with any hematologist provider in the clinics, but those centers, they are comprehensive, have limited

resources and that is the limited number of social workers, nurse practitioners, the support staff. And that is just a financial issue across the country. This is a national problem.

CHAIRPERSON NARCISSE: Things are complex when it comes to underserved communities and yeah.

TONI EYSSALLENNE: Yeah, hi. I just wanted to add to what my colleague was saying in terms of you know what DOH is doing. Specifically, we share your passion for eliminating inequities that are occurring across the city. When it comes to medical care in general, we're talking about educating clinicians, the history of discrimination within the medical field and applying our equity lens to clinical practices and the importance of cultural sensitivity and so, all of those things are at the forefront of what the Health Department is doing specifically for healthcare in the city. And so, we are in support of everything our H + H colleagues are doing.

CHAIRPERSON NARCISSE: Uhm, I'm going to jump to DOHMH but before I do so, I want to recognize Chair Joseph joining us on Zoom.

Alright, data collection reporting that we have. When was the last time sickle cell's related data was

collected in New York City? According to our finding, the most recent data was published in 2008. That is more than 15 years ago. Why has there been no reporting on sickle cell disease in recent years?

TONI EYSSALLENNE: Thank you so much for the question. Just like we were talking about before and I wanted to get this opportunity to explain the data a little bit better. Collecting sickle cell data is really complex because the data is not regularly collected by the state or federal government. Additionally, various aspects of the data including data on the number of patients treated, disaggregation that you were asking about earlier, the diagnosis. They are held by different insurance and hospital entities with limitations on what data can be accessed to ensure that there is patient privacy.

As a result, the data available to us is limited. With that said, our agency utilizes the most recent New York State SPARCS Sickle cell data as well as CDC's Sickle Cell data to inform our understanding of this issue. So, let me explains SPARCS real quick. It's the Statewide Planning and Research Cooperative System. SPARCS, also known SPARCS. It is an all

payer, data reporting system operated by the New York State Department of Health.

SPARCS collects patient level data on patient characteristics, diagnosis and treatment and it's an important source of data for conditions just like sickle cell since it allows us insight into hospital utilization on patients with sickle cell. However, it does not include information on sickle cell incidents, prevalence or treatment outside of the hospital setting. And there is a lag, there is a day lag between one to three years.

CHAIRPERSON NARCISSE: I'm going to turn it over to Chair of Hospitals, I mean Chair of Health because we need more information. So, I'm going to pass it onto my colleague Chair Schulman.

CHAIRPERSON SCHULMAN: Thank you. I'm actually going to ask uhm, my colleague Selvena Brooks-Powers has another appointment, so I'm going to give over the questioning to her and then I'll take it back.

COUNCIL MEMBER BROOKS-POWERS: Thank you Chairs. I just have three brief questions. First, if I'm an adult looking for comprehensive care for sickle cell anemia, how many facilities are there outside of Manhattan that can provide that care? Next, what

size of hospital or medical facility is required to support comprehensive care for sickle cell anemia. And can you talk about the cure for the sickle disease? What makes it so risky? And is there progress being made toward making this cure more widely available?

DR. KENNETH RIVLIN: I'm sorry, I didn't jot your questions down. Can you repeat your first question?

COUNCIL MEMBER BROOKS-POWERS: Absolutely. If I'm an adult looking for comprehensive care —

DR. KENNETH RIVLIN: Okay.

COUNCIL MEMBER BROOKS-POWERS: Okay.

DR. KENNETH RIVLIN: So, for uhm comprehensive care, you can work with community-based organizations to find out what's going on. So, outside of Manhattan, we have Kings County, a long historical center that provides comprehensive care, Queens Hospital. There is other medical centers that would be part of the National Alliance of Sickle Cell Centers. In the Bronx, you have Montefiore Medical system has a comprehensive center. In Manhattan you have Columbia and Mount Sinai. In Brooklyn, it's Kings is the best, so there are ways to do it. I would ask my community-based organizations. I would

ask community-based organizations where they would recommend you go.

So, those first questions, did I answer it?

COUNCIL MEMBER BROOKS-POWERS: I'm piecing and counting how many you said but you know it would be interesting to know in terms of beyond Queens Hospital. Are there any more in Queens besides that?

DR. KENNETH RIVLIN: I do not know the answer to that. I deal with the Health + Hospital system and I deal nationally with the National Alliance of Sickle Cell Centers and I do not remember another center. I could be wrong. Your second —

CHAIRPERSON NARCISSE: This is unusual. Usually we have this panel answer the question, now since you have a thing, I guess I'm going to allow you one second to say it loud and clear, so she can hear you.

[INAUDIBLE 00:54:11-00:54:28]

CHAIRPERSON NARCISSE: Okay.

[INAUDIBLE 00:54:28-00:54:40]

CHAIRPERSON NARCISSE: Okay, so thank you because she wanted to hear you. Usually we don't do it that way. No, now we can't. We have to go back until it's your time. Alright, no more from you. We're going to continue this way. Thank you.

DR. KENNETH RIVLIN: Your second question, I'm sorry.

COUNCIL MEMBER BROOKS-POWERS: No problem. What size of a hospital or medical facility is required to support comprehensive care for sickle cell anemia?

DR. KENNETH RIVLIN: I, just speaking in general, I don't think there is a size that defines it. It really is the support staff. There is a National Alliance of Sickle Cell Disease guidelines on what makes up a center of excellence and there are some — I'm here to testify about Health + Hospitals. There are rural centers with just a few patients that provide excellent care. You just need the support staff to do it.

COUNCIL MEMBER BROOKS-POWERS: Do the Gotham Centers often have support for that, because I know in Rockaway for example, we have a Gotham Center that's going to be opening up that is Health + Hospitals. So, would that be a facility that offers sickle cell anemia services?

DR. KENNETH RIVLIN: I believe they can provide good primary care for the patients and they can refer the patients to sickle cell experts within the system.

COUNCIL MEMBER BROOKS-POWERS: Thank you.

DR. KENNETH RIVLIN: And I'm sorry, your last question was about curative therapies and uhm, I just think it's important to touch on that and the potential for curative therapies is real and will happen in most of our patients' lifetime.

The problem with curative therapies is your need to do a bone marrow transplant or gene therapy and that requires us to suppress the persons system. We need to get rid of the bone marrow that they have and replace it or with either a donor's bone marrow or a gene modifying. And that immune suppressive therapy is life threatening.

COUNCIL MEMBER BROOKS-POWERS: Thank you and thank you Chairs.

CHAIRPERSON NARCISSE: Thank you.

CHAIRPERSON SCHULMAN: Alright, so I want to recognize that we have Council Member Feliz has joined us. So, I want to ask does DOHMH have any working mechanism to collect data on SCD and SCT?

TONI EYSSALLENNE: Thank you Council Member for your question. As I said, as I mentioned earlier, the collecting system for this disease is complicated and it's complex and we have to depend on SPARCS data

in order to see exactly what's going on with the state of that disease. We don't specifically collect it. We use what the state has available. And then there's a one-to-three-year lag.

CHAIRPERSON SCHULMAN: Is there anything that can be done to make that an easier process?

TONI EYSSALLENNE: I would have to get back to my colleagues. It's something that we think is of high priority and understanding how we can get this data and leverage this data to help our community.

CHAIRPERSON SCHULMAN: Because if we need to ask our colleagues in the state legislature or if there's anything we can do, we'd like to be able to do that. So, if you could do that for us.

TONI EYSSALLENNE: I will definitely take that back.

CHAIRPERSON SCHULMAN: Okay, thank you. Uhm, since 2006, all U.S. hospitals are required to perform newborn screening to identify health risk factors in infants. Newborn screening typically includes testing for a core set of conditions, which may include metabolic disorders, genetic diseases, endocrine disorders and hemoglobinopathy, such as sickle cell disease and thalassemia. Since SCD and

SCT related data has already been collected at birth by New York State, how do DOHMH and H + H utilize that data to make decisions for SCD care at your facilities?

DR. KENNETH RIVLIN: All infants identified with sickle cell disease are connected with a state designated hemoglobinopathy center.

So, disease it's a required entry into care. Our goal is to see those patients identified within two months and start them on penicillin prophylaxis and begin the education of the families within that time period. So, for Sickle Cell Disease, we have a good system of care.

TONI EYSSALLENNE: Yeah, for the DOHMH, we don't provide those clinical services but we use that data to inform the work that we're doing across health inequities in New York City and figuring out ways to decrease those inequities across the city.

CHAIRPERSON SCHULMAN: What initiatives are in place to increase public awareness about SCD and SCT?

TONI EYSSALLENNE: Yeah, thank you for the question. We are trying to — we are currently in an exploratory phase and having conversations with our CBO's and FBO partners and trying to uplift their

concerns in the way that we are actually going to address these issues in the city.

CHAIRPERSON SCHULMAN: If we can, if you can share with us what you put together to do that, I know that we want to — that's something that's really important and in line with that, uhm, you know maternal health is obviously an issue and do we talk to uhm, pregnant people about SCD and SCT and when they come in for prenatal care?

TONI EYSSALLENNE: Right, you want to take that?

DR. KENNETH RIVLIN: Yeah, uhm, the American College of Obstetrics recommends that all patients, all pregnant women get tested for hemoglobinopathies.

CHAIRPERSON SCHULMAN: Okay.

DR. KENNETH RIVLIN: And that's just part of routine standard care now.

CHAIRPERSON SCHULMAN: Okay, uhm, how much does DOHMH spend on SCD each year, do you know?

TONI EYSSALLENNE: I do not have that information.

CHAIRPERSON SCHULMAN: If you can get that for us?

TONI EYSSALLENNE: I can ask.

CHAIRPERSON SCHULMAN: Yeah, that would be great. What are some — in line with that, what are some of your funding streams for SCD and how do you distribute it between treatment, educational efforts and research? So, if you have to get back to me, you can just do that. I want to recognize Council Member Gutiérrez has joined us. Uhm, I'm going to ask you about the legislation that we have that we're talking about today. So, there's a Resolution and an Intro. So, Resolution 711, what are your thoughts on our Resolution in support of Senate Bill 1839A and Assembly 2609 and S1890/A2661 the Sickle Cell Treatment Act?

As you may know, S1839A/A2609 aims to establish a sickle cell disease detection and education program within the New York State Department of Health to provide information and resources to individuals at FCD, their families, healthcare providers and the general public. Whereas the Sickle Cell Treatment Act, if passed, would establish five sickle cell centers of excellence and ten outpatient treatment center staff by specialists dedicated to serving SCD patients. If passed, how would these two state bills impact SCD care in New York City?

DR. KENNETH RIVLIN: I defer to the State Department of Health. Let me start. We uhm, I'm sorry. We tremendously support the prioritization of sickle cell disease. As representing New York City Health + Hospitals, I can't comment on specific legislation, so I will defer to New York State, New York City.

CHAIRPERSON SCHULMAN: And do you expect the Center of Excellence to be under the per view of H + H I presume, so.

DR. KENNETH RIVLIN: We would love to have the Center of Excellence but uhm.

CHAIRPERSON SCHULMAN: Okay, I'm going to hand over some more questioning to my colleague Chair Narcisse. Thank you.

CHAIRPERSON NARCISSE: Thank you and before I get into it, I have Council Member Barron. He cannot speak because we don't have the quorum but I want to say I'm going to say what to say. He would like this body to acknowledge that we should not discuss sickle cell without discussing the work of the Black Panther Party to raise awareness and fight for individuals living with SCD. And I think you did Dr. Rivlin. So, uhm, we appreciate his work as well for bringing

it to the forefront and I appreciate the fact that you yourself mentioned it.

So, uhm, Intro. 968A, a Local Law that would amend the Administrative Code of the City of New York in relation to a professional education program and public outreach campaign regarding sickle cell disease. What are your thoughts on this bill, its implementation and impact? Can you outline any anticipated challenges or barriers in implementing the education program and outreach campaign? And what strategies are in place to overcome them?

TONI EYSSALLENNE: So, the Health Department supports efforts to raise awareness and promote more equitable access to treatment for patients with hemoglobinopathies including sickle cell. And while the disease disproportionately affects Black New Yorkers and other people of color, Black New Yorkers also disproportionately face these barriers to accessing that appropriate care.

Professional and medical education is also important when addressing healthcare access barriers for people living with sickle cell disease. And as a clinician, I believe we need a well-rounded approach and that’s what we’re talking about today. To ensure

that patients have the information that they need to advocate for themselves. That also includes ensuring that clinicians are trained to the best of their abilities to address the best care for patients effected by these hemoglobinopathies.

CHAIRPERSON NARCISSE: So, if passed, how do you plan to implement this program? Do we have any similar programs that we can use as a model?

TONI EYSSALLENNE: As I said before, we are in the exploratory phase, working with our colleagues to make sure that we're uplifting the community as we're making our programs.

CHAIRPERSON NARCISSE: It is sad, right to talk about this right now. While when I was a kid, we talk about in the 80's when Haiti was in 80. Unfortunately it's not right now. But that's another thing. What is the expected timeline for ruling out the education program in launching the Public Outreach Campaign and what milestone and benchmarks will be monitored to track progress?

TONI EYSSALLENNE: Yeah, like I mentioned, we're in the exploratory phase but I will get back to you.

CHAIRPERSON NARCISSE: Hmm, I think I had some other question before I pass it on to the Chair. Oh,

somebody have a question. Perfect, so before I continue my question, I think uhm, our Council Member has a question or some question.

COUNCIL MEMBER GUTIÈRREZ: Thank you Chairs and thank you both for hosting this joint hearing today on this really important topic. I want to be very honest, the first time I ever heard about someone having sickle cell disease was left eye from TLC and it was something that growing up I learned obviously acutely impacted Black people and people of color and so, I think this is such an important hearing and certainly support both pieces of legislation. And I'm sorry I'm late so maybe you addressed this and I missed it but my understanding is that there's very limited funding to support — is it testing specifically for sickle cell disease in communities? Or is there a time when it can be detected in people and it's not being detected? What is the process like to evaluate whether someone I guess and upon reading the report, I understand they can carry the trait versus the disease. I'm speaking about the disease. At what point are we made aware that someone has the disease?

DR. KENNETH RIVLIN: If you're born in New York State, you're automatically tested for the disease. If you present to physicians with anemia, it will be part of the workup for — so if you're born outside of New York State, you uhm, and you present with anemia, it's part of the workup for anemia.

COUNCIL MEMBER GUTIÈRREZ: Understood and how soon in New York State, is that — how early in someone's life are they tested for this?

DR. KENNETH RIVLIN: They're tested at birth, so either the day of birth or a day later and the results come back within a week.

COUNCIL MEMBER GUTIÈRREZ: And in these instances, are pregnant people known to carry the trait? Is there a different kind of testing that happens or it's only testing that you can do once the child is born?

DR. KENNETH RIVLIN: Testing can be done at any time in a persons life. It's a genetic disease, so we can easily test by doing a simple hemoglobin electrophoresis and determine whether you have the trait or not.

COUNCIL MEMBER GUTIÈRREZ: Right but they — you're not — there is no — the testing happens once

they're born. You cannot test like in other certain blood work while a person is pregnant, that you can test for to rule out?

DR. KENNETH RIVLIN: We test pregnant women to see if they have the trait to offer them reproductive counseling about it. New York State is trying to set up a process and we are trying to do it as a quality improvement initiative here. So that if you want this information and you were born in New York State, the trait information can be given to you. If you are at reproductive age and you want to be tested, any primary care provider can provide that testing.

COUNCIL MEMBER GUTIÈRREZ: Wonderful, thank you. And then my next question is, in adults who are out of New York State growing up in New York State come here and test for anemia. You mentioned then at that time they can be tested for — only if they present with anemia.

DR. KENNETH RIVLIN: You'd only as a provider, you would only test someone for if you think they have the disease.

COUNCIL MEMBER GUTIÈRREZ: Right.

DR. KENNETH RIVLIN: The clinical history is consistent with the disease; you would do the

appropriate testing for it as a hematologist or a primary care doctor.

COUNCIL MEMBER GUTIÈRREZ: And is there a time that is — so and I understand that. Total respect what you're saying. I guess what I'm trying to ask is are there instances where adults age may not be aware that they have anemia because I know it's an excruciating, it's a painful disease to live with and you know the I guess the notion that's out there about women that are often times not believed by doctors that are in pain. Black people that are often in pain and not believed by doctors, so I'm just trying to get to like the technical. So, adults with anemia whether they're in New York State or not, know they have it or are there instances where it's not life threatening, that they could just move about and not know they have it?

DR. KENNETH RIVLIN: There are people living with sickle cell disease that do not know they have it. I can tell you personal incidents of one of the parents of a patient who was diagnosed with sickle cell disease and he was a physician. He had sickle cell disease. He had a mild variant of sickle cell disease. He was a physician and never knew he had

it. So, after we tested the child, we offered testing to the family.

COUNCIL MEMBER GUTIÈRREZ: Okay, thank you. I know my time is up but I'll stick around. Thank you so much Chairs. Thank you.

CHAIRPERSON NARCISSE: If you have — do you have extra questions?

COUNCIL MEMBER GUTIÈRREZ: Yeah, I guess and this is what we're here for today, right is to like make sure that we ultimately pass legislation that is uhm responsive to this need. In those instances where people are living with it, I guess what are some of the things that we can be doing? What are the support that physicians and our institutions need to really raise awareness about why at this point, isn't not just safe to ensure that everyone gets tested for this early? Like it's just uh in the way that we test for all type of illnesses when someone is young. Is that not a step towards better data, better management potentially?

DR. KENNETH RIVLIN: I understand your question and it's if you have symptoms, you should be tested. If you are asymptomatic, then it's a personal choice on what you want to do. So, having sickle cell —

COUNCIL MEMBER GUTIÈRREZ: But if you're asymptomatic, you don't even know right? You don't know to like let me talk to my physician to specifically test for this.

DR. KENNETH RIVLIN: If you're anemic, you get — your known to have anemia. A person does a CBC, they see your hemoglobin is low. They look to see if your blood cells are high. They're going to make the diagnosis. Those would be rare instances.

COUNCIL MEMBER GUTIÈRREZ: Okay.

DR. KENNETH RIVLIN: And it becomes a personal decision between you and your physician how you work things out.

COUNCIL MEMBER GUTIÈRREZ: Okay and so, my last question sorry Chair. Uhm, like the numbers that we have, are the numbers not staggering enough for us to fill that testing for — or is the testing very expensive? Like, what I'm trying to say is like there are a small population but still instances where people might not know they're anemic right? And that's really like the impetus for testing for this disease. But is it more cost effective that we're not just testing everybody across the board or is it because we just don't — there is just not a

high enough need I guess is what I'm trying to understand. For me, not being an expert, not being in this field, it feels like the safest thing to do with the information that we have is to test everyone. You know but if that is not cost effective or not realistic, I guess that's what I'm trying to get. Because what you're saying is, someone has to be under some kind of you know have health insurance to be testing frequently, right? Know that they're anemic and then potentially have symptoms to even think to ask, what do I have? Because if they're asymptomatic, then this is not like a line of questioning that they're asking.

TONI EYSSALLENNE: Yeah, I wanted to jump in. Thank you. From a primary care perspective, I'm an internist and a pediatrician, so I get to see both of these and I'm not a specialist so this is — you're really raising something important in terms of what we're doing for primary care and how we're accessing primary care and that's another one of the places where DOHMH is working on. Because people like your saying, people shouldn't be walking around not knowing their status.

COUNCIL MEMBER GUTIÈRREZ: Right.

TONI EYSSALLENNE: And the only way they're going to know if they are asymptomatic is if we can get our hands on them, right? If we can get them in front of a primary care doctor, so that we can do an assessment and actually say, hey, something is not right. We might not feel okay but something is not right, let's check these things.

And so, part of the reason why folks are not potentially walking around without having knowledge is that we can get our hands on them in the primary care space and there are inequities with that, right? In terms of who is going to get access to primary care space. And so, we have to like get to the root of the problem, right. Sickle cell is a symptom of all of the things that we're talking about here, which is the fact that you know Black folks in New York City are disproportionately affected and have disproportionate access to care and that's where we have to focus on it because then they won't walk around with anemia that they don't know.

COUNCIL MEMBER GUTIÈRREZ: That's right, that's right and so I guess thank you. Thank you both. This is not an attack.

TONI EYSSALLENNE: No, no, no, we love the passion. We love the passion.

COUNCIL MEMBER GUTIÈRREZ: I guess it's in your — in like in your expertise is it not just better to test every young person, every kid, is that not realistic enough?

TONI EYSSALLENNE: So, if you have sickle— and you can jump in on this part but I'm going to say from the primary care perspective, if you have first of all, you should be looking for the newborn screen right? The newborn screen is going to tell you if they have sickle cell or not, right? So, this is the point that H + H is making. That we're like hey, you know everybody who's born in New York State, everybody who is born in New York City, you're going to get a newborn screen and we should know.

If for some reason that didn't happen for you and you get into a primary care office for example, we naturally screen everybody for everything. Are your kidneys okay? Is your liver working? And are you anemic. These are routine testing that we normally do. If you're not anemic there's no reason to go down that road. If you are and even slightly anemic, then there's a process to actually investigate.

What's the cause of that anemia? And so, there is blanket testing for newborns, so that's correct. When it comes to identifying folks who may be asymptomatic, the asymptomatic is going to come with an indication of anemia and at that point, there's a workup that needs to be done from there.

COUNCIL MEMBER GUTIÈRREZ: Okay, thank you.

CHAIRPERSON NARCISSE: And I thank you, that's what I was about to touch because you are anemic and uhm, even if you have sickle cell trait, you still are anemic. There should be signs for it but the thing that we're doing right now is having the discussion and educating folks because if you're born before you start testing, which is 2006, which is killing me by knowing that. But those generations prior will be tested and the thing about it, one of the things that I observe myself knowing, dealing with sickle cell trait, it just sometimes the test is done but the conversation is not being passed to the families, to the father. It's later on they find out the child has sickle cell trait and I'm going to tell you, if I did not ask, I would not have known for each of my child because I was interested to know because knowing that I have sickle cell trait.

Those are the things that we need to have the conversation and engage in school, in everywhere especially when we're talking about the underserved community. We're not focusing on preventive care in those areas in the Black communities and Brown communities. My district don't even have a healthcare center. We don't have any hospitals, so the teaching has to be done throughout for people to be knowledgeable and taking the step that they need to take for themself and their family and I do believe in preventive care and it's not just like it is something. It is cost effective. We're spending $1.6 million for female and at least average $1.7 million in a male. So, now if you do preventive care, people know early.

First of all, they would not engage in having children more likely because when you're looking at the chart, it's specific. It tells you what's going to happen to you. So, I have a chart here, which I encourage everybody that's listening and following, if you don't have that chart, pull out the chart to see that is the real statistic. Numbers you know tell you. Like when you have a father with a trait and you have a mother normal, which I call — I don't

want to say the word normal, they still use normal. I will say the one without the sickle cell trait and sickle cell disease when I say normal.

So, their children, two will be born with the trait and two will be born without anything. But when you have the father with the sickle cell anemia and you have the mother without anything, which is what we call normal, so all the children will be born if they have four kids. I based it on four, sorry. I'm basing the statistic on four.

So, the four will be born with the sickle cell trait and if you have the father with the sickle cell disease and the mother with the sickle cell disease, all the children, if you have four will end up with a sickle cell disease.

So, those are the things that people need to know. That chart should be posted and for folks to open their eyes, even their ER, they should have a literature where people know what's going on. If you're pregnant especially when you have folks getting pregnant, they need to know their risk. They need to know what they're dealing with and even before they get married, even in the place where they get the license, should have those information for

people to think. Because it's really a disease that really no one wants to have a child. Because I'm telling you, my niece, two of my nieces have sickle cell disease.

So, coming back, I had some questions that I want to ask. Uhm, oh the chart? Oh sure. No, you can have it. Yeah, uhm, so coming back to culturally sensitive care, what kind of cultural sensitivity training do NYC H + H nurses, doctors and other healthcare providers currently receive? If so, what content is covered and how healthcare practitioners held accountable for failing to provide culturally sensitive care for their patients. There are channels for patient report is not appropriate or discriminating behavior, discriminatory behavior. Are you working with any community-based organizations or other non-profit to spread awareness and increase access to SCD care? I'll stay with that before I continue because I don't want to create too much confusion.

DR. KENNETH RIVLIN: With regards to culturally sensitive training, that's part of staff education within Health + Hospitals. With regards to uhm, what happens when a patient doesn't get that? We're

trying to train patients. One of the new tools we just developed is advocacy training about sickle cell disease. We're trying to train patients how to advocate for themselves about it. Those are the two I remember. I didn't remember the last question.

CHAIRPERSON NARCISSE: Especially folks that are serving in high minority area populated Black folks and Hispanic to be well trained around that. Funding, how much does H + H spend on SCD each year? What are some of your funding streams for SCD and how are you distributing it between treatment and research? Do you want me to repeat it?

DR. KENNETH RIVLIN: No, I uhm, I don't have those answers. We'll have to get back to you about that. With regards to research, that's a separate topic and we participate with clinical trials because it's important for patients to have the opportunity to participate in research. So, we're part of pharmaceutical drug trials. We are part of the national. We're part of the American Society of Hematology Sickle Cell Clinical Trial Network. So, we want our patients to have the opportunity to participate in research. So, that's a separate topic and the funding doesn't come from patient care.

CHAIRPERSON NARCISSE: So, H + H don't have direct like numbers you can tell me that you're spending on that?

DR. KENNETH RIVLIN: I can't. I'm a primary care. I'm a hematologist. I'm a country doctor in many regards. I don't know that financial information.

CHAIRPERSON NARCISSE: So, I'm guessing that we're going to get it if we follow up email?

DR. KENNETH RIVLIN: Yup.

CHAIRPERSON NARCISSE: Alright, uhm, so I want to say thank you for your time because since we have another hearing coming, we'll keep you all day. As you know it's personal. Like they said in Jamaica, you have a skin in the game. So, uhm, thank you so much for your time and we're looking forward to addressing the inequities in New York City. Thank you so much.

TONI EYSSALLENNE: Thank you.

COMMITTEE COUNSEL: Thank you Chair. We will now turn to public testimony. We will be limiting public testimony today to two minutes each. For in-person panelists, please come up to the table once your name has been called.

For virtual panelists, once your name is called, a member of our staff will unmute you and the Sergeant at Arms will set the timer and give you the go ahead to begin. Please wait for the Sergeant to announce that you may begin before delivering your testimony. For our first panel, we would like to call Thomas Moulton, Milton Wade, Yadira Navarro, Michael Landau, and Dr. Kusum Viswanathan if they are available on Zoom at this moment. We will be calling the five of you for this first panel. Thank you.

Sorry, I would also like to note that written testimony can be submitted for up to 72 hours after the close of this hearing. Thank you. Can Mr. Thomas Moulton please go first. And can you please recap what you said earlier about the Centers that are available in Queens.

THOMAS MOULTON: Yeah, so uhm I'm Dr. Thomas Moulton. I've been treating, I have treated sickle cell patients for over 30 years in the Bronx. I left practice primarily because hospital administrators have destroyed at least three programs that I put together for sickle cell disease and it became very frustrating for me to be able to continue to try and

give quality care when administrators would not support the programs.

I want to try and address some of the things that have been brought up. Yes, there is testing for sickle cell disease in pregnancy but the interpretation of those results is completely lacking. I had one patient come in who was told; the mother was told she did not have sickle cell trait and so therefore she could not have a sickle cell disease patient. Her son came in diagnosed with sickle cell disease because she had beta zero thalassemia. And so, doctors do not understand that sickle cell disease is not one genetic type of disease but there are four main different types and because they don't understand that then that mother was given false information during her pregnancy. We do have a medical model for sickle cell disease. That's the Sickle Cell Day Hospital. That's been known since 2000, that's been published and that was published right here in the Bronx from Montefiore Adult Hospital.

So, I would encourage that all of city hospitals have a day hospital instituted in them. Access to care is limited. Patients with sickle cell disease

have silent stroke, not just overt stroke, so 13 percent of patients will have had a silent stroke by age one. And 27 percent will have had a silent stroke by age 6. So, these effect how patients are able to perform in school and as they get older, to be able to help hold a job and be able to actually figure out how to come in to keep their appointments and that sort of thing. So, sickle cell disease patients are thought of. Adult sickle cell disease patients are thought of as being bad patients because they miss their appointment and part of that is because they can't remember. And if you know an adult person then sends them out you know from there, you know just discharges them from their clinic because they're "bad patients" but they don't realize that they have a reason.

You know if you were a Down Syndrome patient, you wouldn't expect them to be able to perform adult duties like anybody else, but they expect that from sickle cell disease patients. We've had a sickle cell bill in the New York State Senate since 2011 and we've been lobbying since 2011 and even though we can prove that the care that would be coming from that bill would save them more money than the expense of

the bill, there has yet been no movement in terms of the bill and I have very little hope in terms that the New York State legislature will move any forward on any of the bills that are now before them.

We've had newborn screening in New York State since 1975. 2006 is when all 50 states have had newborn screening. The problem with Newborn screening you know as Dr. Rivlin said, is that the disease get into care but the trait do not necessarily get educated. If they do get educated, they get educated when they're babies and not educated when they're teenagers and they could get out and get pregnant.

So, many of the mothers forget to tell their children, oh, you have sickle cell trait and then all of a sudden now they have a child with sickle cell disease because they're not continuing in terms for their education with that.

The other thing is that again, when we're doing — you know immigrants are not necessarily tested. They come into primary care; their primary care doesn't necessarily test them. If they do, they may test them wrong. There are two different types of testing for sickle cell disease. Sickle tests only tells you

whether or not you have traits, like the S trait, it does not tell you whether you have any other trait that will give you a chance for sickle cell disease.

I've had one mother who knew that she was sickle cell trait, wanted her father being tested —

CHAIRPERSON NARCISSE: Can you try to wrap it up because we have to leave the room?

THOMAS MOULTON: Okay. Uhm, so the military tested him wrong. He had C-trait so they now have two children with sickle cell disease because the father was given the wrong test. Research can be difficult because patients don't enroll in programs. Many of the sickle cell disease research studies have been closed for lack of enrollment. So, this is also an issue in terms of the sickle cell population does not trust the medical environment.

I have many more things I'd be very happy to talk to you afterwards but there are many more other issues in terms of sickle cell disease and particularly in New York State, which happens to be the second most popular state for sickle cell disease.

CHAIRPERSON NARCISSE: Thank you.

COMMITTEE COUNSEL: Thank you so much. Could we please have Milton Wade speak please.

MILTON WADE: My name is Milton Wade. I am a retired New York City School teacher and I'm also a sickle cell trait carrier.

I have a personal story to tell, not only my own various illnesses that I've endured throughout my life currently with edema and Stage II kidney disease but most importantly, I'm an advocate because on the 25th of September will mark two years since my son lost his life to Renal Medullary Carcinoma, which is a disease, an aggressive kidney cancer caused by sickle cell trait status.

When he was born I was told that I had nothing to worry about. He only has the trait and I'm here advocating for not only for sickle cell trait but for sickle cell disease because it's personal for me. I've had students with sickle cell disease as a teacher but I also have been a sports coach and I see a need for the education within the school system. Currently, the public-school athletic league ironically, they do have on the medical form questionnaires for sickle cell trait and sickle cell disease and also, on the website, it's hard to find,

is there for exertional sickling, which comes from someone having sickle cell trait and exertional sickling means that's when red blood cells sickle and uhm, that person will go into an emergency uhm, close to being — if they do not receive aid, they would die on the field.

The sad part is as a coach, I had asked myself why am I not trained? And I've been coaching as a New York City public school high school coach for 27 years and we're not taught anything. So, even if a child was having an exertional sickling episode or the fact that someone on my team puts down that they have sickle cell disease or sickle cell trait, I wouldn't know how to respond.

And there are 46,000 kids per year in the New York City Public Athletic League who participate in sports and there's a void that needs to be filled. Not only that, what comes back to the hospital when we talk — when the question was asked by that doctor about the statistics, uhm I do know that minority organization or NIH funding, the timespan actually, they do not have to report till September 29th. So, you're asking for data that they really do not have yet and that's in defense for them.

Now, in regards to what needs to be done, I'm here advocating, this is my — I've been on this journey for three years contacting my state representative, congressional representative and uhm, you know it gets sent to File 13, which no one hears about. So, uhm, I'm well aware of sickle cell disease and the trait and Ms. Narcisse, I'm working with one of your assistants and afterwards there's some amendments and changes given to the proposed of how it's written where I believe some changes need to be made in the wording. But most important, what needs to be done as far as getting and gathering data, it has to come from the State Legislature, which will require a sickle cell trait registry, which was needed. So, the Health + Hospital corporation cannot get information because it's not provided, then we have to talk about the private hospitals. Are they participating? But if you have a sickle cell SCT registry or any registry with sickle cell disease where moving forward, the physician could keep track of that child and parents are aware and by the time they reach the reproductive age, then genetic counseling could be in place.

So, we all talk about newborns but I'm an immigrant. I came here from Jamaica in 1965. And so, uhm this city is a city of immigrants. It's an influx of immigrants. So, we're putting everything within a framework of just newborns but what about the new arrivals? The parents and what we have — kids who are now flown in from different states who are now part of our public education system, flown in from Florida or Texas wherever they came from, they should not be excluded from the group.

And also, sickle cell disease and sickle cell trait, it's not just a Brown and Black thing. There are Caucasians, Asians and we're talking about the entire fabric of New York City. And so, it's not just one community, it's the whole community of New York City that should be involved in this educational process.

And until the education is in place, we're going to keep having babies born with sickle cell trait. The average lifespan is 50 years and this has been going on since the public law 92294, which was passed by the — it was a public law passed by New York's Congress and Senate. That's 52 years nothing has been done. The importance of this law is it will be

the first one in the nation, in the nation that deals with sickle cell trait and genetic testing in someone. And I'm here advocating for that because with this said, I now have a platform to take to other states and other legislatures, so I can make my case and make sure to see if this could become a national debate more so than just a local issue because it's global and it's national but more important again, in five days it will be the second anniversary of my son's passing. And I had to deal with that and carry that burden. Why didn't I know? Could I have made a difference if I had known? And that is the trauma that I'm carrying.

CHAIRPERSON NARCISSE: I am dealing with my two nieces and I understand it's scary and that's the reason that I say that I have hope in New York City and I'm here to talk about it and testify and I understand as a nurse. I'm a registered nurse as well, so sorry for your loss and uhm, you can make the difference nationally and you have a friend here. We're going to make sure that people listen.

MILTON WADE: Thank you.

CHAIRPERSON NARCISSE: Thank you.

COMMITTEE COUNSEL: Thank you for your testimony. Uhm, next we can please call Yadira Navarro. Thank you.

YADIRA NAVARRO: Yes, thank you. Hello, my name is Yadira Navarro and I am the Director for New York Blood Center. Thank you Council Member Narcisse, Council Member Schulman and the City Council for your support of New York Blood Center and the Community Blood Supply.

We appreciate the opportunity to support this important bill alongside three of our sickle cell awareness partners and are proud to serve the community with the highest quality blood and stem cell products over the last 60 years. NYBC has a world renown research institute known for its novel and innovative research positively impacting public health through the development of products, technologies and services with the humanitarian impact. And we're home to the largest, rare blood inventory serving patients worldwide.

The needs of the sickle cell community go hand and hand with the robust and diverse blood supply. One in three African American blood donors are a match for these patients. So, here representation

truly matters. Blood transfusions remain a critical treatment option for sickle cell disease with nearly 90 percent receiving at least one transfusion by the age of 20. As part of this proposed bill we're fully committed to our mission of collecting and providing precise match units for these patients and will continue to provide education training and information in our blood donor outreach programs. Our researchers will continue to focus on hematological disorders and are involved in pursuing discovery science programs centered on the development of novel treatments and strategies, including drugs and self-based therapies for sickle cell patients.

Currently, NYBC is in a blood emergency due to dangerously low blood supplies. The pandemic has devastated blood centers across the country and expose the vulnerability of our nations blood supply, showing the need for broad scale awareness and increase donations, as only two percent of the New York City population actively donating. New York Blood Center asks for your support of the proposed bill to provide the education and assistance needed to effectively support our sickle cell community. We

also support the need for accessibility to genetic testing to aid in the publics ability to make better, informed health and family planning decisions. A healthy and diverse blood supply is essential to the health of our sickle cell disease warriors; therefore we request the inclusion of education on the need for blood from all genetic makeups to ensure we have what is needed to endure this disease.

Additional details were submitted online for your review and thank you again to the Council on — excuse me, the Committee on Health and the Committee on Hospitals for your time.

CHAIRPERSON NARCISSE: Thank you.

COMMITTEE COUNSEL: Thank you for your testimony. Could we please have Michael Landau speak.

MICHAEL LANDAU: Thank you very much. I'd like to dedicate this — my presentation to Josephine Asisa(SP?), a colleague of mine in Uganda who passed away three weeks ago from sickle cell.

So, Madams Chairwomen and esteemed Committee Members, my name is Michael Landau, Chairman of CTI LifeHealth and the Founder of the CTI Foundation. Thank you for the opportunity of offering testimony to this very important piece of legislation. CTI

LifeHealth has built a digital healthcare ecosystem focused on the worlds underserved communities to democratize access to better patient experience in primary healthcare. We have started in Uganda in Africa where sickle cell is prevalent and I was shocked by the lack of treatment, support, research in sickle cell despite the overwhelming number of worrier births.

Sickle cell is the epitome of inequality and inequity in healthcare. Sickle cell is a dual recessive gene that both parents need to posses the trait, then there is the 25 percent rush and roulette chance of having a child with sickle cell.

Ashkenazi Jews have a similar and even more devastating disease called Tay Sachs, which is all but being eradicated because of the incredible efforts and leadership of Rabbi of Dorishorim and similar organizations that then ensure that potential parents get tested for the trait before marriage and having kids. It’s all about testing for the genes and testing for the trait and so, at CTI we have built the life registry as well as multiple cartoons to create awareness and education around the disease

and show it's hereditary and that no stigma should be attached to the disease of sickle cell.

It is critical that all people at risk, which is all people till the age of 45 or 50 or to whatever age people have children, get tested for the trait and that the city legislature plays its part in ensuring that all the insurances will cover the cost of the genetic testing or regular testing.

We have numerous resources available to our website at CTI Foundation and our website for the Life Registry. In addition, we have developed an app, which I'd love to speak to you about called, Life Blood, which is available on the Google Play Store and the Apple Store, which empowers patients with sickle cell testing as well as blood type testing and we have created several educational cartoons explaining the sickle cell that are available on our CTI You Tube channel.

In addition, CTI has developed a unique way to be able to collect data, all the questions that you were asking before about which facility can do what. We've built systems so far in Africa but we can build them here in New York very quickly and within weeks or months together with the Department, with the

Health + Hospital organization, you can be seeing data instantly, visually, and that can be available for all of the sickle cell warriors themselves, their carriers, their families and we built systems that really are available.

And so, CTI Life Health and the CTI Foundation remain committed to eradicating all sickle cell births by 2030 and we look forward to finding collaborative paths for empowering the value on sickle cell warriors of today with better access to knowledge and personalized healthcare. And working together with the City Council and hopefully with others around the country and around the world to go and literally eradicate sickle cell by 2030, the same way that in our community Tay Sachs is pretty much being eradicated through knowledge and through people caring. And that's the critical thing and you're caring and you'll make the difference. Thank you.

CHAIRPERSON NARCISSE: Thank you for your time. I appreciate it. And all the panel, thank you for the work that you've been doing and I'm looking forward to partnering with you to get going and making sure that we do the right thing by the people,

not only in New York City but the world that they're in because we have to lead by example. Thank you.

COMMITTEE COUNSEL: We have one more participant in this panel. So, if you could remain seated very quickly. Uhm, could we please have Dr. Kusum Viswanathan on Zoom participate. Please wait until a member of our staff unmutes you and the Sergeant at Arms sets the timer. Thank you.

SERGEANT AT ARMS: Your time will begin.

DR. KUSUM VISWANATHAN: Thank you. Can you hear me?

COMMITTEE COUNSEL: Yes, we can hear you.

DR. KUSUM VISWANATHAN: Yes, thank you. Thank you so much for giving me this opportunity to present. My name is Kusum Viswanathan, I'm a Pediatric Hematologist Oncologist. I'm right now the Chief Medical Officer of One Brooklyn Health at Brookdale Hospital Medical Center and also the Director of Pediatric Hematology Oncology and the Comprehensive Sickle Cell Program.

I represent today One Brooklyn Health Comprehensive Sickle Cell Programs at Interfaith Medical Center and Brookdale Hospital Medical Center. Both programs are in Brooklyn and they have a long

history of providing coordinated, family-centered, and comprehensive medical and psychosocial care to children and adults with sickle cell disease for more than fifty years.

As we all know, Sickle Cell Disease is an inherited disease, diagnosed at birth by newborn screening and patients can have recurrent, unpredictable pain crises that require hospitalizations and narcotic pain medications and they develop complications in organs like the lungs with acute chest syndrome, strokes leaving disabilities, silent strokes, gallstones, sudden enlargement of the spleen causing shock and death, enlarged heart, pulmonary hypertension, retinopathy of the eyes, avascular necrosis of the hips, kidney failure requiring dialysis, and tendency for severe infections, leg ulcers and priapism.

So, One Brooklyn Health has offering comprehensive care and in fact Interfaith was part of the cooperative studies and started doing this in 1978 from the NIH Cooperative Studies. So, what do we do? We follow up of newborn screening referrals and New York State has been reporting patients to us since 1975. We enroll them in the program, we do

individualized pain management programs, regular assessment for all of the end organ damage, and I won't repeat everything including transcranial Doppler testing, infection management, transfusion therapy —

SERGEANT AT ARMS: Time expired.

KUSUM VISWANATHAN: Hydroxyurea administration; disease modifying treatments like Crizanlizumab and Voxeletor, which were approved about three years ago, iron chelation therapy. We have referred 15 patients for a cure for bone marrow transplant and 14 of them were cured of the disease. We vote for you know renal counseling and education. Uhm many of these programs we were able to also do because we had grants starting in 1995 but these grants have been limited and they take into account a region. Like only one or two grants for a whole region and do not take into account that New York City has more patients than even entire other states.

CHAIRPERSON NARCISSE: So, please wrap it up.

KUSUM VISWANATHAN: So, I just want to say that tremendous
strides have been in made in the treating and preventing the complications of Sickle Cell Disease

in children and 95 percent of children now reach the age of 18. However, adults with the most severe forms of disease have a very short, much shorter life span and the lack of access to high quality comprehensive care explains the increased mortality rate. And many sickle cell programs lack funding for support services like social work and case management services which makes patients end up in the emergency room for care.

So, I'm going to end by suggesting we have participation in many clinical trials and have partnered with many community-based organizations to help our patients but we support the proposal to conduct professional education and genetic screening and public outreach campaigns. Over the last 30 years, we've conducted numerous outreach and education activities to be PTA, schools, faith based and community-based organizations, and we encourage people particularly of childbearing and teenagers to get tested to absolutely know their status. In fact, many of operations, they know your status. Do you know your sickle cell status?

CHAIRPERSON NARCISSE: Thank you doctor.

KUSUM VISWANATHAN: Yeah, okay.

CHAIRPERSON NARCISSE: Thank you. You can send us — you can email us all the rest of it. Thank you.

KUSUM VISWANATHAN: I will do that. Thank you.

COMMITTEE COUNSEL: Thank you so much to this panel. You can be seated now. Next, we'll be calling up Merlene Smith-Sotillo, Brendan Fay, Jason Crites, and Ginger Davis. I apologize in advance if I mispronounced your names. Merlene Smith-Sotillo, you may begin your testimony when the Sergeant starts the clock. Thank you.

CHAIRPERSON NARCISSE: Before you start, I have to remind everyone, since we have to leave the room, so try to tidy up first. Thank you. I appreciate it.

MERLENE SMITH-SOTILLO: Good morning everyone. My name is Merlene Smith-Sotillo. I am the President and CEO for the Sickle Cell Awareness Foundation Corp International. And I know that you guys have already talked about Sickle Cell, you know what it is, how it impacts you, so I'm not going to discuss all that again. I would just like to — today is a sad day for me, which as the young man said, my son passed away after we — I mean, we introduced the sickle cell bill in 2011, as Dr. Moulton was talking about and he's

not here today to see the progress that we have made so far with the Sickle Cell Bill.

So, I mean, I just want to ask you guys to s support the bill. I'm not going to go into all the details. I just want to say thank you for the opportunity to be here. Thank you kindly.

CHAIRPERSON NARCISSE: Thank you. Thank you.

COMMITTEE COUNSEL: Thank you very much. Uhm, could we please have Brendan Fay speak?

BRENDAN FAY: Sure. Good morning and thank you Council Members for this hearing. I've been here at other hearings in previous years. I'm here. I'm the spouse of Dr. Thomas Moulton and it was from Tom that I learned about Sickle Cell. I was already engaged in HIV and AIDs Awareness and so many others. I was appalled at my own ignorance and silence and stigma around sickle cell. And when I would be going on a date with Tom, he said I can't see you I'm going to a funeral parlor. On our self, we have a book with the images of children that he cared for who died through the years.

To me, they're beautiful New Yorkers whose deaths were unnecessary and reflect you know our lack of New York care. I just want to say there's so much that

we can do and in this city from the Department of Education to the Department of Corrections. Every school could have an awareness day. Posters: I look forward to the day when on a bus, shelters, and our trains there are posters about — I would like to see our city naming streets and tell the stories of the pioneering medical doctors. You know like Dr. Doris Louis Weathers. You know like Dr. Evette Francis Mack Bernette who dedicated their lives to caring for people with sickle cell. Everywhere I've gone and every single Council district, there are people waiting for leadership and action from this city and from Albany.

Tom and others have gone out and testified and it got pittance compared with California that can give $15 million for their citizens with sickle cell and other states. New York lags way behind. It's a disgrace. We need to do better. Today is a day of hope. When I saw Council Member and I check your bio. Nurse, I said, "Oh my God, at last someone that's not about a political career but how to use the city." We can do better. New York can and today is — I urge you of course to pass the Resolution and I hope that every single one of the 51 Council

Members enthusiastically signed up. I wish this place was packed with New Yorkers telling their stories. I was at the walk-in center; I apologize and a beautiful community of New Yorkers with pictures of their loved ones and passionately working for change and hope and healthcare. And that's what I came here today for. Thanks very much. We can do it.

CHAIRPERSON NARCISSE: Yes, we can and as you said the room to be packed, that's what's in my head. When I come in, I say something so important but it seems like people don't know the importance of it because we are having babies having babies with sickle cell and for generations to come, we're going to suffer from that too.

It's not cost effective and we can do better as the City of New York and I hear you. Thank you.

BRENDAN FAY: Okay and I just want to say from Rikers Island, the homeless shelters, I speak to people who are there that say — yeah, thank you very much.

CHAIRPERSON NARCISSE: I'm going to keep on talking about it. It's important. Thank you.

BRENDAN FAY: Thank you.

COMMITTEE COUNSEL: Thank you so much for your testimony. Jason Crites, please go ahead.

JASON CRITES: And you pronounced it correctly, thank you. So, my name is Jason Crites and I flew in at the request of the Sickle Cell Patient Network.

So, well, that was unexpected but maybe not, so but privacy and patient advocate. I spent 18 years at IBN where I was fortunate to work on some pretty interesting projects and bidding some things that also led to some of the things that were part of Watson Health.

So, part of what I'm advocating for is for every rare disease group to have their own registry that is ethically compliant that preserves the privacy of the patients and fixes some of the issues that we heard today around lack of proper data. Because without proper data, we in structured in the way that we can submit to the FDA for clinical trials, we have the same issues that we heard today.

But it has to be done in a way that's ethical. Where the patient is at the center. Has full control and visibility in what's done with their data at all times. A lot can stop right? And some of the advances that the rare disease groups have had

specifically around the registries, have really enabled additional resources to be brought to bear, including diagnostics, therapeutics and educational materials. As well as you know when patients — I mean when patients look like me, I get different resources when I show up in the ER and these patients have this information provided from their care providers as well as within the EMR that is not that complicated for us to have, especially within you know New York City.

We can affect change for when these patients present to the ED. So, there were more prepared statements but you know that's really what I'm advocating for and I also want to give awareness that Florida is actually already signed into law. Funding for registries and educations, and obviously the political climate is vastly different in Florida and that should serve as a wakeup call for New York and New York City that other states that aren't as progressive as New York need to catch up.

So, I'm available for any questions afterwards.

CHAIRPERSON NARCISSE: Thank you so much. I appreciate it and we're looking forward to continue working together. It's not just the hearing. I'm

looking forward to work with all of you to collaborate, to make sure that we address it once and for all. So, thank you.

COMMITTEE COUNSEL: Thank you so much for your testimony. Ginger Davis, please go ahead when the Sergeant starts the clock.

GINGER DAVIS: Good morning everyone. I'd like to thank Manhattan Borough President Mark Levine, the former Chair of the Health Committee here at the City Council who has kept up his support for sickle cell disease and requested this hearing. Thank you to Chairwomen Mercedes Narcisse and Lynn Schulman and to your Committees for doing this proposed amendment to the Health Bill to include Sickle Cell provider education, public education, genetic screening, and just kind of to echo things that have already been said.

I just wanted to know, should there be testing for everybody? The answer is yes emphatically. People should not be finding out during a pregnancy or after a child is born and the newborn screening comes back positive for trait or disease to hear about sickle cell. People should know so they can make informed choices and like our associate Michael

Landau said, people know that they have the trait and making informed choices about having children, whether they stay together or a couple or not, can eradicate over time, this disease. So, that's something that our organization Sickle Cell Thalassemia Patients Network and all the other sickle cell CBO's across this country and around the world want to do. We want to see the end of the suffering. It is so vitally important that this legislation get passed. That the whole City Council could be one member supported because the impact continue after 12 years of you know introducing legislation to the state to give us money to build comprehensive treatment centers across the state. It has remained dead on the floor. The money that we asked for has been gutted and for what's left over, we can't really do or be successful at what we're trying to accomplish like the state of California to provide comprehensive care throughout all life stages.

Right now, all we have is pediatric care. It's still being treated as a pediatric disease and we are losing lives after our young people transition out of pediatrics into adult care because the emergency room becomes their primary, rather than a cohort of

trained physicians, multi-discipline, keeping a person healthy, keeping them out of the ER. Not only that they impact to Medicaid and Medicare, which we constantly address in our legislation. We can prove or we have the data and Jason and Michael and their companies to help us emphatically show that comprehensive care not only will save lives, improve the quality of our community but lessen the impact to Medicaid and Medicare and take our families out of poverty because we are living in object poverty the way the system is now.

So, thank you very much for this legislation. Anything that you need us to do, we will be here for and I also want to say that all of our organizations and every member of our staff is HIPAA certified, project ECHO trained and we are able to do provider training as well as the healthcare professionals and our organization should not be left out of any process in this bill when it comes from provider education to public education, genetic screening and counseling, we should be there every step with the professionals. Thank you.

CHAIRPERSON NARCISSE: I thank you and yes, we do need comprehensive treatment everywhere for all

levels, not just newborn and I'm in agreement with you. And people have to have information so they can make an informed decision for themself and their family. So, thank you so much.

COMMITTEE COUNSEL: Thank you so much for your testimony and thank you to the entire panel for contributing. We will now be calling a Zoom panel. I believe that Ms. Candice Deler, Chanel Rice Purnell and Mabacke Thiam. Again, I apologize if I mispronounce your name. We call you to the next Zoom panel. In addition, we ask Quindoline Louis(SP?) and Zuliette Saleman(SP?) to also participate in the panel if they are in attendance but I don't know if they are.

In that case, Candice Deler, when the Sergeant starts the clock, please feel free to start.

SERGEANT AT ARMS: Your time will begin.

CANDICE DELER: My name is Candice Deler and I have sickle cell disease. My mother has the trait, my father stated that he didn't have the trait and uhm, not because he didn't want to be honest but because he was not educated, he did have the trait.

I am married and my husband does not have the trait but I have two sons that have the trait. So,

22 years ago, I founded Candice's Sickle Cell Fund Incorporated. We're a non-profit organization in the Bronx. We educate people about sickle cell disease and even though we do not have legislative path, we do the best that we can to give a patient with sickle cell disease quality of life. And what that means is that we provide scholarships. We've given out over $100,000. We provide messages for patients who are constantly in pain and need a break. We send families to Great Adventure. We send families to Sesame Place to make people feel normal for the day or for the week.

Whatever it is that we can do, we try to provide assistance to the families because there is not enough funding and there's not enough support and so, throughout all the boroughs, if patients are sent to us, we make them feel special.

We provide patients with catered meals after they come out of the hospital because a lot of times patients do not come home well. We are in the hospital for weeks and still come home and have to attend to our families and are not well still. So, we provide a week of catered meals for families to get back on their feet.

While we're waiting for legislation to be passed —

SERGEANT AT ARMS: Time expired.

CANDICE DELER: Please utilize our service and allow us to educate. We go into the schools. We raise awareness. We talk about trait testing. Utilize your CBO's. All of our CBO's that have been mentioned today work together. Please utilize us and allow us to make a difference while we're still waiting for legislative to be passed. Thank you for allowing me to speak today.

CHAIRPERSON NARCISSE: Thank you.

COMMITTEE COUNSEL: Thank you so much for your testimony. Next, can we please have Chanel Rice Purnell?

SERGEANT AT ARMS: Your time will begin.

CHANEL RICE PURNELL: Good afternoon everyone. Thank you for having me here. My name is Chanel Rice Purnell. I was diagnosed with sickle cell at birth. I currently attend Interfaith Medical Center, which is part of One Brooklyn Health Sickle Cell Clinic. I am here to advocate for the bill, as well as advocate for the reform of emergency room protocols across New York City. I am an adult living with Sickle Cell

Disease and often times I find that there is little to no transition for pediatric patients going into adulthood. Primary care doctors pretty much just do away with learning about sickle cell disease and often refer to us to go to a hematologist. And there are it's very like, very uhm — it's very difficult finding a hematologist that specialize in sickle cell across New York City.

So, often times the programs that we do have, do see pediatrics on through adulthood and often adults utilize their emergency room as a form of primary care doctors to get effective and equitable care.

So, I am advocating for a reform of hospital emergency room protocols across the board. Often times sickle cell patients are stigmatized going into the hospitals. You know they are often labeled as drug seeking. They are not able to get medication, which prolongs care, leads to blood transfusion, so on and so forth. So, and we can kind of like work towards advocacy in hospitals and emergency rooms with sickle cell disease. I think that would be a great form of change and also, work towards adult treatment with sickle cell because we are out here and often times we aren't counted in the numbers

because there's no one you know looking at us. Thank you for your time.

CHAIRPERSON NARCISSE: Thank you. Appreciate your time. Looking forward to continue the work. Thank you.

COMMITTEE COUNSEL: Thank you so much for your testimony. Mabacke Thiam, please feel free to start as soon as the Sergeant starts the clock.

SERGEANT AT ARMS: Your time will begin.

MABACKE THIAM: Hello everyone. I'm sorry. My name is Mabacke Thiam, I am the housing and House Community Organizer at CIDNY, Center for the Independence of the Disabled. So, I'm here also to say that I'm happy and excited about the work that you are doing in order to help the people with disabilities, especially people with sickle cell.

So, CIDNY is an organization that is a voice for folks with disabilities since 1978. We are part of the Independent Living Centers Movement, a national network of grassroot and community-based organizations that enhance opportunities for all people with disabilities to [02:10:43] our own life.

I'm here to testify in support of the bill Intro. 968-A for education and program and public outreach

campaign regarding the sickle cell. I put emphasis on bringing awareness about the program for people with disabilities and their family members, as well as people with chronic disease.

I didn't hear about outreach strategies in order to help folks for minority groups in order to help people who are not in the mainstream. So, I really look forward to see strategies and plan that will help the people see themself in the program and be able also to take advantage of it and recover and be taken care of.

So, I am here. I will draft my testimony and submit it but I just wanted to make sure that folks with disability are aware of the program and also other strategies that will help them hear the message. Thank you.

CHAIRPERSON NARCISSE: Thank you sir. Thank you. I appreciate your work.

COMMITTEE COUNSEL: Thank you so much. Uhm, let's see. Uhm, at this point, I would like to ask if there is anyone in the room or on Zoom who has not yet had the opportunity to testify and would like to do so. And if so, please identify yourself and state your name if you would like to participate.

Hearing nothing, I would like to note that written testimony, which will be reviewed in full by Committee Staff maybe submitted to the record for up to 72 hours after the close of this hearing by emailing it to testimony@council.nyc.gov.

Uhm, and seeing no one else, uhm I believe that we have concluded public testimony for this hearing Chair.

CHAIRPERSON NARCISSE: So first, I want to say thank you. I'm looking forward for us to continue partnering to make sure that once and for all, that we address the sickle cell trait and disease in our city. And uhm since we are the capital of the world, let's lead by example.

So, uhm, you see what's in front of us right now is to consider the Intro. 968-A and the Preconsidered Resolution that we have as well. Before I conclude everything, I want to say thank you to all the team that's here keeping up and trying to get the best out of our city. Address the preventive care is the best way to go.

So, I want to say thank you to my staff Frank Shea of course Deputy Chief of Staff and my Chief of Staff Saye Joseph an alleged person that is really

pushing forward to make sure that we get uhm, the healthcare, the bills to pass and making sure that we address the inequities once and for all. Our Policy Analyst Mahnoor Butt, thank you and to the Finance Analyst Julia Fredenburg of course James Wu and Alicia Miranda for their work on this issue and everyone, everyone that come out and H + H thank you. DOHMH, thank you and everyone that participate and give from their heart, their testimony from their heart. Uhm, we will address this and we'll continue to fight with this and I hope when I do call for you, you're not only bringing yourself, you bring all the team around you and something so important like this, we should have the crowd waiting. But uhm, yes, but we maybe a few but the difference is going to be made in New York City and for the world to see.

So, thank you and God Bless you all and we're looking forward. Thank you. [GAVEL]

C E R T I F I C A T E

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.

Date September 27, 2023