CITY COUNCIL CITY OF NEW YORK

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TRANSCRIPT OF THE MINUTES

Of the

COMMITTEE ON HEALTH

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February 26, 2020 Start: 12:16 PM Recess: 12:26 PM

HELD AT: 250 Broadway - Committee Rm. 16^{th} Fl.

B E F O R E: MARK LEVINE

Chairperson

COUNCIL MEMBERS: Alicka Ampry-Samuel

Inez D. Barron Andrew Cohen Mathieu Eugene Robert F. Holden

Keith Powers

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

2 (sound check) (pause)

3	CHAIRPERSON LEVINE: Welcome everybody. I
4	am Mark Levine, Chair of the City Council Health
5	Committee. I am pleased that we are joined by fellow
6	Health Committee members, Council Member Alicka
7	Ampry-Samuel, Council Member Andy Cohen, Council
8	Member Bob Holden, Keith Powers, and we're also
9	joined I'm pleased by one of the sponsors of our bill
10	today Council Member Danny Dromm. We'll be joined by
11	our other sponsor Council Member Miller momentarily.
12	Out topic today is sickle cell disease with a hearing
13	on this in September, which many of you attended. One
14	of the most impactful I think we've done in the
15	Health Committee. I encourage anyone who didn't
16	attend to watch the video. It's quite emotional and
17	meaningful. We-we're pushing in that hearing for
18	state action in favor of creating demonstration
19	sites—demonstration sites around the state to
20	increase the resources, education and attention to
21	this disease. That has not yet happened. So we're
22	moving forward today with a resolution that is led-
23	the lead sponsor is Council Member Dromm calling on
24	the state to pass two pieces of legislation that
25	would authorize the creation of this network of sites

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to serve those suffering from this disease, and those are in the Assembly Bill Number 6493 and in the Senate Bill Number 2281, and I am please to the cue Council Member Dromm for a few words in favor of this important resolution.

COUNCIL MEMBER DROMM: Thank you very much Chair Levine. First, thank you for holding this vote on Resolution 335-A, which calls on the New York State Legislature to pass and the Governor to sign vital legislation that will direction much needed attention and resources to sickle cell disease and sickle cell traits. Of course, I would be remiss if I did not also recognize the state bill's two sponsors, Senator James Sanders and Assemblywoman Alisha Hyman-Alicia Hyman. Sickle cell related conditions highlight health disparities in our system as communities of color are disproportionatelydisproportionately affected. Sadly, New York falls behind other states in rectifying this problem by fully funding the programs needed to enhance outcomes and quality of life for those with sickle cell disease. At the hearing last year we heard from Assemblywoman Hyman, healthcare professionals and advocates. Especially compelling was the testimonies

of New Yorkers who have sickle cell disease and are
trying to live full and productive lives despite the
challenges. I want to give a shout-out to on special
young witness at that hearing: Abigale June along
with the entire fifth grade class of Ms. Duflian
(sp?) at P.S. 38 in Brooklyn. Abigail wrote me this
morning to urge us to act. I ask the members of the
Committee on Health to do so-to do so as Abigail and
her classmates have asked—have asked for a vote on
Resolution 335-A, but even more than that I ask
Albany to pass A.6493 and S.2281 the legislation that
will improve the lives of Abigail and countless
others across New York. I want to express my
gratitude do Dr. Tom Olson who first brought this
problem to my attention, and who has advocated
tirelessly for better treatment of this community,
and Tom Olson is here with us as well. Thank you,
Tom Olson, Dr. Olson, and thanks finally to the
Health Committee staff: Zay Emanuel Hailu, Sarah Liss
and Emily Valcan (sp?). Thank you very much.

CHAIRPERSON LEVINE: Thank you very much, and while we're waiting for Council Member Miller, we're going to call the vote in case any of our

familiar with what was happening with him, and his

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healthcare needs, they asked him continuously what kind of drugs was he on, and just different things that he should not have had to go through and he collapsed into a coma and died. And like I said, Timothy was 26 years old and this was in April 2018, and it tore our family apart, and just one year later I had a very close friend Sean Brooks from Brownsville, grew up in Van Dykes who was also suffering with sickle cell, and he came to our office January of 2019 for help with medication because they increased the cost of his medication, and because of that he started to swell and had a lot of subsequent health problems between January of 2019 and August of 2019 when Sean died at the age of 42. And so this is so critical. We all understand how critical it is in our community to have more funding and resources for education and working with healthcare professionals, but I think it's critical that we continue to tell the stories of young people who are suffering now, but those who passed away and there was nothing that we can about it or things that we could do about it that we did not, and so I vote aye in support of thethe bills, but again that's in memory of Timothy

McVay and Sean Brooks. Thank you.

CHAIRPERSON LEVINE: What a tragedy for
you Council Member. Thank you for sharing that. I
wish I could say that's the first story like that
I've heard, but it's not unique. We have a
healthcare system that has inadequately responded to
this. We've also as we've spoken about a lot here
we've not adequately—adequately financed research
into this disease (bell) which is slow work towards
cure. It's hard to separate any of that from the
fact that this is a disease which overwhelmingly
affects people of color particularly African-
Americans, and also Hispanic Americans to a lesser
degree and so, I'm happy that you and other leaders
here are stepping to speak on that, and Mr. Martin,
if you want to continue the roll and then we'll hear
from Council Member Miller in a moment.

CLERK: Council Member Barron.

COUNCIL MEMBER BARRON: I vote aye on all and commend the sponsors for introducing this legislation.

22 CLERK: Holden.

COUNCIL MEMBER HOLDEN: I vote aye.

24 CLERK: Powers.

25 COUNCIL MEMBER POWERS: Aye.

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2 CLERK: By a vote of 7 in the
3 affirmative, 0 in the negative and no abstentions

both items have been adopted by the committee.

CHAIRPERSON LEVINE: And Council Member (applause) Council Member Miller, we thank you for your sponsorship of one of the important Resos today and I'd like to cue you for some words if you'd like.

COUNCIL MEMBER MILLER: Thank you so much, Mr. Chair and thank you to my colleagues forfor your vote on this important reso-these important resolutions this afternoon. Obviously we know that sickle cell is a disease that disproportionately impacts communities of color, and yet we receives a fraction of the funding of the other comparable diseases receives the treatment, and for instance Cystic Fibrosis, which affects mainly whites have a third of the number of sickle cell patients-patients that sickle dose, but receives nearly four times the amount of research and funding nationally. Reso 980 aims to address this disparity by educating and informing the public about the severity of the disease and needs for additional funding and treatment in centers in New York—around New York I'd like to thank my colleagues for supporting

this legislation. I'd like to thank the Chair, but I		
also would like to thank Council Member Dromm for hi		
leadership on this and this is not something that-		
it's-it's funny that could you imagine that something		
of this magnitude, and I have a trait myself, and-and		
so-and-and I could only tell you that the pain that-		
that comes along with thatthat folks can't imagine		
in their lifetime with that, and-and-and we've seen		
diseases really be eradicated in our lifetime, right		
and when there's the will to do so, and—and—and we		
have to make sure that this Council is at the		
forefront of that, and I'd like to thank the		
advocates for the work that they do to ensure that		
the State prioritizing that we prioritize it. Day in		
and day out folks like Gloria Rochester from-from		
Queens Sickle Cell Advocacy and I—I saw her sneaking		
around here somewhere there, but she's absolutely		
directless (sic) in this throughout the country that		
there are people on the front lines fighting this		
fight and—and—and it fills my heart to know that the		
members of this committee is—is leading the charge.		
So, thank you very much.		

CHAIRPERSON LEVINE: Thank you, Council
Member Miller. We'll have to work together for this

COMMITTEE ON HEALTH year's June 19th to make this an important day, and we've actually had full attendance of the committee and an unanimous vote. So, we're going to wrap up. Thank you to everyone and thank you our sponsors. [gavel]

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 March 15, 2020 _____