Testimony

of

Winfred Wu, MD
Medical Officer, Primary Care Information Project
New York City Department of Health and Mental Hygiene

before the

New York City Council Committee on Health

on

Intro 4, Intro 643, and Intro 1243

September 9, 2019
Council Chambers, City Hall
New York City

Good afternoon Chair Levine and members of the Committee. I am Dr. Winfred Wu, Medical Officer in the division of Prevention and Primary Care at the New York City Department of Health and Mental Hygiene. I am joined today by my colleague, Dr. Cheryl Lawrence, Medical Director in the Office of School Health. On behalf of Commissioner Barbot, thank you for the opportunity to testify today on the proposed legislation, which would require the Health Department to provide a list of the organizations the department regularly consults with regarding the prevention and management of chronic diseases, place automated, self-administered blood pressure machines in certain public places, and establish standardized procedures for treating students with tick bites.

The mission of the Health Department is to protect and promote the health of all New Yorkers. A primary component of our work is therefore aimed at reducing the burden of chronic disease by addressing the underlying risk factors that lead to obesity, heart disease, cancer, diabetes and stroke. In recent years the Health Department has expanded our work specifically to address hypertension control. We engage with a variety of stakeholders to inform and improve our approaches to reducing the burden of chronic disease. These organizations include, but are not limited to, academic institutions, community-based organizations, and non-profit organizations that aim to prevent and reduce chronic disease or, more broadly, address the social determinants of health that impact chronic disease.

I will now turn to the legislation under consideration today. Intro 643 would require the Department to provide automated blood pressure machines for self-testing use in public space, such as parks. Hypertension is a leading risk factor for heart disease and stroke, two conditions that contribute to more than one in five premature deaths in the city. Making community-based blood pressure kiosks as accessible as possible is a Health Department priority, as they serve three main purposes: 1) enhancing awareness of blood pressure among the general public; 2) serving as an engagement tool in early detection of hypertension following a high blood pressure reading which is then confirmed by a clinician, and; 3) offering a free, accessible way of monitoring blood pressure between visits with a health care provider when other preferable methods are not available.

The Health Department supports increasing access to blood pressure measurement, including through automated machines. One type of blood pressure machine is a kiosk, and the Health Department currently maintains 60 blood pressure kiosks throughout the city. This includes

55 kiosks at community pharmacies and five kiosks in partnership with other city agencies. Community pharmacies are a strategic location for the placement of blood pressure kiosks, as they offer kiosk users access to pharmacy staff who can answer questions and offer educational materials on blood pressure. Between June 2017 and June 2019, close to 200,000 readings have been reported from these kiosks, with a monthly average of 7,955 readings. A 2019 field survey found that the kiosks were beneficial to users and nearly half reported using a kiosk weekly to track their blood pressure. As a result of using the kiosk machines, users indicated they intended to report their blood pressure results with their doctor, and some also planned on making changes to their diet and physical activity. Location information for these kiosks and other sites that offer free blood pressure checks are available online via the NYC Health Map. The NYC Health Map is promoted on Agency social media channels, and Agency staff have previously distributed educational materials to primary care provider offices and pharmacies about the importance of getting your blood pressure checked.

The Department supports the Council's interest in improving hypertension control efforts through the placement of blood pressure monitors in public spaces. We look forward to working with the Council to discuss the best ways to reduce hypertension amongst New Yorkers.

Next, Intro 4 would require the Health Department to provide a list of non-governmental organizations that we routinely consult with on the prevention and management of chronic diseases. We currently work with hundreds of community partners and other organizations on many aspects of this work. We support providing this information and look forward to discussing the details of this legislation further with the Council.

Lastly, Intro 1243 would require the Health Department to promulgate rules that establish a procedure for school nurses to respond if a student appears to have a suspected tick bite. As part of the standard procedure for school nurses for students presenting with health issues, in the rare occurrence that a student presents at the school nurse's office with a tick bite, the nurse would assess the area, provide first aid, and inform parents to refer the child to the student's medical providers for any treatment needed. This is part of an established mechanism that emphasizes the importance of seeking care from primary care providers for health issues. We are confident that school nurses are well-equipped to handle any student that presents with a suspected tick bite and would like to further discuss the proposed legislation with Council.

Thank you for the opportunity to testify. We are happy to answer any questions.

New York City Council Committee on Health
Testimony of Gloria Rochester
President and CEO of the Queens Sickle Cell Advocacy Network
September 9, 2019

Good Morning, Chair Levine and fellow members of the Health Committee.

My name is Gloria Rochester, and I am the President and CEO of the Queens Sickle Cell Advocacy Network or QSCAN.

I speak not only on behalf of my fellow advocates but also as the mother of a child with sickle cell disease or SCD.

QSCAN's mission is to empower those afflicted with sickle-cell disease by providing them with the knowledge and skills needed to better navigate the healthcare system, so they can be more effective advocates for their personal care, and promote accessibility to services that meets the sickle cell community's needs.

We are asking the City Council to support Resolution 335, sponsored by Council Member Daniel Dromm, which calls on the New York State Legislature to pass and fully fund, and the Governor to sign the bill now known as A.6493/S.2281, legislation that would establish eight demonstration programs throughout New York State and one coordinating center to improve the care of sickle cell disease patients and educate about sickle cell trait.

We are also calling for it to support Resolution 980, sponsored by Council Member I. Daneek Miller, to declare June 19 of each year Sickle Cell Awareness Day in the City of New York.

Morbidity and mortality increase sharply for patients in the United States diagnosed with SCD after the age of 18 years. The cost of treating sickle cell disease is estimated at $1.1 billion per year. The average cost per patient per month is $2,000.

Seventy percent of SCD births in New York State were born in New York City, and nearly 90% of them were Black or African American. New York State's health care system has failed to ensure the continuity of care sickle-cell patients require, resulting in the increased use of emergency department and inpatient resources. Fifty percent of SCD patients in the State depend on Medicaid. Each costs $15,000, which is 50% more than those living with HIV. One year, 70 SCD patients cost its Medicaid program $6 million.

New York State gave $250,000 in FY20 funding for sickle-cell disease. Comparatively, the state of California gave $15 million. We're seeking $3 million in next year's Adopted Budget to fund the creation of specialized treatment facilities and a coordinating center to help educate the public and use preventative care measures which could save the State between $4 million to $5 million dollars.

Accessibility to services that meets the needs of the sickle-cell community is dependent on the State prioritizing the care of its 10,000 SCD patients.

We urge the City Council to support our call for action. Thank you for your consideration.

SCAC

Sickle Cell Advisory Consortium of New York

SCAC is an organization for physicians, nurses, social workers, genetic counselors, health educators, other health professionals, community base organizations, patients and families - All interested consumers

September 9, 2019

Good Morning, my name is Dr. Rita Bellevue and I am here to testify on behalf of SCAC the Sickle Cell Advisory Consortium of NY for RESOLUTION No. 335 and for RESOLUTION No. 980

Few Words About SCAC:

In the late 70'sand early 80's under the leadership of Dr. Doris Wethers a group of sickle cell professionals with a strong commitment to sickle cell patient care, joined forces with parents, patients and family, for the accomplishment of mutual goals. From its foundation SCAC's role has been education, outreach, lobbying and advocacy through its own subcommittees. SCAC is now a non-profit organization for physicians, nurses, socials workers, physicians assistants, other health professionals, sickle cell community based organizations, support groups, patients and families. During regular meetings we discuss matters pertaining to sickle cell disease, for the purpose of policy making, problem sharing and solving, promoting sickle cell awareness and providing unique opportunities for networking and collaboration with participants from the community based organizations, patients and families. SCAC meetings and symposium provide a forum to discuss and promote, patient care, new treatment, clinical care and update in treatment guidelines.

Another important role of SCAC is to establish linkage between New York City and New York State. SCAC had a major input into the State Implementation of Newborn Screening for sickle cell disease and sickle cell trait. SCAC is among the strong voices for the Sickle Cell Community and always participate in sickle cell related events: Sickle Cell walkathon, award events, National sickle cell awareness day, World sickle cell Day, sickle cell meetings etc. Although there has been progress made in the approach of the treatment and management of sickle cell disease and its complication, comprehensive health care is not available to most young adults and adult patients in NYS.
There are not followed by a hematologist or are not receiving appropriate comprehensive care. They have multiple emergency department visits, repeated admissions, opiate dependency, multiple preventive complications which include chronic pain, depression and poor health outcomes. The Medical literature shows clearly a decrease in mortality and morbidity, a better quality of life when a patient receives proper care, with a marked decreased in medical costs. Sickle Cell Disease is the most costly disease for NYS Medicaid. Despite this, NYS budget for sickle cell disease is minimal decreasing progressively, from $ 750,000 in 1980, $500,000 in 2001, $250,000 presently to help improve patient care.

Rita Bellevue, MD Kusum Viswanathan, MD Miren Blackwood

SCAC Coordinators

For many years the Sickle Cell Advisory Consortium of NY have been actively involved through members of the legislative subcommittee, working actively with the Advocacy Group under the leadership of Dr. Tom Moulton a very caring Pediatric Hematologist. SCAC members went to Albany networking with the community base organizations, contacting members of Senate and Assembly Senate to sign and Co-sponsor the sickle cell Bill a key legislative issue important for patients living with sickle cell disease and their families who are hoping for better health care access and education about sickle cell disease and sickle cell trait.
I am here today as an advocate to testify at this hearing on behalf of the participants of the Sickle Cell Advisory Consortium of NY:

1.- First in support of the City Council Resolution No. 335 CM Dromm's
Calling upon the New State Legislature to pass and fully fund, and for Governor Cuomo to sign A.5313/S.4054, sponsored by Senator James Sanders Jr. and Assembly Member Alicia Hyndman , Legislation that would :

- Establish eight Demonstration Programs throughout New York State
- Establish One State Wide Coordinating Center to provide Education and Assistance to each program, establish goals for standard of care, collect Data and monitor progress
- -Improve the care of patients with Sickle Cell Disease, increase the average age life expectancy for SCD patients, decrease the cost of care and Educate communities about Sickle Cell Disease and Sickle Cell Trait.

2- Second in support of Resolution No. 980 by Council Members Miller and Barron.
Whereas, June 19 is recognized by the United Nations as World Sickle Cell Day
Resolved, that the Council of the City of New York declares June 19 of each year Sickle Cell Awareness Day in the City of New York.

Respectfully submitted,

Rita Bellevue MD

Jacqueline Baker
16 Adela Court
Yorktown Heights, New York 10598
September 6, 2019

The New York City Council
City Hall
City Hall Park
New York, New York. 10007

Re: NYS Senate Bill: 2281 and NYS Assembly Bill: 6493

Dear New York City Council Members,

I am the parent of two adult sons who were unfortunately born with sickle cell disease. Raising my two sons as a divorced parent has been a challenge. Both of my sons have and continue to endure painful crisis throughout their lives. I have spent most of my adult life in and out of hospitals to care for my sons.

Sickle cell disease affects a large population of African Americans, Hispanic, and Indian communities. Since red blood cells carries oxygen to all parts of the body, sickle cell disease prevents this from happening and as a result, this causes repeated episodes of severe pain. These severe crisis complicate other medical problems and can cause organ damage, serious infections, and/or a stroke.

Sickle cell disease has affected each of my sons differently. My oldest son showed a high risk of a stroke at age 5 and was put on chronic transfusions from 13 to 34 years old. My son had limited growth spurts and lagged behind his peers in physical, academics and social abilities. He was hospitalized many times for weeks which has caused him to miss many days of school. He wanted to play several sports but due to the pain and problems with sickle cell disease he was not able to carry out a full year of any sports activity.

My youngest son started having painful crisis at age 6 years old and continues to have painful crisis at his current age of 30 years old. He was just hospitalized on April 27,2019 for severe pain in his head and there was fear that he might have suffered a stroke. Thank God, an MRI showed no stroke occurred. He was screaming for relief of pain and waiting at least 48 hours for the pain medication to finally help and give him some comfort. This happens a lot with sickle cell patients as many medical staff don't quite view the disease as a priority. With sickle cell disease, my son has missed school, repeated a year in college at a very high tuition cost, and lost some employment opportunities. My son was fired from his job due to a long hospital stay.

There is currently only one cure for sickle cell disease and that is a bone marrow transplant which is very risky and sometimes fatal. There are only two FDA approved medications for sickle cell patients, in spite the fact, sickle cell disease has been around for more than a century. Most of the time, my son and other patients with sickle cell disease are in constant pain all day, every day. Their quality of life is greatly compromised as a crisis can happen anywhere, anytime.

It is very disheartening to watch my sons suffer in pain for hours and worst of all, they not always get the medical attention they need and deserve. After a painful crisis, my youngest son becomes depressed because he was not able to work or go to school for some length of time. Depression can lead to mental illness which can affect your everyday life. It's extremely difficult to live with a disease that affects every part of your body and you try your best to accomplish your goals and hopefully you can live your dreams. The life expectancy for sickle cell patients have greatly decreased due to poor patient services and inadequate health care. Many sickle cell patients have died between the ages of 30 and 40 years old.

Other chronic diseases such as Cystic fibrosis, Parkinson's, and HIV have increased their life expectancy due to new and improved treatments, and most of all a tremendous amount of funding from their prospective State budgets. Sickle Cell Disease deserves the same amount of funding from the NYS budget to increase life expectancy, provide quality healthcare, and develop more research to find a cure for the disease.

I am asking you to please pass Resolution #335 and ask the Governor to fully fund the two legislation bills currently in the Senate and in the Assembly in the amount of $5,000,000. Only through adequate funding can treatment programs be developed in New York State Hospitals which can reduce long stays, and improve patient care. This can save NYS over $3,000,000 in Medicaid annually, covering the cost of the Sickle Cell Treatment Bills.

I also urge you to support the above bills so that patients/families with sickle cell disease can receive the medical care they need to live productive lives, and to educate others about the disease in their communities.

Lastly, I want to congratulate Council Members Miller and Barron for passing Resolution No. 980 and declaring June 19 of each year Sickle Cell Awareness Day in the City of New York. This is a major step in educating the communities about Sickle Cell Disease and how we can all work together to help patients/families manage the pain.

Respectfully yours,

Jacqueline Baker

Jacqueline Baker tchexc@hotmail.com

Statement for SLR 335 Hearing

Sickle Cell Disease (SCD), was given its clinical name over a century ago. Today, sickle cell still lags far behind other chronic disorders due to little or no government funding for people suffering from sickle cell disease and their families. There has been a decrease in life expectancy for individuals with SCD, due to poor or inadequate health care. Other chronic illnesses seem to benefit from new and improved treatments, however, there has only been one medicinal therapeutic approved in more than 20-years. While there is movement in research for better treatments and to find a cure for sickle cell disease, comprehensive treatment centers are needed now, to diagnose and manage pain and other complications.

According to several studies, other chronic diseases such as: Cystic Fibrosis, Cooley's Anemia and Parkinson's receive substantial funding, which has improved the quality of health care and increase the life expectancy for people affected by these diseases.

The 2019 Sickle Cell Treatment Act needs to be passed by the state legislature this year, and the Governor needs to allocate the $3 million requested into the state budget to implement the development of Sickle Cell Treatment Centers throughout New York State.

Maya Priest myzen11@gmail.com
Statement in Support of SLR 335 September 9, 2019

My name is Maya Priest, I am a 41-year old woman with Sickle Cell Disease (SCD). Sickle cell is an insidious illness that causes damage and pain, not just to our physical bodies, but to every aspect of our lives.

Though living with Sickle Cell Disease is a battle in and of itself, I have to say that my hardest battles have been with those entrusted with taking care of me, the medical community.

The Sickle Cell community has been very vocal over the years about the stigma we face in receiving proper and humane medical care. We have spoken about the drug addict labels, the " your pain can't be THAT bad", and at times the absolute unwillingness on the part of doctors and nurses to educate, reeducate, and update their knowledge of Sickle Cell Disease. Very rarely are we able to show how these biases affect the lives of SCD patients. So I am going to tell the story of my friend.

Ebony was 21, and engaged to be married to her grade school sweetheart. She was one of the first friends that I made with SCD. Ebony had just come back from vacation and was admitted into the hospital at the same time that I was. She had always had severe crisis pain in her legs. This admission she told me and my mom that she had clots in her leg, and we could actually feel it.

Ebony had a great personality. However, because of gossip, labels and stigmas placed on her from the pediatric department at our old hospital followed her to the adult program in a new hospital. Ebony was labeled and exaggerator, uncooperative, and a drug seeker. These labels would eventually end up being the catalyst for her death. A few days after being admitted, Ebony coded and passed away from a pulmonary and cardiac embolism. Her autopsy identified that she had multiple clot, which she did not receive treatment to resolve. Our nurse at the time came I to my room crying, saying " I didn't know, I'm sorry I didn't know". The nurse proceeded to tell me that she had just given Ebony her pain medication when Ebony pushed the nurses bell. No one went to her room for 20-minutes or more. The nurse said " I thought she was going to ask for

more medication". Ebony was ignored, and left to go into cardiopulmonary arrest alone. To add to the sadness of this story, our doctor confided in me, that the leader of the code team basically gave up on her resuscitation; "I don't have time for this, I have someplace to be", he said. Our doctor was visibly shaken and said "you don't just give up on a 21-year old". The biases and lack of compassion that Ebony lived with for most of her life, combined with the complications related to sickle cell disease, took her life.

I fear the hospital more than I fear death. I can't imagine suffering and dying in a place that has the ability to comfort and save me, but chooses not to. So I stay home, and I use the science that my community mentors taught me to get through the pain. The science that is lacking when I've been admitted. I am terrified of going into crisis, so I limit myself a lot. I don't have a cushion to fall on if I get sick. This way of dealing with adults living with sickle cell disease is commonplace and it shouldn't be.

My last two admissions a few years ago were extremely traumatic. Without going into too much detail, I need you to know that both experiences made me fear for my life. I was left alone for hours in intractable pain. I called my pediatrician to tell him what was happening, and he told me; "...to leave, because it is too dangerous for you to stay there". A nurse who cared for me during one of those admissions, confided that she thought I should have been in the ICU. She couldn't understand why the doctors didn't admit me there. This is the reality of thousands of people living with SCD nationwide. The hospitals are supposed to be institutions of care and healing, however, time and time again our SCD community has our health and lives measured and judge by people steeped in bias and prejudice.

To the state legislators, passing the Sickle Cell Treatment Bill, and allotting funds to open treatment facilities is long overdue. We deserve to feel safe, and confident that we will receive quality, compassionate care from trained professionals. These centers will also help in the collection of important data on Sickle Cell Disease that will advance care protocols. Nurses and doctors are such a big part of our lives. When you help our community you are also helping the scientific community at large. Breakthroughs in sickle cell treatment can mean breakthroughs for other illnesses as well.

Geneva Marie Farrow

Healthy Warrior Mom

Sickle Cell Mom, Advocate and Educator

Testimony Presented Monday September 9th 2019

5:10am Tylenol with Codeine in the ER (didn't kick in until 6am)

7:15am Toradol (kicked in at 8am)

9:15am oral Tylenol

10:25am Oxycodone

12:30pm Morphine

1:22pm Toradol (2 ½ hrs of sleep up at 3:50pm)

4:09pm Oxycodone

5:15pm Tylenol (sleep with breakthrough crying)

544pm screaming in pain at 5 min intervals

6pm Morphine

6:20pm fell asleep

7pm Toradol

9:20pm Oxycodone

11:20pm screaming in pain

11:40pm Morphine

12:48am Toradol

2:54am Oxycodone

4:50am Morphine

This was the first 24hrs of my sons last hospital stay. He was hospitalized due to a pain crisis in his feet after a trip to the beach. Dylan is 5yrs old and 42lbs with Sickle Cell Anemia SS.

Prior to this hospital stay Dylan had not visited the ER or had a hospital stay in 20mos 29 days. Prior to his long stretch of being healthy we were in the hospital regularly. While I was giving birth to my youngest son Dylan was 2 floors below admitted due to Sickle Cell complications. 2 months later he was admitted again. The complications have varied from Pain to Pnemonia, RSV and Flu. The stays have varied from 3 days to almost 14 days.

The most challenging part of having a child with Sickle Cell Anemia is the lack of support and information provided on the disease. The information provided is also inconsistent and varying between hematology, internal medicine and the other specialty teams. The medical direction I received when Dylan was 5 weeks old was to give him folic acid and penicillin daily. Keep him hydrated and bring him to the ER if his fever was over 100.4. That's it.

During our last hospital stay I had one resident try to assure me that it's extremely difficult for Sickle Cell patients to become addicted to morphine. I had protested giving him morphine because of its addictive nature and eventually agreed because no other pain intervention was helping. Less than 5 min after that doctor left a nurse came in and told me about a 14yr old Sickle Cell patient who is addicted to morphine. This type of inconsistency is consistent across the sickle cell community.

After doing my own research I came up with a list of vitamins and herbs to help keep Dylan healthy and out of the hospital. I take him in for his regular appointments and check-ups and his hematology team is amazed at his success. It's unfortunate that simple holistic treatments are not being studied or recommended. There are only 2 FDA approved medications for the treatment of Sickle Cell Anemia. One of those treatments is a chemotherapy drug that causes infertility. This drug is now being pushed on healthy 7 month old infants who will undoubtedly be infertile in the future. The parents of these children feel hopeless and many of them are not being informed by their physicians of the harsh side effects of the drug. Do the risks outweigh the benefits? I don't believe they do.

Vitamin B12

B Complex

Vitamin C

Vitamin D3

funding provided to educate parents on healthier eating, which can also contribute to better outcomes?

Tomorrow we celebrate 2 months since Dylan was released from the hospital. We will continue to decline the chemotherapy drug and focus on our holistic approach. We will continue to have smoothies daily and eat a predominantly plant based diet. We will continue to say our health affirmations daily. Dylan will continue to defy to odds that say he will be hospitalized regularly. However I want those same outcomes for other children with Sickle Cell Anemia. I want all parents and patients aware of their options and not be forced into medical decisions out of fear based pressure and coercion in some cases. I want those parents and patients to feel hopeful and empowered.

I hope that sharing my testimony today will encourage the committee to approve funding requests made for educating Sickle Cell parents and patients on staying healthy. I hope the committee is also able to provide tangible resources to support parents and patients in their pursuit of health. I hope that there will be an increase of funding for studies of holistic treatments. Finally I hope that the Sickle Cell medical community will come to a consensus that helps improve the health outcomes of Sickle Cell Patients everywhere.

Thank you!

9/9/2019 Testimony for City Council Resolution 335.

Hello, I am Abigail Jean and I am 10 years old.

My baby sister is only 2 years old and has sickle cell disease.

I've already lost count of how many times she been in and out of the hospital.

This hurts and disappoints me, because I know that we are not the only family suffering with Sickle Cell.

We all need to do something to help pass and fund the Sickle Cell Bill, which would change hundreds of families lives for the better.

We need our elected state officials, including Governor Cuomo to increase funding for treatment and awareness.

I am so very proud of my local officials, Senator Kevin S. Parker and Assembly person Rodneyse Bichotte for their continued support of this bill.

I now ask them to make sure that the Sickle Cell Bill is passed and fully funded.

In addition, we need to provide more financial and medical support for these families as well as increase education for our communities to learn about testing and finding resources.

Thank you for your attention.

My name is Halima Heyward, I am 45 yrs old, and I have the distinction of belonging to a very small club, within a very small rare disease. I was born with and recently cured of sickle cell, ss type, disease. My life with sickle cell was one of hundreds of hospitalizations and thousands of blood transfusions. I have had most of the complications that sickle cell can create. My complications have included: inability to make enough red blood cells, damage to bones, silent strokes, memory issues, kidney failure and liver fibrosis.

21 months ago, I decided to risk my life in order to be cured of sickle cell disease. I fought for years to be able to receive a bone marrow transplant that could possibly cure me of sickle cell disease. I had a 40% chance of this procedure failing and, therefore, either leaving me with sickle cell disease or dead. That's how desperate I was to be rid of sickle cell disease and it's effects on my life. The cure worked, but I am still left with the damage that sickle cell has done to my body. I am now on dialysis and in need of a double hip replacement. Medicaid has been a life saving program that I am very grateful for. If it were not for medicaid and funding to sickle cell programs over the years I would have been dead as a child, like my sister who died at 3 yrs old from sickle cell disease. Funding for Medicaid and sickle cell programs have afforded me the ability to be seen by top doctors for much needed maintenance and specialty care. Funding saves and improves the quality of life of people who most often are of low socio-economic background and allows them to pursue some semblance of normalcy within their lives. I am thankful that I was able to find care and to be able to get the treatment I needed. Most adult sickle cell patients are not so lucky. We need to change that and make sure that the sickle cell bills in Albany are funded and passed. That way more adult sickle cell patients are able to get the comprehensive care and the chance to save their lives.

Thank you in advance for supporting our efforts to live well with sickle cell.

Sincerely,

Halima Heyward

TESTIMONY

NYC COUNCIL HEARING ON SICKLE CELL DISEASE

SEPTEMBER 9, 2019

I am the parent of a son that was born with sickle cell disease. My son, Shakir Lateef Cannon died on December 5, 2017 due to acute complications attributed to sickle cell disease. He was only 34 years old. He was a devoted husband and loving father of a 5 year-old daughter. He was employed in Information Technology at the State Department of Health in Albany, NY.

Shakir's passion was advocating for sickle cell disease and his personal motto was "any day without pain is a good day". His personal motto is inscribed on his headstone. His advocating took him to Washington, DC where he attended the White House Precision Medicine Initiative Summit in 2016.

My son went beyond merely accepting his condition. He worked tirelessly to increase awareness, needed research and treatment of sickle cell disease. I also have a son and three grand children who have sickle cell trait.

I have been advocating to improve care for sickle cell patients for over 30 years. My advocacy began with the birth of my youngest son Shakir. Shakir was diagnosed with sickle cell disease at birth through new born screening.

Shakir was followed by a regular pediatrician until he had a stroke at age three. After he had the stroke, he was followed by a hematologist. Transfusion therapy was the only treatment as there was a high risk of having another stroke. My son received transfusions every three weeks from age 3 to 34.

Being a parent of a child with a chronic illness such as sickle cell disease is very challenging. My husband and I were our son's primary care givers. I worked midnight to 8am to be able to care for our son during the day and my husband worked 3pm-11pm to provide care for him at night. Many parents of children with sickle cell disease are unable to be gainfully employed due to their child's frequent hospitalizations. As parents, my husband and I was aware of our son's needs and medications. We were trained to care for his port-a-cath and how to give him his medication. We gave him nightly infusions of Desferal via a port-a-cath to reduce iron overload, which if not treated could be fatal.

My son received coordinated care for his sickle cell disease from age 3 until age 21 when he transitioned from pediatric to adult care. Most adult patients are not in care with a hematologist or a primary doctor. Care is very inconsistent. Many of the adult patients are seen in the emergency room when they are in pain crisis. As an adult, my son experienced frequent changes to his hematologist and no longer received the comprehensive care that he received in pediatrics.

Sickle Cell Disease is a complex disease with worsening complications and organ damage, including lungs, heart and kidneys, as patients age. The life expectancy for sickle cell disease patients is decreasing. The median life expectancy for men is 38 years and women 42 years. Sickle cell disease requires specialized care to achieve the best possible outcomes for patients. Sickle cell is the most costly disease per patient to NYS Medicaid. However, Federal, State and

private funding for sickle cell disease is severely lacking. In 2018, sickle cell funding in the NYS budget was cut from $250,000 to $170,000.

There is currently a Sickle Cell Treatment Bill in the NYS Legislature, Assembly Bill 06493 and Senate Bill 2281. This bill will establish eight demonstration programs throughout NYS and one coordinator center to improve the care of sickle cell disease patients and educate about sickle cell trait.

I urge you to support and pass the 2019 - 2020 Sickle Cell Treatment Bill and to increase the amount allocated in the next budget to $3,000,000 to fully fund the bill.

The passing of this bill will positively impact the lives of individuals living with sickle cell disease in New York State, the lives of my three grandchildren who have the sickle cell trait, and the lives of future generations who will inherit the sickle cell gene.

Thank you for your consideration,

Cheryl A. Cannon
Parent Advocate
Capital District Sickle Cell Support Group
cca9828066@aol.com

Facts on Sickle Cell Disease

Thomas Moulton, MD
Sickle Cell Thalassemia Patient's Network (SCTPN)
NYC Council Resolution 335-2018
Sept. 9, 2019

NYS and Sickle Cell Disease

Approximately 100,000 people live with sickle cell disease (SSD) in the US, with approximately 10% living in NYS.

Sickle cell disease is most common in African-Americans, but also occurs in Hispanic, Mediterranean, Middle Eastern and Indian communities. In NYC Tibetan and Asian communities have also been affected.

Births	United States	New York State
African American	1:365	1:230
Hispanic	1:16,300	1:2,320
Caucasian	1:80,000	1:41,647

In NYS, 1:1,146 live births have sickle cell disease with 12% of those births in the Hispanic community. Higher birth rates occur in mothers who were born outside of the US.
Genet Med. 2013; 15:222–228

Approximately 80% of individuals diagnosed with sickle cell disease in NYS live in the NYC **area.**
76% of newborns were born in NYC and 24% of newborns were born outside of NYC
Genet Med. 2013; 15:222–228
https://www.cdc.gov/ncbddd/sicklecell/documents/SCD_in_NY_Prov.pdf

3,000,000 people in the US have sickle cell trait. Approximately 1:12 African Americans have sickle cell trait.

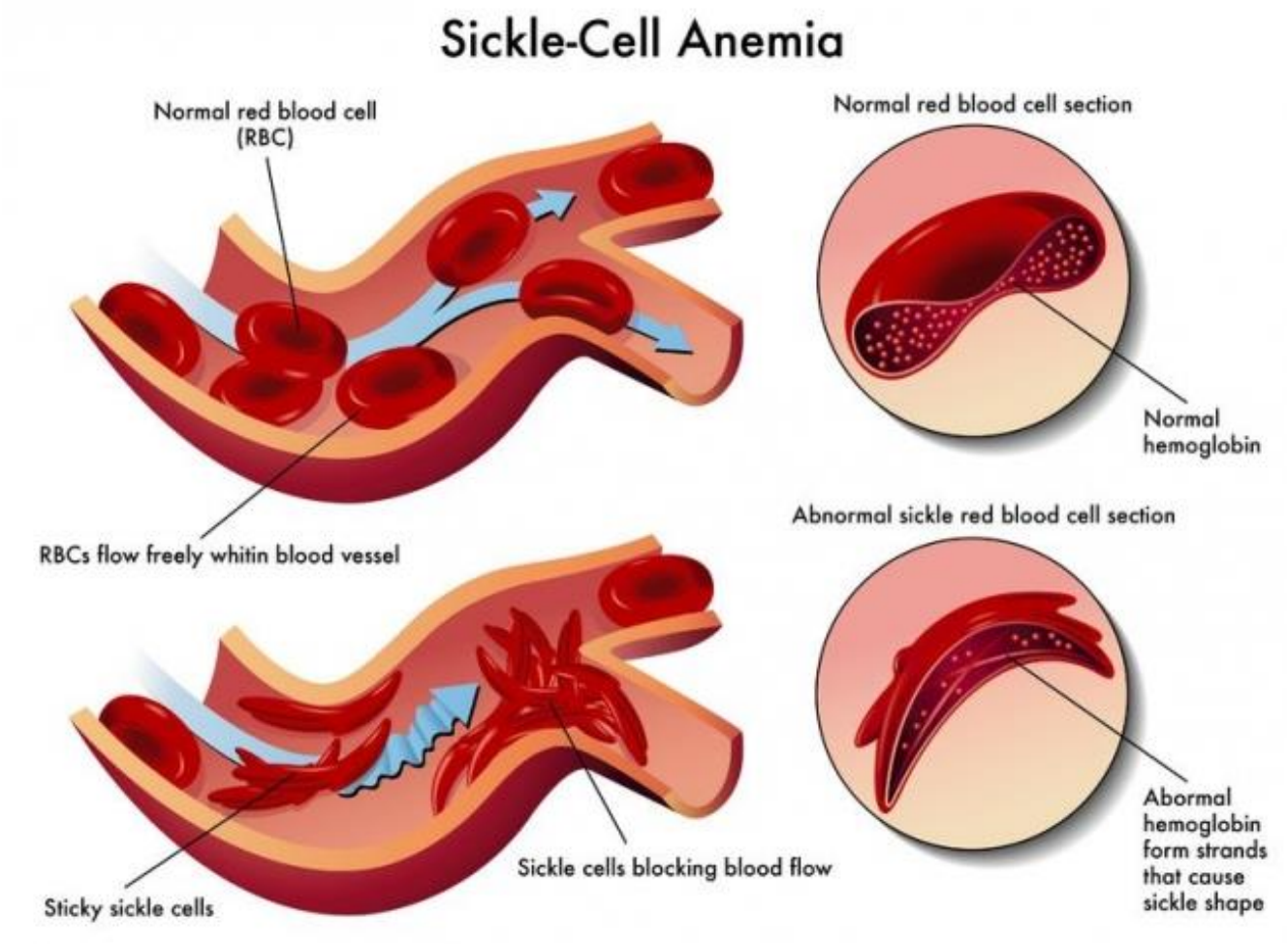
What is Sickle Cell Disease and What are its Complications?

SSD is an inherited blood disorder that is caused by a mutation in the hemoglobin protein (the part of the red blood cell that carries oxygen throughout the body). There are 4 main types of sickle cell disease – SS, SC, $S\beta^{+}$ Thal, and $S\beta^{0}$Thal. To have a child with sickle cell disease one parent must have the sickle gene (S) and one must have one of the other genes (S,C, βThal). A person who has one sickle gene (S) and one normal gene (A) has sickle cell trait (AS).

The sickle cell gene is prevalent within the Malaria belt and it is believed that sickle cell **trait** is protective against malaria.

Complications
Since SSD is a disease of the blood and the blood goes to all parts of the body, all parts of the body can be affected. In addition, while sickle cell trait has less complications than disease, it can, under certain circumstances, have all of the complications of sickle cell disease.

The complications from SSD arise when the red blood cells change shape (from a donut to a sickle shape) and become rigid. These cells then cause a cascade of events that then clog up (clot) the small and medium sized blood vessels subsequently starving the cells beyond the blockage of oxygen. When this happens, those cells die. Most of those cells do not regenerate and so **as a patient gets older more and more areas of the body die off until the organs fail. Therefore, SSD is a cumulative disease that get worse as you get older.**



The complications of SSD are too numerous to list here, but some of those that are more serious and potentially life threatening are listed.

Additionally, there has not been any steady decrease of hospitalization rates noted from 1998 to 2008 in sickle cell disease admissions, with only a slight decrease in length of hospital stay of 5.38 days in 1998 to 5.18 days in 2008
Renal Failure in Sickle Cell Disease: Prevalence, Predictors of Disease, Mortality and Effect on Length of Hospital Stay. Hemoglobin. 2016 Sep; 40(5): 295–299.

Pain (painful crises, VOC)

Pain results when cells are starved of oxygen and die. The larger the die off of cells the more severe the pain and the longer the duration. Bone pain is the most common. It is not that it

feels like a broken bone, it is as if the bone is crushed and multiple fractures occur. It can cause severe and excrutiating pain.

The majority of medical contacts in sickle cell disease (SCD) are for exacerbations of pain due to vaso-occlusive episodes, commonly called "crises".
Pain. 2009 September ; 145(1-2): 246–251.

Adult respondents in the Pain in Sickle Cell Epidemiology Study (PiSCES) reported SCD pain on 54.5% of the 31,017 days surveyed. Importantly, 29.3% of respondents had pain on greater than 95% of the days surveyed.

Those who described being in pain on 96% to 100% of days reported a mean pain intensity of 5.1 ± 0.2 on pain days and 6.2 ± 0.2 on crisis days, whereas those who described pain on 5% or fewer of days reported an intensity of 3.5 ± 0.4 on pain days and 4.5 ± 0.6 on crisis days. Opioid use was strongly correlated with pain intensity.

Pain in SCD is not only common, but also severe. Utilization due to SCD pain increased as patients grew older, from 0 to 30 years, and declined thereafter. Most SCD pain, even "crisis" pain, is managed at home, without emergency room or hospital utilization. The 8-state study reported a rate of **acute care encounters, 2.59 per patient per year. Re-hospitalization rates for the 8-state study were frequent: 22.1% and 33.4% at 14 and 30 d, respectively.**

Impacts of SCD Pain: on Depression, Psychological, Neurological Impacts, health related quality of life and sleep

ASH Education Book, **December 4, 2010** vol. 2010 no. 1 **409-415**

People with SCD may face long wait times before seeing a health provider in the ED and before receiving appropriate medicines.[1,2]Health providers in the ED may hold inaccurate beliefs about patients with SCD. Research shows that ED providers may suspect patients with SCD to be drug-seeking when they arrive in the ED.[3,4]

1. Haywood C Jr, Tanabe P, Naik R, Beach MC, Lanzkron S. The impact of race and disease on sickle cell patient wait times in the emergency department. Am J Emerg Med. 2013 Apr;31(4):651-6.
2. Tanabe P, Myers R, Zosel A, Brice J, Ansari AH, Evans J, Martinovich Z, Todd KH, Paice JA. Emergency department management of acute pain episodes in sickle cell disease. Acad Emerg Med. 2007 May;14(5):419-25.
3. Shapiro BS, Benjamin LJ, Payne R, Heidrich G. Sickle cell-related pain: perceptions of medical practitioners. J Pain Symptom Manage. 1997 Sep;14(3):168-74.
4. Waldrop RD, Mandry C. Health professional perceptions of opioid dependence among patients with pain. Am J Emerg Med. 1995 Sep;13(5):529-31.

SCD patients experienced wait times 25% longer than the General Patient Sample, though this difference was explained by the African-American race of the SCD patients. SCD patients waited 50% longer than did patients with long bone fracture even after accounting for race and assigned triage priority.
Haywood C Jr, Tanabe P, Naik R, Beach MC, Lanzkron S. The impact of race and disease on sickle cell patient wait times in the emergency department. Am J Emerg Med. 2013 Apr;31(4):651-6.
All of this is made more difficult by the fact that sickle cell patients, adult primarily, cannot find/get the specialized care that they need to prescribe pain medication and to prescribe adequate pain medication. The "opiod crisis" is preventing sickle cell patients, and all chronic pain patients, from

getting appropriate care. Remember most sickle cell patients treat their pain at home. With inadequate pain treatment more and more of them will have to seek care from ERs.
If a chronically ill patient comes into an ER, such as an insulin dependent diabetic, and they know how much insulin they should be getting, they are considered a good patient. However, when a sickle cell disease patient with chronic pain comes into an ER and knows how much pain medication they need to control their pain, they are considered drug seekers/addicts and are usually ignored and not given appropriate medication for their pain. This results in inadequate pain control and then the patient needs to be admitted to the hospital rather than discharged home with appropriate medication to get them over their pain crisis.

Stroke/Silent Stroke

Incident ischemic stroke was more frequent among those with SCT (13%) than those with homozygous hemoglobin A (10%).
Melissa C. Caughey, Laura R. Loehr, Nigel S. Key, Vimal K. Derebail, Rebecca F. Gottesman, Abhijit V. Kshirsagar, Megan L. Grove, and Gerardo Heiss. Stroke October 2014 Vol 45, Issue 10

Sickle cell trait may not be associated with incidence of ischemic stroke among African Americans. JAMA Neurol. 2018 Jul 1;75(7):802-807

The risk (for stroke) is enormous in SCD. Approximately 11% of SCD patients have clinically apparent strokes before the age of 20.**9** That risk increases to 24% by the age of 45.

The ischemic variant, which constitutes 54% of all cerebrovascular accidents (CVAs),[9]is **highest during the first decade and after age 30. During the 20s, ischemic CVA is replaced by hemorrhagic CVA.**[9] Although not characterized as age-dependent, 10% to 30% of SCD patients have silent strokes that exhibit radiologic findings consistent with diffuse white matter disease.[12-15] These silent infarcts are associated with cognitive deficiencies.[14]

Sickle cell disease and stroke, Luis A. Verduzco and David G. Nathan, Blood 2009 114:5117-5125

High prevalence of silent cerebral infarcts[4] and their association with lower IQ,[8,15] poor academic performance,[7] and increased risk for stroke.

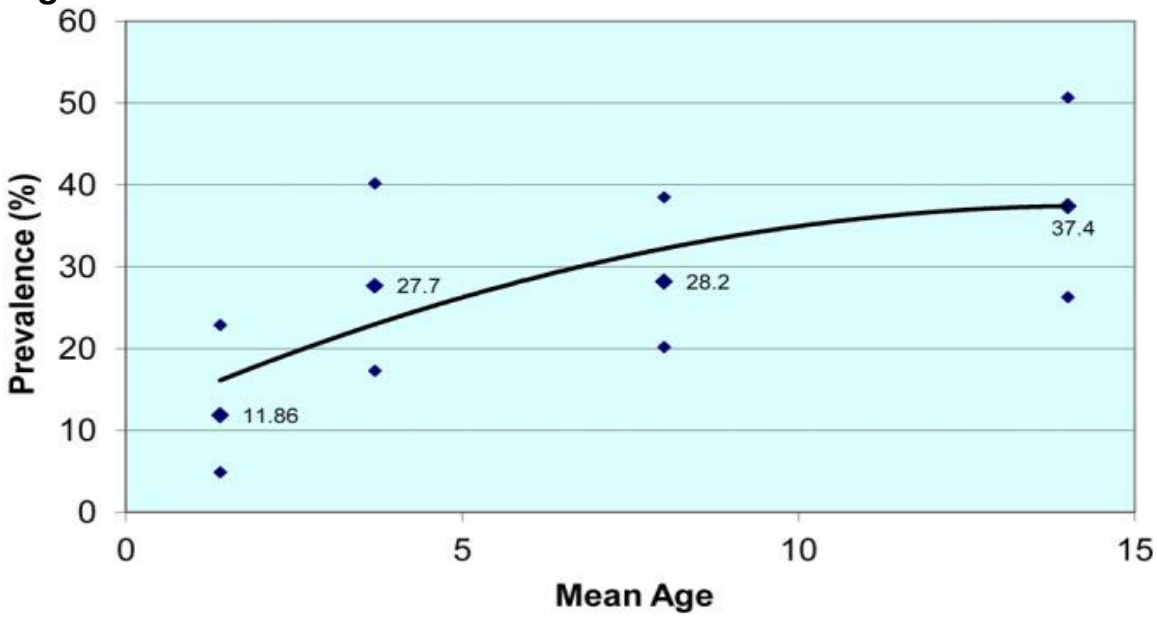
Silent Cerebral Infarct is defined as abnormal magnetic resonance imaging (MRI) of the brain in the setting of a normal neurologic examination without a history or physical findings associated with an overt stroke.

In a small study, the prevalence of silent cerebral infarcts at an average age of **13.7 months** was **13%.**[22] In a second study, in which surveillance MRI was conducted among children **up to 6 years** of age, the prevalence of silent cerebral infarct was **27%**.[23] In a third study, the prevalence **by 14 years** of age was **37%**.[4] Thus, the majority of silent cerebral infarcts have occurred in children with sickle cell anemia by 6 years of age.

AGE	% with Silent Stroke
13.7 months	13%
Up to 6 years	27%
By 14 years	37%
Up to 36 years	45%

Controlled Trial of Transfusions for Silent Cerebral Infarcts in Sickle Cell Anemia. N Engl J Med 2014; 371:699-710

Figure 5



Prevalence of SCI with 95% CIs plotted against age from 4 studies.[1,2,23,24]
Blood. 2012 May 17; 119(20): 4587–4596.

Among adults with SCA 43% had SCI at baseline. Of participants with baseline SCI, **30% had new or progressive SCI over 2.5 years** compared to 6% with no SCI at baseline

Silent infarct is a risk factor for infarct recurrence in adults with sickle cell anemia
Neurology August 21, 2018; 91 (8)

Silent cerebral infarctions are common in adults with SCD. Silent cerebral infarcts were present in 45% and overt strokes had occurred in 13% of adults with SCD.

Silent Cerebral Infarcts and Cerebral Aneurysms Are Prevalent in Adults with Sickle Cell Disease
Adetola A. Kassim, Sumit Pruthi, Matthew Day, Michael R. DeBaun and Lori C. Jordan
Blood 2014 124:2712;

SCI is a risk factor for clinical stroke (14 fold higher) and progressive SCI

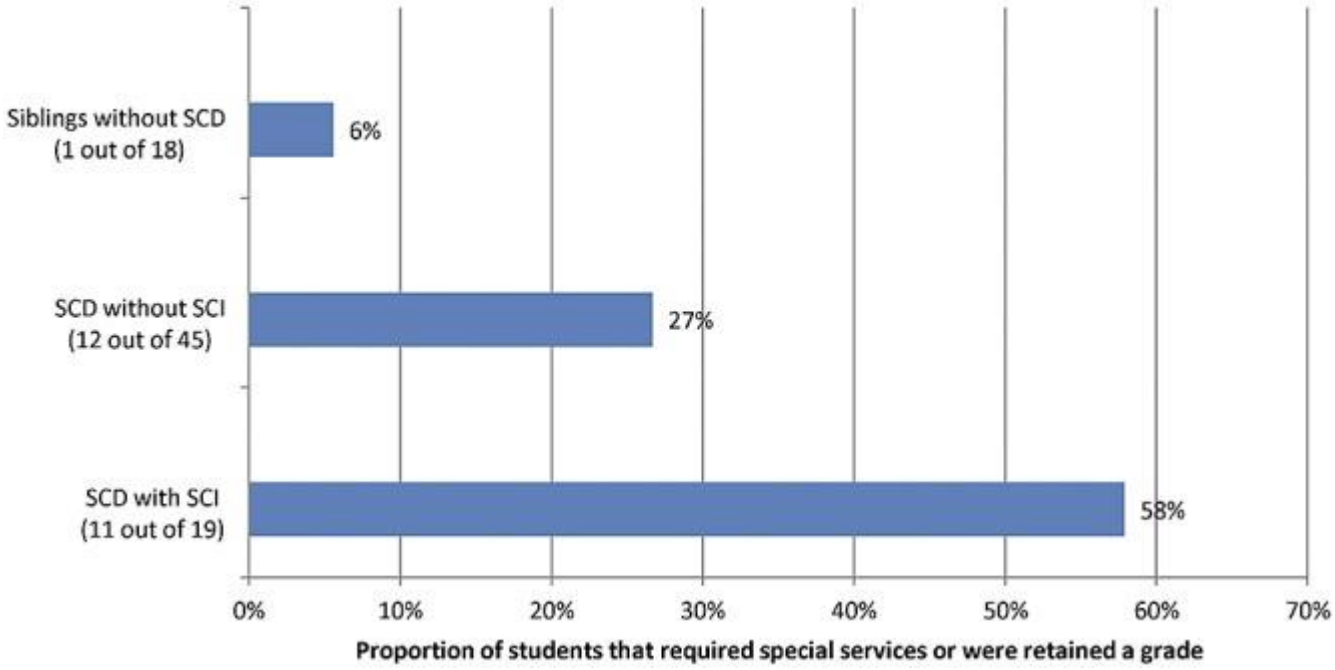
Children with SCI have lower cognitive test scores compared with children with a normal MRI of the brain. Poorer global intellectual function[17,22,26–28] has been reported in several studies, with function below the average range for the general population, but better than that of children with overt strokes. In a summary of global intelligence quotient in children with SCA and controls, Hogan et al graphically displayed data from multiple studies that included the Full Scale IQ (FSIQ) in controls without SCA, children with SCA with or without SCI, and children with SCA and overt stroke.[29] The gradient in FSIQ demonstrated the following consistent pattern: ethnically matched control children without SCA had a mean FSIQ greater than children with SCA and without SCI, who in turn had a FSIQ greater than those with SCI and covert and overt strokes

Specific areas of deficit have been associated with SCI, including executive functions like selective attention, card sorting, working memory, and processing speed,[4,30–32] visual motor speed and coordination,[4,22] vocabulary,[17,22,28,33] visual memory,[34] and abstract reasoning and verbal comprehension.[17,35] As a consequence of these specific deficits, academic achievement in math and

reading are also affected, with one study reporting that the 35% of children with SCA and SCI had twice the chance of academic difficulties as those without SCI.[26]

SCI are associated with a specific cognitive profile correlating with their distribution in the frontal lobe, and are associated with cognitive deficits and academic difficulties

Figure 7



The proportion of students with SCA with and without SCIs and sibling controls that have either failed a grade or received special services.[26]

Silent cerebral infarcts: a review on a prevalent and progressive cause of neurologic injury in sickle cell anemia. Blood. 2012 May 17; 119(20): 4587–4596.

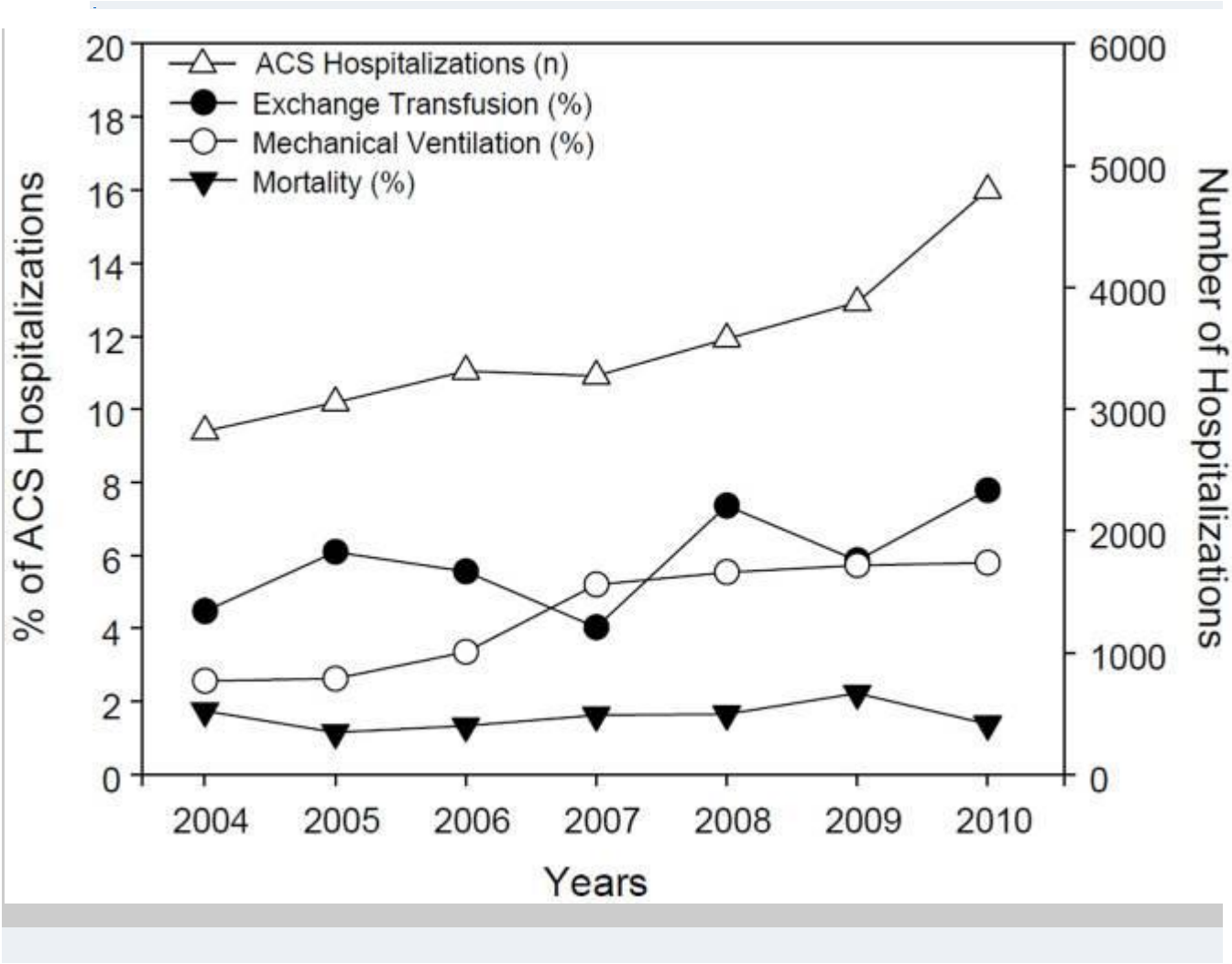
Acute Chest Syndrome

ACUTE CHEST SYNDROME (ACS) is a frequent complication of sickle cell disease (SCD) in patients hospitalized with vaso-occlusive crisis (VOC). It is associated with a high risk of sickle cell-related mortality and morbidity in children, including prolonged hospitalization. More than half of all children with homozygous SCD (HbSS) experience at least one episode of ACS in the first decade of life.[1] Recurrent episodes may herald the onset of debilitating chronic lung disease.[2]

The highest incidence of ACS is in children <10 years of age[36] with frequently occurring triggers in the form of pulmonary infections. Older children and adults more frequently present with dyspnea (labored breathing) and chest pain and tend to follow a more severe course.

Nearly half of all ACS episodes occur between 1 and 3 days after admission for severe VOC. Neurological complications, such as infarctive stroke, silent cerebral infarcts, and posterior reversible leukoencephalopathy syndrome, have been shown to be higher after severe episodes of ACS in children

Acute Chest Syndrome in Children with Sickle Cell Disease. Pediatr Allergy Immunol Pulmonol. 2017 Dec 1; 30(4): 191–201.



Acute Chest Syndrome Hospitalizations and Outcomes per year.

The descriptive figure shows the number of acute chest syndrome hospitalizations per year- identified by "n" (2004 to 2010)- Right y axis. Outcomes such as Exchange transfusion (%), Mechanical Ventilation (%) and Mortality(%) are shown as percentages of acute chest syndrome hospitalizations.(2004 to 2010)- Left y axis.

Close to 95.5% of all hospitalizations occurred on an emergent or urgent basis. About 29.6% of the hospitalizations were covered by Medicare, 40.5% by Medicaid, 20.2% by private insurance, and 3% by other insurance plans. About 6.7% were uninsured.

The mean hospital LOS was 7.8 days.
Outcomes of acute chest syndrome in adult patients with sickle cell disease: predictors of mortality. PLoS One. 2014 Apr 16;9(4):e94387

Kidney Failure
Renal involvement contributes substantially to the diminished life expectancy of patients with SCD, accounting for 16–18% of mortality. Once ESRD (end stage renal disease) is reached, the mortality of patients who are on haemodialysis and have SCD is increased severalfold.

As improved clinical care promotes survival into adulthood, SCN imposes a growing burden on both individual health and health system costs.

Proteinuria (protein in the urine) occurs in up to 27% of patients in the first three decades,[15,58] and in up to 68% of older patients.[15,59]

In a study that involved 98 patients over 5 years the prevalence of CKD (chronic kidney disease) rose from 29% to 42% over this period.

Prior studies demonstrate that irreversible kidney damage (defined by a serum creatinine level >132.6 μmol/l) occurs in approximately 12% of patients with SCD.[62]

In SCT (sickle cell trait), only 40% of RBC haemoglobin content is HbS: the rest is normal HbA. Nevertheless, this amount of HbS is sufficient to cause common complications such as haematuria (blood in the urine) and impaired concentrating ability. A 2014 analysis demonstrated that SCT is clearly associated with an increased risk of CKD and a reduction in GFR.
Sickle cell disease: renal manifestations and mechanisms. Nat Rev Nephrol. 2015 Mar; 11(3): 161–171.

Both ARF (acute renal failure) and CKD (chronic kidney disease) were associated with higher risk of inpatient mortality, longer duration of the hospital stay and expensive hospitalizations. The yearly incidence of new ARF in sickle cell disease patients was 1.4% and annual CKD incidence was 1.3%.

the prevalence of CKD in adults with sickle cell disease was 5.0% and ARF was 4.0%, and incidence of both almost tripled compared to adults without sickle cell disease. Both CKD and ARF conditions were associated with higher mortality and health care utilization in this study.

in a prospective trial that enrolled 725 patients with sickle cell disease, 4.2% developed renal failure, with a median survival of 4 years and **median age at diagnosis of 23 years. The incidence of renal failure increased to 12.0%, with a median age at diagnosis of 37 years.**

Both ARF and CKD were associated with increased mortality during hospital admission. There was a 3.6 relative risk (RR) for death on admission with CKD (95% CI: 2.6–5.0) and an even higher 9.5 RR for death on admission with ARF.

It is now evident that age is a predictor of developing renal failure in sickle cell disease.
Renal Failure in Sickle Cell Disease: Prevalence, Predictors of Disease, Mortality and Effect on Length of Hospital Stay. Hemoglobin. 2016 Sep; 40(5): 295–299.

Life Expectancy

For HIV
This means that a 20 year-old person living with HIV in these regions (including the US), starting treatment after 2008, can now expect to live to 78 (vs life expectancy of 45 years for sickle cell disease).

https://www.avert.org/news/life-expectancy-people-hiv-now-near-normal-%E2%80%93-only-those-accessing-treatment accessed 1.25.19

For Sickle Cell Disease

The median age of death for sickle cell disease in the US has decreased from 1994 – 2005. A decrease in median death of 4 years for males and 6 years for females. Life expectancy can be improved/increased with optimal management of their disease.

For SS patients the median age of death for males was 42, for females was 48 in 1994

Mortality in sickle cell disease. Life expectancy and risk factors for early death.

Platt OS[1], Brambilla DJ, Rosse WF, Milner PF, Castro O, Steinberg MH, Klug PP.

N Engl J Med. 1994 Jun 9;330(23):1639-44.

Median age of death for males in 2005 was for males 38, for females 42

Mortality Rates and Age at Death from Sickle Cell Disease: U.S., 1979–2005
Sophie Lanzkron, MD, MHS, C. Patrick Carroll, MD, Carlton Haywood, Jr., PhD, MA
Public Health Rep 2013;128(2):110–116

In NYS, from 2004-2008, only 14% of sickle cell disease patients were 51 years or older.
https://www.cdc.gov/ncbddd/sicklecell/documents/SCD_in_NY_Prov.pdf

Cost of Disease

For an average person with SCD reaching age 45, total lifetime health care costs were estimated to be nearly $1 million, with annual costs ranging from over $10,000 for children to over $30,000 for adults.

Teresa L. Kauf, Thomas D. Coates, Liu Huazhi, Nikita Mody-Patel and Abraham G. Hartzema,
"The cost of health care for children and adults with sickle cell disease,"
American Journal of Hematology 84, no. 6 (March 2009): 323-327.

The most recent data available shows that costs for hospital stays due to sickle cell disease complications were estimated at $488 million (2004)
https://www.cms.gov/About-CMS/Agency-Information/OMH/about-cms-omh/blog/sickle-cell-disease-care.html accessed 1.25.19

SCD is a major public health concern. From **1989 through 1993**, an average of 75,000 hospitalizations due to SCD occurred in the United States, costing approximately $475 million.
https://www.cdc.gov/ncbddd/sicklecell/data.html accessed 1/25/19
Obviously, costs have increased since then and, as noted below, are now about $1Billion
Sickle Cell Disease is the most costly disease/patient to NYS Medicaid

Sickle cell disease costs~$15,000/patient while the next costly disease/patient is HIV at ~$10,000/patient. Therefore, sickle cell disease costs ~ 50% more/patient than HIV
Personal communication

Other states will a smaller population of sickle cell disease spend more on sickle cell disease care than NYS.

North Carolina	**$4.25M**
Pennsylvania	**$1.26M**
Illinois	**$500,000 for one sickle cell program**
California	**$15M for 5 centers**

NYS has cut funding for care of sickle cell disease patients over the last 20 years by about 66% ($500,000 to $170,000)

With a decrease in cost of ~3.3%/patient to NYS Medicaid, NYS Medicaid could save between ~$4-$5M/year.

For hospital stays primarily due to SCD, "66% were paid by Medicaid and 13% were paid by Medicare
The cost of hospitalizations for treating acute pain alone is now estimated at ~$1 billion

https://www.forbes.com/sites/judystone/2015/06/19/sickle-cell-disease-highlights-racial-disparities-in-healthcare/#3da803723b75 access 1/25/19

Sickle Cell patients on Medicaid receive poorer care than those on commercial insurance.

Use of hematology/oncology care was strikingly low among Medicaid SCD patients. This finding suggests that SCD patients in Medicaid plans may have less access to hematologists/oncologists than patients with commercial insurance. This limited use of specialty care may reduce the preventative care Medicaid patients receive. The higher ED and inpatient use and lower HU compliance in the Medicaid population may be indicative of greater severity and/or unmet need.

Access to Care for Medicaid and Commercially-Insured United States Patients with Sickle Cell Disease

Carlton Dampier, Julie Kanter, Robin Howard, Irene Agodoa, Sally Wade, Virginia Noxon and Samir K. Ballas Blood 2017 130:4660;

Costs to community hospitals is a burden
40.5% having Medicaid, and 54.1% with Medicare

As healthcare costs continue to be scrutinized, a more conscious effort will need to be placed on delivering high quality cost-effective care to our sickle cell population. From this analysis, there is a clear economic burden of sickle cell related hospitalizations to community hospitals. It is also clear that there is a small subset of patients who consume a large percentage of the resources. This may lend itself well to focused collaborative care management services of these high consumers of healthcare resources.

The inpatient management of sickle cell vaso-occlusive crisis is well known, but the goal of treatment extends beyond that of just inpatient management. Patients with SCD need effective management in the outpatient setting in hopes to prevent readmissions, reduce hospital length of stays, and ultimately decrease the economic burden to our healthcare system.

Economic Impact of Sickle Cell Hospitalization: Rahul Singh, Ryan Jordan and Charin Hanlon Blood 2014 124:5971

Lack of funding for sickle cell disease

Average annual NIH funding per affected individual was 3.4-fold greater for CF than SCD from 2008 to 2016. Between 2008-2012, private foundation funding was 161-fold greater for CF than SCD. Between 2013-2016, private funding was 971-fold greater for CF than SCD. There were 1.8 times as many PubMed publications for CF compared to SSD.

Table I: Funding and Research Output for Sickle Cell Disease (SCD) and Cystic Fibrosis (CF)

DISEASE CHARACTERISTICS	**Sickle Cell Disease (SCD)**		**Cystic Fibrosis (CF)**	
Prevalence (USA)	90,000		30,000	
Estimated new cases annually (Global)	300,000		1,000	
Average Life Span (years)	48		41	
AVERAGE ANNUAL FUNDING	**2008-2012**		**2013-2016**	
	SCD	CF	SCD	CF
NIH Funding	$69 million	$85 million	$78 million	$81 million
NIH Funding per individual affected	$769	$2847	$867	$2700
Foundation Revenue	$6.4 million	$342 million	$6.4 million	$2.2 billion
Foundation Revenue per individual affected	$71	$11,420	$72	$69,177
RESEARCH OUTPUT	**2008-2012**		**2013-2017**	
	SCD	CF	SCD	CF
Average Annual PubMed Publications	799	1505	1049	1856
Total Interventional Clinical trials	92	128	137	130
Average Annual Total Trials	18.4	25.6	27.4	26
Average Annual NIH-Federal Funded	5.4	2.2	5	1.2
Average Annual Industry Funded trials	6.8	14.4	6.4	15.4
Average Annual university/philanthropic funded trials	6.8	9.6	16.6	9.4
New FDA Drug Approvals	0	2	1	2
New FDA Drug Indications	0	6	2	5

Disparities in Foundation and Federal Support and Development of New Therapeutics for Sickle Cell Disease and Cystic Fibrosis. Faheem Farooq, MD, MPH[1*] and John J Strouse, MD, PhD. ASH Poster 2018

Little Data on Sickle Cell Disease and Sickle Cell Trait in NYS

There is shockingly little data on sickle cell epidemiology in the U.S., since there is very limited national surveillance data, explained Suzette Oyeku, MD, MPH, a sickle cell expert and health services researcher at The Children's Hospital at Montefiore/Albert Einstein College of Medicine. She also stressed that the transition time from pediatrics to adult care "is a critical time period. The risk of early death increases in this time frame."
https://www.forbes.com/sites/judystone/2015/06/19/sickle-cell-disease-highlights-racial-disparities-in-healthcare/#3da803723b75 accessed 1/25/19

1. How many sickle cell disease patients are currently residing in NYS
2 How many trait patients currently reside in NYS?
3 How many sickle cell disease patients are not in care – ie can't find a primary physician or primary hematologist to take care of them
4 How well do community hospitals do with the care of sickle cell disease patients?
5 How much does it cost to take care of a sickle cell disease patient?

6 How much are hospitals and physicians actually reimbursed to take care of sickle cell disease patients?
7 How can we educate communities, particularly immigrant communities, about sickle cell trait/disease?
8 How can we educate healthcare professionals to treat sickle cell disease patients with respect and dignity?
9 How do we erase the stigma of sickle cell disease?
10 How do we erase the healthcare disparities for sickle cell disease patients?
11 How do we get hospital administrators to prioritize the health and well being of sickle cell patients?

The department of health has many programs, but to avail yourself of a program and you have to be in the care of a healthcare provider. Since most sickle cell disease patients avoid healthcare institutions because of the bias they receive most patients/programs don't know of available programs.

Montefiore had a program for a day hospital for sickle cell disease patients in the 90s and early 2000s. It was subsidized by being one of 10 national comprehensive sickle cell centers. Dr. Benjamin reviewed data before the hospital was opened and compared to 5 years after. Patients, usually with painful crisis could go to the day hospital, when beds available, instead of the ER. In the year prior to the day hospital opening 92% of patients were admitted to the hospital, while in the last 3 years only 6-10% were admitted from the day hospital. With the reduction in admissions and decrease in LOS, it was estimated to save $1.7 million (much more in today's dollars) in addition to providing superior care/outcomes.
Sickle cell anemia day hospital: an approach for the management of uncomplicated painful crises. Blood 2000 95:1130-1136;

Yet this day hospital was closed by hospital administration shortly after the Federal Government stopped funding the national comprehensive sickle cell centers despite the outcry from patients. Why would this program close when it clearly provided better care to patients in painful crisis and saved money?

Sickle cell disease patients require much support to avail themselves of the healthcare system. Most patients are lower socioeconomically and so have difficulty with transportation to many clinic visits, are cognitively impaired by the silent strokes and so have difficulty with memory and problem solving to get to appointments, and frequently do not have adequate availability of social work staff to help them navigate these myriads of problems.

Dr. Kato from Pittsburgh has an anecdote about an adult patient who was scheduled to see a kidney specialist. The patient arrived in time for his appointment but was so confused about the maze of buildings and could not problem solve how to get to his appointment. He gave up, went home and missed his appointment. The cognitive deficits affecting the health of sickle cell patients are very real and very underappreciated.

Mental health issues that arise from having a debilitating chronic illness coupled with brain dysfunction and deficits is also a big issue for sickle cell disease patients and usually not very well addressed.

The previous sickle cell bill submitted to the legislature would address many of the issues above, and it is hoped the new bill will as well. Funding is needed to improve the care of patients with sickle cell disease/trait NOW and to formally collect data, so desperately needed, to better understand and address the healthcare disparities that sickle cell disease patients endure in NYS.

My name is Halima Heyward, I am 45 yrs old, and I have the distinction of belonging to a very small club, within a very small rare disease. I was born with and recently cured of sickle cell, ss type, disease. My life with sickle cell was one of hundreds of hospitalizations and thousands of blood transfusions. I have had most of the complications that sickle cell can create. My complications have included: inability to make enough red blood cells, damage to bones, silent strokes, memory issues, kidney failure and liver fibrosis.

21 months ago, I decided to risk my life in order to be cured of sickle cell disease. I fought for years to be able to receive a bone marrow transplant that could possibly cure me of sickle cell disease. I had a 40% chance of this procedure failing and, therefore, either leaving me with sickle cell disease or dead. That's how desperate I was to be rid of sickle cell disease and it's effects on my life. The cure worked, but I am still left with the damage that sickle cell has done to my body. I am now on dialysis and in need of a double hip replacement. Medicaid has been a life saving program that I am very grateful for. If it were not for medicaid and funding to sickle cell programs over the years I would have been dead as a child, like my sister who died at 3 yrs old from sickle cell disease. Funding for Medicaid and sickle cell programs have afforded me the ability to be seen by top doctors for much needed maintenance and specialty care. Funding saves and improves the quality of life of people who most often are of low socio-economic background and allows them to pursue some semblance of normalcy within their lives. I am thankful that I was able to find care and to be able to get the treatment I needed. Most adult sickle cell patients are not so lucky. We need to change that and make sure that the sickle cell bills in Albany are funded and passed. That way more adult sickle cell patients are able to get the comprehensive care and the chance to save their lives.

Thank you in advance for supporting our efforts to live well with sickle cell.

Sincerely,

Halima Heyward

City Council Jail ULURP Testimony 9-5-2019

My Name is Dave Ehlke, living in the neighborhood of the Brooklyn Detention Center. I am a member of the Justice Ministries Committee of the Presbytery of NYC. I urge our City Council to vote **Yes to the Mayor's plan <u>with these conditions.</u>**

1. Closing the remaining 9 active jails on Rikers island is a moral imperative and human rights crisis. Action needs to be taken **immediately** to **close and demolish at least 4 of the remaining Rikers Island jails,** which are not needed due to reduced population and excess capacity. This can create **immediate cost savings to provide funds for alternative programs to incarceration. It also frees up the land for more productive use.**
2. Because of recent criminal justice reform in the State, the total capacity for borough-based jails should be **3000 people instead of the 5000** planned. This reduced population should be distributed to the 4 proposed borough-based jails plus a separate **Women's facility for 100 people and a separate facility on Staten Island for 100 people.**
3. **The planned capacity of the new facility at 275 Atlantic Ave, Brooklyn and the other 3 borough-based facilities should each be reduced to 700 people.** This would **significantly reduce the height and mass of the building to 10 stories** which includes 2 ground level floors plus 8 housing floors. The design should be flexible to enable jail floors to be converted to drug or mental health treatment facilities in the future.
4. **Operation of the new Facility:** The City must create facilities with the least restrictive conditions that support a **restorative and rehabilitative approach** to incarceration as opposed to the punitive approach currently in use. **The people managing and running the new facilities must be capable of and willing to provide a healing environment. This requires a different Social Services oriented staff & management with new job descriptions that must run the facility**. It is imperative that the punitive environment of Rikers jails not be transferred to the new facilities.
5. **Current Correctional officers and staff:** They should be offered training in a new training facility to compete for these radically different positions and also be offered positions in other city departments since the new facilities will require a much smaller and different staff.
6. **Closing Rikers Island jails is an urgent human rights issue that we cannot delay closing. It is an embarrassment to our city. We must continue this fight but do it in a way that respects our local community as well as the people incarcerated and the employees being displaced.**

Sept. 2, 2019

My name is Adaeze Ubawike. I am a 5th grade math learning specialist and I live with sickle cell anemia. To the world, it may not seem like much that I live with this disease but I try not to allow the burden of living with it affect me too much.

In all honesty, living with this disease has not been easy. I deal with pain that is usually onset by stress or extreme weather temperatures – mainly the cold. There are complications that have resulted from it as well. I have developed avascular necrosis (AVN) in both of my hips. As a result, I sometimes have pain in my hips and it is difficult for me to walk or sit for long periods of time. I also have developed leg ulcers as a result of poor circulation in my legs. These are extremely painful and most times causes swelling in my legs. Over time, I have dealt with at least 5 leg ulcers at different times. I am currently dealing with one leg ulcer. For treatment, I see a wound doctor for debridement and wound dressings/treatment. A few months ago, I started hyperbaric oxygen treatment as another regimen to help close the ulcer. Treatment is done Monday to Friday for 90 minutes in a closed chamber. In order for me to keep up with this treatment, I had to take permission from work to leave early on a daily basis as I work in Brooklyn and treatment is done in Yonkers. Though it has been going well and I have been seeing some progress, treatment has been inconsistent as I have needed to be hospitalized for crisis pain.

I experience pain regularly but try to avoid going into the hospital as I have found that my pain often gets worse before it gets better which lengthens my admissions. This is usually because I have a difficult time in most emergency rooms convincing doctors of the care I need when going through a crisis. Many doctors are afraid/hesitate to give the dosage of medicine I ask for because they feel the dose is too high. I often respond by asking them to reach out to my hematologist and/or look into my hospital records for evidence of past treatment that has helped me to get better. If I am lucky, the doctor will follow through and end up giving the required dose. However, most times, that is not the case. Most times, the doctor will proceed to give the dose they are most comfortable with which is 75% less than what actually works for me. As a result, I end up having to be admitted which usually lasts for 1.5-2 weeks depending on how quickly the attending doctors and I agree on a treatment regimen for my pain.

Due to the irregularities and disagreements between myself and the doctors, I try to care for my pain at home. This includes natural remedies such as heat therapy, massages, and drinking plenty of tea to ease my body in addition to painkillers.

After all I have been through with this disease, I try my best to not let it get to me. I am a special education teacher. And, despite the distance I travel to work, I truly love what I do. I love my students. I love teaching them and I love the ambition and drive I try to instill in them on a daily basis. I can't lie though. It is very difficult to navigate having a full time career with all the issues that come with having sickle cell anemia – various appointments with different specialists, multiple admissions in a year that

you try your best to avoid and your best to get discharged just as quickly as you got admitted, complications with pain several times a week that may not require an admission but definitely require a break from your daily routine. I sometimes find myself fighting with healthcare professionals to view me a professional as well – one who holds a full time job, an actual career – so that they can understand the difficulties I face and find a way to make it easier for me to deal with. I don't want to fight the disease and those that have to care for me as well. It shouldn't be this complicated. With all my thoughts, all I go through on a daily basis, my interactions with healthcare professionals, I find myself asking "do the lives of sickle cell patients truly matter?" Until I am met with consistent healthcare that is compassionate, considerate and respectful, that question cannot be answered with a confident, "Yes". Please pass the New York State budget requested by our Sickle Cell Community to enhance our quality of care.

Sincerely,

Adaeze Ubawike

September 1, 2019

Greetings,

My name is Daniqua Brooks and I am 38 years old. At two months old, I was diagnosed with Sickle Cell Anemia (SC). As a result of minimal research and awareness about triggers, causes and effects of this debilitating disease, my Mother thought my diagnosis meant a death sentence. Due to the doctor's limited understanding about Sickle Cell Anemia, my mother's hysteria was warranted as he too communicated that my life would be one of extreme hardship, blood transfusions, low quality of life and a short life expectancy. Fortunately, God's will is in charge, blessing my life with grace and mercy.

Despite my best efforts to stay healthy and hydrated, I suffer from multiple crisis' that require hospitalizations. Every day, my joints are in pain all over my body which require me to take strong pain medications. The pain swells my knees and limit physical activity. One main issue I have is how medical staff treat me when I have to go to hospital, time to time. Due to many painful crisis and frequent trips to the ER, some staff assume I am drug seeking and/or refuse to honor my pain regiment. When that happens, I have to hope and pray that my doctor is contacted to advocate on the care I need. There must be advocacy for those

afflicted with Sickle Cell to ensure effective treatment, in the same way cancer is.

At 38 years old, despite my hereditary disease, I have accomplished much in my life. I have defied the odds and assumptions people have about Sickle Cell Anemia. I hold a Bachelor of Art Degree in Secondary Education (7-12) and two Masters of Arts (Reading Literacy K-12 and Education Administration). For the past 10 years, I worked as a high school History teacher for 6 years and then became a Middle School Principal in Brooklyn, NYC. The best title I hold however is that of a wife and mother of 2 dynamic sons. Despite my ongoing battles with Sickle Cell Anemia, I can attest to the fact that a person can thrive and enjoy life with proper support in place. Someone dealing with chronic pain shouldn't have to be punished because our state legislature alleges that there's too many people addicted to pain medications. Access is NECESSARY and it is a human right to live pain free or as pain free as possible. I demand advocacy and equal access to funding for proper medical treatment. Please pass the New York State budget requested by our Sickle Cell Community to enhance our quality of care.

Yours Truly,

Mrs. Daniqua Brooks

National Sickle Cell Disease Bill

Bill in Congress – HR 1807

No known bill in Senate

Contact your Congress person

Contact your National Sickle Cell Disease Groups: SCDAA (Sickle Cell Disease Association of America) and FSCDR (Foundation for Sickle Cell Disease Research)

Sickle cell disease patients are the most costly patients to NYS Medicade at $15,000/patient/year, yet NYS only appropriates ~$250,000/yr only to improving sickle cell care

With only a 3% decrease in costs/patient/year, NYS could save ~$5,000,000/year in costs

Mot adult patients are either not in care with a hematologist or not receiving appropriate disease modifying medication – despite the medical literature which shows costs can be decreased wihile increasing quality of life for sickle cell disease patients

Assembly bill A05398 and senate bill S03256 are a start to rectify them but need further improvements to make sure that we have a greater likelihood of success

Would encourage all lawmakers to consult with the sickle cell community (providers, patients and care giver) on ways to improving respective bills

We would encourage both the Assembly and Senate to pass those amended bills

Sickle cell disease is an inherited disease

Sickle cell disease is a blood disorder

Since blood goes to all parts of the body, all parts of the body, all parts of the body can be affected

Most frequent symptoms in adults are severe pain and fatigue

These cause severe limitations for their ability to go to school or work

NYS has about 10% of all sickle cell disease patients in the US

CDC states that sickle cell disease is a major health concerns. Despite this, federal, state, and private funding for sickle cell disease is severely lacking, particularly when compared to other genetic disorders

The last time Grassroots Advocacy worked: Sickle cell treatment Act of 1972, Sickle cell treatment Act of 2003, Tennesee increased state funding

What the Bill says:

Purpose: To include primary and secondary preventative medical strategies, treatment, and services, including genetic counceling and testing, for individuals who have Sickle Cell Disease in the City of New York and for no more than five counties.

-Focus on Stroke and Stroke treatment

-Provides that the Health Dept be responsible for medical assistance and counseling for prevention of sickle cell disease to receivemedical services for individuals who have sickle cell disease.

-Establish Treatment and Prevention Demonstration Programs

-One Center in NYC and up to 5 in other counties

-Provides $1million funding

12% of sickle cell disease births are Hispanic

1.3% of sickle cell disease births are Caucasian

African immigrant mothers have a 2 fold risk for sickle cell disease

~10% of the USA sickle cell disease population lives in NYS and ~80% of sickle cell disease patients live in NYC area

In Early 2000's NYS Funded $500,000

Now NYS Funds $250,000

Other states: Pennsylvania $2million and North Carolina $4million

NYC Council Hearing on Sickle Cell Disease

My name is Vivian Okwuagwu, and I have Sickle Cell Disease. I'm writing testimony in support of ·Res. 335-2018 to establish 8 demonstration programs and 1 coordinating center in New York State.

I am sure you have been apprised of what sickle cell disease is, the large patient population in NY City and State, and the pressing need for treatment/coordination centers.

To all this I will add- as a patient with a rare blood disorder (who also happens to be a black woman), accessing healthcare in NY hospitals is an exhausting, frightening and often dehumanizing process.

I have personally run the gauntlet from depraved indifference to outright hostility from Emergency Room and Hospital medical professionals.

Have reported a Kings County Hospital doctor to the Board for telling me "I was not sick enough to justify treatment", and spent an hour crying so hard I couldn't see outside the ER of New York Methodist Hospital after a nurse gleefully accused me of being a drug seeker, and threatened to call the police (on what charges, no one knows).

Being denied or receiving inadequate care by doctors and nurses who have the barest understanding of SCD (maybe they missed that day of school) is a large part of the reason for our rapidly declining life expectancy.

Having dedicated treatment and coordination centers will effectively eliminate these problems, and provide sickle cell patients with direct access to medical professionals who approach us with *knowledge and dignity*, and who have ALREADY done the important personal work of correcting their harmful racial biases.

Thank you.

okvee_100@yahoo.com

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. _____

☐ in favor ☐ in opposition

Date: _____

(PLEASE PRINT)

Name: Nadine Bates

Address: _____

I represent: _____

Address: _____

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. _____

☐ in favor ☐ in opposition

Date: _____

(PLEASE PRINT)

Name: Wilma Soto

Address: 108-03 16th Ave Corona

I represent: Sickle Cell Awareness Fdn

Address: _____

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. _____

☐ in favor ☐ in opposition

Date: _____

(PLEASE PRINT)

Name: KEN COHEN

Address: REGIONAL DIRECTOR

I represent: HARP NYS CONFERENCE

Address: METROPOLITAN COUNCIL

Please complete this card and return to the Sergeant-at-Arms

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. ________ Res. No. ________

☐ in favor ☐ in opposition

Date: ________

(PLEASE PRINT)

Name: Merlene Smith Sotillo

Address: 108-03 164th Place Jamaica NY 11433

I represent: Sickle Cell Awareness Foundation Corp Int

Address: ________

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. ________ Res. No. ________

☐ in favor ☐ in opposition

Date: ________

(PLEASE PRINT)

Name: Abigail Jean

Address: ________

I represent: ________

Address: ________

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. ________ Res. No. ________

☐ in favor ☐ in opposition

Date: 9-9-14

(PLEASE PRINT)

Name: PandorA Burns

Address: 892 163 St. EJ Jam[illegible]

I represent: Queens Hospital Center / [illegible]

Address: [illegible] 164 St

[illegible] 11432

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THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. _____

☑ in favor ☐ in opposition

Date: _____

(PLEASE PRINT)

Name: Doris Tolanco

Address: 917 Sheridan Ave #5D

I represent: SCTPN

Address: _____

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. _____

☒ in favor ☐ in opposition

Date: _____

(PLEASE PRINT)

Name: GARRY RISSMAN

Address: 255 W. 43rd St., #602

I represent: MYSELF

Address: NY, NY 10036

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. _____

☐ in favor ☐ in opposition

Date: _____

(PLEASE PRINT)

Name: Ginger Davis

Address: 129 Baltic Street

I represent: Sickle Cell Thalassemia Patients Network

Address: _____

Please complete this card and return to the Sergeant-at-Arms

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. _____

☐ in favor ☐ in opposition

Date: 9/9/19

(PLEASE PRINT)

Name: Ada Gonzalez

Address: 95 W. 95 St #21-H

I represent: Myself. Member) SCTPN

Address:

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. _____

☑ in favor ☐ in opposition

Date: _____

(PLEASE PRINT)

Name: Jeremy Griffin

Address: 315 W. 36th St

I represent: New York City Hemophilia Chapter

Address: 315 W. 36th St

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. _____

☑ in favor ☐ in opposition

Date: _____

(PLEASE PRINT)

Name: BRENDAN FAY

Address: 22-22 28th St, Astoria, NY 11105

I represent: Sickle cell ~~Alty~~ Advocacy

Address:

Please complete this card and return to the Sergeant-at-Arms

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. _____

☐ in favor ☐ in opposition

Date: 9/9/2019

(PLEASE PRINT)

Name: DR RIT BELLEVUE

Address: 301 EAST 79th ST NY NY 10075

I represent: SCAC THE SICKLE CELL ADVISORY

Address: CONSORTIUM, OF NY

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. _____

☒ in favor ☐ in opposition

Date: 9/9/2019

(PLEASE PRINT)

Name: Epiphany Samuels

Address: 1209 Gilbert PL 1pt 2 Bronx NY 10474

I represent: myself

Address: _____

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. _____

☐ in favor ☐ in opposition

Date: _____

(PLEASE PRINT)

Name: Sarai Santiago

Address: 1331 Bronxriver Avenue

I represent: Sotoin Sickle cell thalassemia patient network

Address: 1194 Saint John place

Please complete this card and return to the Sergeant-at-Arms

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. 335

☑ in favor ☐ in opposition

Date: 9/9/19

(PLEASE PRINT)

Name: ANTHONY DONOVAN

Address: 120 E 4TH ST.

I represent: _____

Address: _____

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. _____

☑ in favor ☐ in opposition

Date: _____

(PLEASE PRINT)

Name: LINDA BUSCHE - 82-68 164th Street

Address: NYC Health + Hospitals/Queens

I represent: _____

Address: _____

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. 335

☑ in favor ☐ in opposition

Date: 9/9/19

(PLEASE PRINT)

Name: CHARLEEN JACOBS

Address: 1 FISHER DRIVE #202, Mt. Vernon NY 10552

I represent: Healthcare Providers for Sickle Cell

Address: _____

Please complete this card and return to the Sergeant-at-Arms

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. 335

☒ in favor ☐ in opposition

Date: _____

(PLEASE PRINT)

Name: TARTANIA BROWN

Address: 229-24 141 AVE Laurelton NY 11413

I represent: Sickle Cell Fair Treatment Act/

Address: Candice Sickle Cell Foundation

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. 335

☐ in favor ☐ in opposition

Date: 9/9/19

(PLEASE PRINT)

Name: JAcqueline Baker

Address: 16 Adela Court Yorktown Heights NY 10598

I represent: Queens Sickle Cell Advocacy Network

Address: 207 Queens Village, N.Y.

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. _____

☐ in favor ☐ in opposition

Date: 9-9-19

(PLEASE PRINT)

Name: Gloria Rochester

Address: 207-08 Hollis Ave

I represent: Queens Sickle Cell Advocacy

Address: 207-08 Hollis Ave Queens Village N.Y. 11429

Please complete this card and return to the Sergeant-at-Arms

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. _____

☐ in favor ☐ in opposition

Date: 9/9/19

(PLEASE PRINT)

Name: Geneva Farrow

Address: 5 E 91st Brooklyn NY 11212

I represent: Healthy Warrior Mom

Address:

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. _____

☐ in favor ☐ in opposition

Date: 9/8/19

(PLEASE PRINT)

Name: Dr. Cassandra Dobson

Address: 28 Lark Ave

I represent: QSCPN

Address: 28 Lark Ave, White Plains NY

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. _____

☐ in favor ☐ in opposition

Date: _____

(PLEASE PRINT)

Name: TOM MOULTON

Address: 2222 28th ST

I represent: SCTPN

Address: _____

Please complete this card and return to the Sergeant-at-Arms

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. 980

☐ in favor ☐ in opposition

Date: _____

(PLEASE PRINT)

Name: Assemblywoman Alicia Hyndman

Address: _____

I represent: 29th Assembly District

Address: 232-06 Merrick Blvd Queens 11413

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. _____

☐ in favor ☐ in opposition

Date: _____

(PLEASE PRINT)

Name: Winfred Wu

Address: _____

I represent: NYC DOHMH

Address: _____

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. _____ Res. No. _____

☐ in favor ☐ in opposition

Date: _____

(PLEASE PRINT)

Name: Cheryl Lawrence

Address: _____

I represent: NYC DOHMH

Address: _____

Please complete this card and return to the Sergeant-at-Arms