New York City Council Hearing

Oversight: Evaluating Access to Sickle Cell Care in NYC

Committee on Health
Committee on Hospitals

Kenneth Rivlin, MD, PhD

Director of the Division of Pediatric Hematology and Oncology at

NYC Health + Hospitals/Jacobi

NYC Health + Hospitals

September 20, 2023

Good afternoon Chairpersons Narcisse, Schulman, and members of the Committees on Health and Hospitals. My name is Dr. Kenneth Rivlin, and I am the Director of the Division of Pediatric Hematology and Oncology at NYC Health + Hospitals (H+H)/Jacobi. I am joined by Dr. Toni Eyssallenne, Deputy Chief Medical Officer at the NYC Department of Health and Mental Hygiene (DOHMH). Thank you for the opportunity to testify regarding access to sickle cell care in NYC. H+H is proud to provide high-quality care to all New Yorkers, including those affected by Sickle Cell Disease (SCD). Historically, with support from the City Council, two of the first comprehensive sickle cell centers in the nation were established at H+H in the 1980's.

To start, I would like to commend the committees for prioritizing sickle cell disease. As highlighted in the National Academy of Science, Engineering and Medicines 2019 Report – Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action – "Sickle cell disease is a microcosm of how issues of race, ethnicity, and identity comes into conflict with issues of health care." Despite being recognized by the federal government as a disparity disease, sickle cell disease receives limited resources and attention compared to other healthcare priorities.

H+H is committed to improving the lives for all those affected by Sickle Cell Disease. As frontline providers we see the inequities in patient experiences,

quality of care, and health outcomes for sickle cell patients, and are actively working to change this. Today, I will be sharing information on the current services H+H provides in regards to SCD and the work we are doing to improve care and outcomes for those living with SCD. We are proud to share that our system is national leader in SCD, tackling patient and provider education, research, and quality improvement to ensure those with sickle cell disease can get the best care possible.

H+H is one of the largest providers of sickle cell care in the nation. We have 6 NYS designated hemoglobinopathy centers that provide services for children identified with sickle cell disease and trait by newborn screening (Lincoln Jacobi, Harlem, Metropolitan, Elmhurst, and Kings), and 2 lifespan comprehensive sickle cell centers (Kings and Queens). In addition, our 11 hospitals can provide state-of-the-art acute care and our ambulatory centers across the network can ensure prenatal testing, genetic counseling, and social services. Approximately one fourth of the 10,000 individuals living with SCD in New York State touch our system each year. Additionally, H+H partners with local Community Based Organizations to offer patient support groups through NYC Health + Hospitals/Jacobi, NYC Health + Hospitals/Queens, and NYC Health + Hospitals/Kings County. These meetings are held on Zoom and extended to those with sickle cell disease across the entire System. Our community health workers also partner with local

organizations to provide educational outreach to the community about SCD and our services.

Systemwide, H+H has implemented procedural changes to better serve those with sickle cell disease. These include developing:

- A sickle cell navigator in our electronic medical record to guide best practices (one of the best in the nation)
- Yearly stigma training for ED staff in partnership with community-based organizations
- A sickle cell patient advocacy tool
- A hydroxyurea training module for staff and providers
- And establishing the use of an individualized pain plan or pain protocols for all our emergency departments

In addition, H+H's Office of Population Health created a quality improvement learning collaborative using the Project ECHO® (Extension for Community Healthcare Outcomes) model. Project ECHO® is an internationally recognized tele-mentoring innovation that leverages telecommunication technology to move knowledge. The collaborative supported efforts to improve health outcomes and the experience of patients with SCD, focusing on goals such as standardized Emergency Room pain protocols, and stigma reduction.

H+H is also a member of various prestigious national networks working to advance treatment and care for Sickle Cell Disease. We are a designated member of the National Alliance of Sickle Cell Centers (NASCC), an organization that recognizes systems that provide high quality comprehensive care. H+H is also a member of the American Society of Hematology's Sickle Cell Disease Clinical Trial Network, whose goal is to accelerate progress in the development of new treatments. Out of the 20 members consortiums we are the only public hospital system. Being a member allows us to provide our patients the opportunity to participate in clinical research and provide our patients voice into how this research is being done. Finally, H+H is part of the Health Resources and Service Administration (HRSA) Northeast Region Sickle Cell Demonstration Program. As the NYS Lead we are working to eliminate inequities in sickle cell care through quality improvement initiatives such as: increasing use of disease modifying drugs, improving sickle cell trait counseling, establishing pediatric to adult care transition programs, and connecting unaffiliated patients to our medical home using community health workers. Other initiatives include decreasing the stigma of sickle cell disease in the emergency department through collective impact with our communities SCD CBOs and utilizing individualized pain plans in emergency departments.

I am also happy to share that H+H was the only center in the country to receive a prestigious grant from the federal Health and Human Services Office of Minority Health for the years 2020-2023 to increase the use of the disease modifying drug – hydroxyurea through a shared mental model and value-based payments. Hydroxyurea has been shown to decrease the chronic vascular damage that occurs in sickle cell disease, increasing the quality of live and decreasing mortality, but less than 50% of eligible patients use this medication. The goal of grant was to increase its use by 10% by having all clinician ED, primary care, and hematologist help support patients' hydroxyurea clinical decisions.

H+H is appreciative of the attention being given to the education, treatment, and outreach towards SCD in New York City. Thank you to the committees for the opportunity to testify and for your continued support of Health + Hospitals. I am happy to answer any questions you may have.

JUMAANE D. WILLIAMS

TESTIMONY OF PUBLIC ADVOCATE JUMAANE D. WILLIAMS TO THE NEW YORK CITY COUNCIL COMMITTEES ON HEALTH AND HOSPITALS SEPTEMBER 20, 2023

Good morning,

My name is Jumaane D. Williams, and I am the Public Advocate for the City of New York. I would like to thank Chairs Narcisse and Schulman and the members of the Committees on Health and Hospitals for holding this important hearing on sickle cell care in New York City.

Sickle cell disease ("SCD") is the most common and historically underfunded inherited rare blood disorder in the United States, affecting approximately 100,000 people. According to the Center for Disease Control, SCD occurs in about one out of every 365 Black or African-American births and one out of every 16,300 Latinx births. About 10% of the total US population affected by SCD lives in New York State yet state funding remains critically low and public awareness and basic understanding of what this disease entails is limited.

To date, the only cure for SCD is a bone marrow or stem cell transplant but for people living with it on a day-to-day basis, SCD can be challenging. Complications of sickle cell disease are extensive, including but not limited to anemia, liver problems, organ damage, blood clots, pulmonary hypertension, kidney problems, stroke, and vision loss. The sickle cell trait, a single gene for sickle cell disease, can be passed from parent to child increasing the likelihood of SCD.

I urge the City Council to pass Introduction 968, which would require the Department of Health and Mental Hygiene ("DOHMH") to develop a professional education program as well as an outreach campaign regarding sickle cell disease, dedicated to its detection, management and treatment. Furthermore, this bill would require DOHMH, in consultation with the New York City Health and Hospitals Corporation, to establish a sickle cell disease genetic screening program for those with sickle cell traits.

With this legislation, I want to emphasize the importance of educating the public on the need to donate blood. Not only is it critically important for our city's overarching supply, which many of our blood banks have seen a shortage of in recent months, but peripherally, these shortages also disproportionately affect people with SCD as they routinely need transfusions for their treatments.

If we are to truly address the health inequities that exist in our city, then this is a critical first step in shining a light on a condition that disproportionately affects Black New Yorkers, its research and treatment programs historically underfunded. Our partners in the State Senate and the Assembly are currently taking steps to redress these gaps in service with bills, S01890 / A02661 otherwise known as the Sickle Cell Treatment Act, which would establish sickle cell centers of care and partner with state universities for research, granting centers $250,000 in funding per year. We applaud their efforts and I hope to see these bills passed soon but I know that New York City must also do its part and I thank the Council for its initiative in holding this hearing today. Thank you.

New York Blood Center

TESTIMONY ON THE PROPOSED INT. NO. 968-A
SUBMITTED TO THE COMMITTEE ON HOSPITALS
(JOINTLY WITH THE COMMITTEE ON HEALTH)

A Local Law to amend the administrative code of the City of New York,
in relation to a professional education program and public outreach campaign
regarding sickle cell disease.

Submitted by Yadira Navarro,
Director of Community & Stakeholder Relations
for New York Blood Center, Inc.
September 22, 2023

Good morning. My name is Yadira Navarro and I am the Director of Community and Stakeholder Relations for New York Blood Center (NYBC). NYBC has been serving the community with the highest quality blood and stem cell products and related medical and consultative services to hospitals and patients in New York City, and the tri-state area, for six decades. NYBC is world renowned for our novel, and innovative research in the fields of hematology, blood banking and transfusion medicine, and cellular therapies, thus advancing these fields and positively impacting public health and the development of products, technologies, and services in these fields with the potential to have a worldwide humanitarian impact.

Thank you, Councilmember Narcisse, Councilmember Schulman, and the New York City Council for your continuous support of New York Blood Center and the community blood supply and for providing us the opportunity to share testimony in support of this important initiative for our sickle cell disease community. New York Blood Center is fortunate to partner with three local Sickle Cell Awareness Organizations: the NYS Sickle Cell Advocacy Network, the Sickle Cell Awareness Foundation International Corp, and the Sickle Cell/ Thalassemia Patients Network, who are also here to support this bill.

It is no coincidence that as I provide this testimony, NYC is experiencing a blood emergency due to dangerously low supplies of certain blood types. Unfortunately, this is not just a local issue as blood centers across the nation are experiencing the same emergency levels of blood. The work we do for our sickle cell disease community goes hand in hand with a healthy and robust blood supply.

The pandemic had a devastating impact on not-for-profit blood centers here in NYC and across the country in meeting the blood and platelet needs of patients in local hospitals, exposing the vulnerability of our nation's blood supply and the need for greater awareness and an increase in blood donors. Currently, fewer than 2% of the population in NYC donate blood; therefore, it is no surprise that we often teeter on the line of meeting the needs of our local patient community. Additionally, post-pandemic, we saw a 50% decrease in youth, diverse, and first-time blood donors. Youth donors, pre-pandemic, accounted for 25% of all blood donations, therefore, gaining this segment of our donor base is critical to the sustainability of our community blood supply.

Blood Donations from our diverse communities are also critical in serving patients requiring chronic blood transfusions such as thalassemia and sickle cell disease. NYBC is proud to have the largest, rare blood inventory in the world, here in Long Island City, Queens. This inventory serves patients with special blood match needs worldwide. Our world-renowned team, of "match-makers" in our Immunohematology Laboratory, search for the most compatible blood for a patient in need. It is important to note that one in three African-American blood donors is a match to a sickle cell patient. Therefore, genetic diversity in our blood supply is crucial in supporting the sickle cell disease community; representation here truly matters.

Blood, and blood product, transfusions remain a critical treatment option for patients with sickle cell disease with as many as 90% of patients receiving at least one transfusion by the age of 20. As part of the proposed NYC Educational Bill on “management and treatment of sickle cell disease”, NYBC is fully committed and will continue in its mission in collecting and providing precise-matched units for these patients and in providing educational training in blood donor outreach programs. Using novel blood typing technologies, we are developing specialized screening platforms that allow for rapid identification and provision of blood products for patients with sickle cell patients in need of life-saving transfusion. Our research programs are focused on hematological disorders, and we are actively involved and equally committed to pursuing discovery science centered on the development of novel treatments for patients with sickle cell disease. Focusing on painful crises, a major symptom of sickle cell disease which occurs when sickle red cells block blood flow and oxygen delivery, our researchers have identified certain white blood cells that can remove the sickle cells from the blocked vessels. As part of our ongoing sickle cell research program, we are targeting these cells by developing new drugs and cell-based therapies to unblock the blood flow and reduce episodes of severe pain. NYBC would welcome the opportunity to share additional information on other sickle-cell-related research projects should the council need it.

As part of our work with our sickle cell disease awareness partners, NYBC has also supported expanded testing for sickle cell trait, as well as antigen markers, in the blood of diverse blood donors. These small-scale efforts over the last 12 months have cost nearly $100,000 and were limited in their effectiveness in identifying blood donors with the trait or donors who could assist our sickle cell disease community. However, accessibility to this testing is important, as those who are able to learn if they are sickle cell trait positive are able to make better-informed health decisions and family planning. If passed, proposed Int. No. 968-A will provide the professional medical community with the assistance they need to do the lifesaving work needed for these patients.

New York Blood Center asks for your support of this bill and requests the inclusion of education on the need for blood from people of all genetic make-ups and ethnicities so that our sickle cell disease warriors have the precise-matched blood they need to endure the challenges of this disease. We are committed to bringing positive change to the treatment of sickle cell patients and know that NYBC is a willing partner in future conversations in reference to this bill.

A healthy and diverse community blood supply is essential to the health of our sickle cell disease warriors.

Sickle Cell Disease Testimony

9/20/2023

To the Committee on Hospitals jointly with Committee on Health

Thank you to Chair Narcisse and Chair Schulman for the opportunity to testify. My name is Mbacke Thiam. I am the Housing and Health Community Organizer at Center for Independence of the Disabled, NY (CIDNY). We are a nonprofit organization founded in 1978. CIDNY is part of the Independent Living Centers movement, a national network of grassroots and community-based organizations that enhance opportunities for all people with disabilities to direct their own lives. CIDNY is the voice of people with disabilities in New York City.

I am here to testify and support bill Int. 0968-2023 for a professional education program and public outreach campaign regarding Sickle Cell Disease (SCD). It is vital for minority groups and students to learn and comprehend that SCD is a group of inherited red blood cell disorders, its symptoms, and treatment options.

If people don't know they have it, they cannot address it. They will not be able to make lifestyle adjustments, or even informed decisions about the course of their lives. If people have SCD, it is crucial for them to know how to stay healthy with the disease and for them to be aware that their life expectancy is estimated to be 52.6 years. It is possible for people to live with SCD and be involved in activities that other people do, without jeopardizing their health. As it stands right now, appropriate education on this disease is not being provided.

It is important to bring awareness about the program to people with disabilities and their family members as well as people with chronic disease. Outreach strategies may need to be developed to involve immigrant families as they have language barriers.

Mbacke Thiam, He/Him/His
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New York City Council Meeting, File Int 0968-2023, 10:00AM on 9/20/2023

Expert testimony by Jason Crites, Founder/CEO of Assurance Health Data

I am Jason Crites, Founder and CEO of Assurance Health Data. I am a 20 year veteran in data and data analytics, having spent a significant portion of my career at IBM and IBM Watson where I helped invent the federated data model and global storage solution. For disclosure, I am not an expert in New York law, New York health systems, nor sickle cell disease. However, I am a patient and privacy advocate and expert and frequently work in collaboration with rare and orphan disease groups to empower patients with these diseases to receive diagnostics, treatment, and care resources that provide them the best possible health outcomes.

It is my ground truth that a patient's data belongs solely to the patient. There is nothing more personal and private than one's own health data. Unfortunately, our health system and biomedical infrastructure is currently set up to take ownership away from the patient and shift it to health systems, pharma and health tech companies, and other entities that are able to derive significant value from patient data without the involvement or benefit of the patient. In the health data industry, these practices exploit the patient and create artificial data silos that enable entities to commercially exploit patient data while creating unnecessary economical and logistical barriers to discovery, development, and delivery of care to the patients.

It is our view that every disease group should have an ethically-formed and patient-controlled registry that collects and structures patient data in an FDA-compatible format on a platform where the patients have full visibility and control over how their data are used. These registries form the basis for connecting patients to educational resources, healthcare resources, and enable emerging technologies such as precision medicines and AI and machine learning.

From the patient standpoint, such a registry enables patients to have full access and control over their comprehensive health data at their fingertips. It enables them and their caregivers to be informed advocates for their health and rapidly disseminate key information to care providers to receive the right care at the right time. It empowers patients to actively participate in clinical trials and research and development for novel diagnostics and therapeutics and connects patients from across the country in a way that would otherwise not be possible in our current health system. It enables delivery of targeted and patient-specific educational materials that can help patients navigate the complexities of their disease.

Additionally, it provides an opportunity to overcome biases and misappropriated care that sickle cell patients frequently experience in our health system. Far too often, sickle cell patients who are experiencing crisis in an emergency room are wrongly stigmatized as drug seekers when in fact a simple blood test or health record on their phone can identify them as a sickle cell patient in need of a specific care pathway. Simply put, we can provide patients, their advocates, and care providers with the information they need to end this needless misery and significant waste of limited healthcare resources.

We live in a data-driven world where data can make an incredible impact on people’s health, but we have the moral and ethical responsibility to patients to create data systems that put them at the center.

Testimony to the CITY COUNCIL on behalf of ONE BROOKLYN HEALTH

Sickle Cell Care in New York City Hearing - Sept. 20 (Committees on Hospitals & Health)

Kusum Viswanathan, MD, FAAP
Chief Medical Officer, ONE BROOKLYN HEALTH- Brookdale Hospital Medical Center
Chair, Department of Pediatrics
Director Division of Pediatric Hematology/Oncology and Comprehensive Sickle Cell Program

I represent One Brooklyn Health's Comprehensive Sickle cell Programs at Interfaith and Brookdale Hospital Medical Centers. These programs have a long history of providing coordinated, family-centered, and comprehensive medical and psychosocial care to children and adults with sickle cell disease for more than fifty years.

SCD is an inherited disease, diagnosed at birth by newborn screening. Patients can present with episodic, recurrent, frequent, and unpredictable pain crises that respond only to narcotic pain medication and require hospitalizations. They develop complications in different organs; acute chest syndrome (lungs) resulting in low oxygen and difficulty breathing, strokes leaving significant disabilities, silent strokes causing cognitive defects, gallstones, sudden enlargement of the spleen causing shock and death, enlarged heart, pulmonary hypertension resulting in sudden death, retinopathy of the eyes, avascular necrosis of the hip bones requiring hip replacement, kidney failure requiring dialysis, tendency for severe infections, leg ulcers and priapism.

OBH offers comprehensive care at Brookdale and Interfaith including: follow up of newborn screening referrals and enrollment in the program, pain management treatment plans; regular assessment for end-organ damage, including ophthalmology, renal, cardiac, neurological, and pulmonary evaluations; transcranial Doppler testing, infection management, immunizations and prophylactic antibiotics for pediatric patients; transfusion therapy; hydroxyurea administration; disease modifying treatments like Crizanlizumab and Voxeletor, iron chelation therapy; referral for bone marrow transplantation and gene therapy, counseling and education.

Tremendous strides in treating and preventing the complications of SCD have extended life expectancy.; Nearly 95% of persons born with SCD in the United States reach age 18 years. However, adults with the most severe forms of SCD have a life span that is 20–30 years shorter than that of persons without SCD. The lack of access to high quality comprehensive care for adults with SCD may explain the overall increased mortality rate. Many sickle cell programs lack funding for support services like social work or Care Management services to help patients with overall better care. Patients need guidance, financial help, emotional support, counseling, and education to navigate the system and to assist them with insurance, transportation, and other non-medical needs. Patients do not follow up with their appointments and end up in the ED for episodic care because they lack the resources and assistance they need.

OBH supports the proposal to develop/conduct professional education and genetic screening and public outreach campaigns about sickle cell and treatment programs. Over the last 30 years, OBH's Interfaith and Brookdale programs have conducted numerous outreach and educational events in many forums including schools, PTA's, faith based and community-based organizations. We are aware of the need to educate the patients, the public, schools and employers in an effort to empower our patients. Patients often have difficulties in working with the school system or employers to enable them to take time off for check-ups or hospitalizations. The education system and employers do not necessarily view the patient with sickle cell as someone with a "disability"- therefore services that may be offered to a person with a disability may not always be offered. This campaign will enable our patients to be understood, accepted, flourish and reach for the stars.

OBH also requests the City Council to support the establishment of the Sickle Cell Treatment Act in NY State which advocates for the creation of five general hospitals or hospices, upon successful application, as centers for sickle cell care excellence. The centers of excellence shall provide specialized sickle cell disease care, treatment, palliative care, education, and related services and shall conduct specialized research into the care, treatment and management of sickle cell disease in affiliation and cooperation with medical colleges and life science research. These are completely aligned with the services provided at OBH and additionally, we are affiliated with medical schools and research facilities. The Bill will allow the commissioner to designate ten hospitals, distributed based on sickle cell patient population concentrations, as sickle cell outpatient treatment centers which shall provide patients treatment for sickle cell disease as an outpatient. The Programs at Brookdale and Interfaith currently follow over 700 patients with sickle cell disease for complete care and hospitalizations. This involves regular care in the outpatient unit, emergency room visits, outpatient pain management, management of complications while hospitalized, participation in National Clinical Trials, education, counseling, and referral for services based on the social determinants of health. This Act will allow Centers like ours that cater to a significant number of patients to have the resources to enhance the care these patients need. Case Management and Social work resources in our centers will greatly enhance our programs.

We thank you for your attention.

OBH One Brooklyn Health

September 22, 2023

One Brooklyn Health (OBH) was disappointed that our hospitals were not included among the descriptions of hospitals providing comprehensive sickle cell care which were included in the Committees' background material at the September 20th hearing of the Committees on Hospitals and Health.

One Brooklyn Health's Brookdale Hospital Medical Center and Interfaith Medical Center have been providers of care for children, adolescents, and adults with SCD for more than 50 years. We serve more than 700 patients. Our Comprehensive Sickle Cell program offers a range of services provided by dedicated teams of hematologists and other medical practitioners, nurses, and social workers to help sickle cell patients manage their medical and social services needs. Through our Hemoglobinopathy Center we provide evaluations of newboms. Other services of our Comprehensive Programs include pain management; ophthalmology, renal, cardiac, neurological, and pulmonary evaluations; infection management; transfusion therapy; disease modifying treatments; counseling and education; and referral for bone marrow transplantation and gene therapy. We conduct monthly support groups for our patients and their families. The OBH hospitals were early participants in national clinical trials for therapies that were subsequently FDA approved for patients.

OBH has a longstanding partnership with community based SCD organizations, such as the Sickle Cell Thalassemia Patient Network. In addition, we have held leadership roles on the Sickle Cell Advisory Consortium.

OBH supports the Council's proposal that professional education and genetics screening be conducted and public outreach campaigns about SCD treatment programs be widely implemented. We ask that our Comprehensive Sickle Cell Programs be listed in any publications that you distribute.

Respectfully,

Kusum Viswanathan, MD, FAAP
Chief Medical Officer,
ONE BROOKLYN HEALTH-
Brookdale Hospital Medical Center
Chair, Department of Pediatrics
Director Division of Pediatric Hematology/Oncology

Comprehensive Sickle Cell Program

Visiting Professor of Pediatrics, SUNY- Health Sciences University

Miren Blackwood, MS
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SICKLE CELL THALASSEMIA PATIENTS NETWORK

Testimony in Support of Proposed Int 968-A Amending the Public Health Law to Address Sickle Cell Disease Care and Education.

Presented to the NYC Council Joint Health and Hospital Committees Hearing.

Teresa Ginger Davis, President, Sickle Cell/Thalassemia Patients Network (SCTPN)
September 20, 2023

1. Introduction

Honorable BP Mark Levine, CM. Chair Mercedes Narcisse, CM. Chair Liz Shulman, Members of the Hospital and Health Committees.

I am privileged to provide this testimony on behalf of Sickle Cell/Thalassemia Patients Network (SCTPN), a NYS-based tax-exempt nonprofit founded by adults living with sickle cell disease (SCD), and thalassemia (Cooley's Anemia) over 40 years ago.

SCTPN strongly supports the Proposed Int 968-A, which seeks to amend the Public Health Law to comprehensively address Sickle Cell Disease (SCD) education and care in New York City. The passing of the Proposed Int 968-A, will address three very significant needs of the SCD community in New York City:

1. Mandating provider training to better understand and treat this complicated disorder and incrementally increase the number of qualified providers able to deliver quality care for the growing SCD population.
2. Improve and increase access to comprehensive treatment centers for sickle cell hemoglobinopathies, particularly for adults.
3. Add verbiage into the legislation to have health payers cover the cost for genetic screening
4. Assist sickle cell CBOs in educating the public about sickle cell traits (SCT), increase access to genetic screening and counseling. Especially for men and immigrants from malarial countries where SCTs are prevalent. Concerted public health education and genetic testing in NYC will help identified carriers to make informed decisions that can, over time, lower the transmission of sickle cell disease.

The long-term goal is to finally eradicate the presence of this genetic disorder.

I have dedicated my life and career to advocating for individuals and families affected by sickle cell hemoglobinopathies, and I firmly believe that this legislation represents a crucial step forward in addressing stigma and healthcare disparities against sickle cell disease, which will ultimately lead to improvements in medical care delivered.

There is a wealth of scholarly research and case studies on disparities in health care relating to sickle cell disease and the economic impact on families, communities, Medicare, and Medicaid. A recent study by LaTosha Lee, PhD, MPH, and notable sickle cell providers, titled "Reducing Health Care Disparities in Sickle Cell Disease: A Review," highlight historical data on the shortage of specially trained providers, barriers that perpetuate reduced access to comprehensive, quality treatment, and how these disparities increase both morbidity and mortality in the adult SCD population.

2. Improving Access to Comprehensive Treatment Centers

One of the most pressing issues facing individuals with sickle cell disease, particularly adults, is the lack of access to comprehensive treatment centers. SCD is a complex condition that requires specialized care to manage its symptoms and complications effectively. Unfortunately, most adults with SCD in New York City are lost to comprehensive services after transitioning out of pediatrics to adult medical care, and struggle to access appropriate healthcare services.

Proposed Int 968-A offers a solution by focusing on improving and increasing access to comprehensive treatment centers for SCD hemoglobinopathies. Sickle cell treatment centers do provide a holistic approach to care, addressing not only the medical aspects of the disease but also the educational and psychosocial needs of patients and families. By establishing and supporting such centers, this legislation will ensure that adults with SCD receive the specialized care they require in health homes with collaborative teams, rather than in emergency departments. Comprehensive care ultimately leads to improved health outcomes, a better quality of life, and longevity.

3. Mandating Provider Training

There are huge gaps and disparities in accessing genetic screening for sickle cell traits, diagnosis, treatment, and continuity of quality care for people with sickle disease. To effectively address SCD, it is essential that healthcare providers receive specialized

training in understanding how to treat this complex condition. Proposed Int 968-A recognizes this need for provider training to better equip medical professionals with the tools to:

1. Enhanced Patient Care and Management: Provider education equips healthcare professionals with the knowledge and skills necessary to effectively diagnose, treat, and manage SCD. This includes understanding the underlying genetic and molecular aspects of the disease, recognizing the signs and symptoms of SCD-related complications, and staying up to date with the latest treatment options and guidelines. With a well-educated healthcare workforce, patients with SCD receive more accurate and timely care, leading to better disease management and improved quality of life.
2. Reduced Health Disparities: SCD disproportionately affects certain populations, including African Americans and individuals from regions like India, South America, and the Middle East with a high prevalence of the Sickle Cell Trait. Provider education helps healthcare professionals develop cultural competence and sensitivity when caring for patients from diverse backgrounds. By addressing disparities in SCD care, provider education can contribute to more equitable access to healthcare services, reduced healthcare disparities, and improved health outcomes for all patients, regardless of their ethnicity, or socioeconomic status.
3. Cost Savings and Healthcare Efficiency: Comprehensive provider education in SCD leads to more efficient and cost-effective healthcare delivery. When healthcare professionals are well-informed about SCD, they can make accurate diagnoses earlier, implement appropriate treatment plans, and prevent costly emergency room visits and hospitalizations. Moreover, by promoting preventative care and monitoring, provider education can help reduce the overall healthcare burden associated with SCD, benefiting both patients, families, and healthcare systems by optimizing resource allocation.
4. Data collection to substantiate the efficacy and efficiency of the proposed amendment, collect needed data on the SCT/SCD population, and verify cost savings attributed to comprehensive and preventive care.

"Nothing for us, without us." 0*Sickle Cell Community*

Regarding provider training, it is important that the community's experience and knowledge be included in training to enhance the knowledge and skills of healthcare providers. Community advocates and community-based organizations (CBO) must be included in the provider education process to foster more compassion, cultural competency, equity, and establish trust between providers, patients, and caregivers. With the increasing prevalence of SCD in our city, it is imperative that all healthcare institutions and their providers be open to centric collaborations with CBO advocates with life experience to support the delivery of quality care to New York residents and anyone living with SCD visiting our fair city.

The Sickle Cell/Thalassemia Patients Network and other sickle cell CBOs in NY participate in three Project ECHO Provider Education Programs – with Johns Hopkins MC and NYCHHC Jacobi MC. SCTPN Chairs the ECHO 2.0 CBO Education Project for SiNERGē (NE Collaborative of SCD organizations), and starting in the spring of this year, is working to develop its own Project ECHO for Community/Provider Education Program. In collaboration with Pathways to Trust, SCTPN will deliver "A Time to Listen to Sickle Cell Disease" provider education pilot project at four (4) NYC hospitals in early 2024. Pending the outcome of the pilot, SCTPN will expand the program with the assistance of its affiliates and chapters throughout the state.

Advocates and organizations are well equipped to support the proposed provider training efforts, and the collection of data to support finding.

4. Educating the Public and Access to Genetic Counseling

Sickle cell disease is a genetic condition, and understanding its inheritance patterns and implications is vital for youth and individuals of childbearing age. Proposed Int 968-A takes a proactive approach to education by assisting Sickle Cell community-based organizations in their efforts to educate the public about who is at risk for carrying a sickle hemoglobinopathy trait and getting tested to learn if they are a carrier. Amending the public health law to increase access to genetic testing and counseling services is vital to state and national efforts to reduce the incidence of inheritance of SCD. Moreover,

the cost of genetic panels varies from $75 to $500. Screening costs need to be standardized and affordable. The legislation should contain language that requires health payers to cover the cost for public trait screening hostes by DOHMH, HHS, and community organizations. We have a chance to replicate the success of the Orthodox Jewish Community, in using testing and genetic counseling to eradicate the presences of Tay-Sachs disease syndromes in their population. It is a future that all sickle cell advocate organizations want to achieve.

An education initiative is especially critical for niche populations, such as men and immigrants from malarial countries where SCTs are prevalent. Many individuals in these demographics may be unaware of their trait status and the potential risks associated with having a child(ren) with SCD. By facilitating public screening to identify people with SCT and providing genetic counseling, we can empower individuals to make informed family planning decisions and reduce the incidence of SCD in the future.

One other issue for public education is that of blood donation among Black, Brown, and immigrant communities. Last week the NY Blood Center (NYBC) declared and emergency about a 'critically low blood supply.' After touring the NYBC's Long Island City labs, I and members of my staff saw for ourselves empty tray for several blood types. Blood pints allocated for rare disease transfusion dependent patients are seriously depleted. Recuring blood donation shortages have and continue to impact transfusion dependent sickle hemoglobinopathy, cancer, and emergent trauma patients throughout the city. Blood donor awareness must be part of any public health education outreach.

In closing, Proposed Int 968-A represents a significant step forward in addressing Sickle Cell Disease in our city. This legislation provides a wonderful opportunity for co-creators like sickle cell CBOs, other health-focused organizations, hospitals, private practitioners, academic institutions, and government agencies to work concertedly for the benefit of children and adults living with sickle cell disease. We see the potential for inclusion, equity, and access to quality healthcare. Free of discrimination, bias, and medical neglect. Undoubtedly, this legislation will enhance the quality of life for individuals and families affected by SCD. SCTPN and its network of organizations urge the Joint NYC Council Committees and DOHMH to ensure the success of the proposed health law amendment, to demonstrate your combined commitment to the health and well-being of all New Yorkers.

SICKLE CELL
THALASSEMIA
PATIENTS NETWORK

Thank you for your attention to this critical matter.

Respectfully submitted by,

Ginger Davis
President
Sickle Cell/Thalassemia Patients Network
gdavis@sctpn.net

I would like to thank Councilwoman Mercedes Narcisse and the other members of the health committee for writing this landmark proposal.

My name is Milton D. Wade, and I am a retired New York City School teacher and sports coach. I am also the father of Micah D. Wade who, lost his battle with Renal Medullary Carcinoma (RMC) on September 25, 2021, at the young age of 20. RMC is a rare and aggressive form of non-clear cell kidney cancer that occurs in in individuals with sickle hemoglobinopathies such as sickle cell trait (SCT). Individuals diagnosed with RMC have a medial survival rate of 13-15 months. My son lived 12 months after being diagnosed with RMC.

I am a trait carrier, and this inherited blood disorder was passed on to my son. Throughout my life I was unaware that the episodes of illnesses that I have endured were the byproducts of sickle cell trait. I personally have a vested interest in seeing this legislation become part of the New York City code due to my son's untimely death and as I had two students with sickle cell disease (SCD).

In 2008, CDC reported that approximately fifty percent of people with sickle cell disease had one emergency room visit and thirty percent had at least one hospital admission. Out of this number twenty-five percent spent eleven or more days in the hospital. The most common complications cited were pneumonia, anemia, renal failure, and asthma. The most common medical treatments and procedures were blood transfusions, MRI, Transcranial doppler (signs of stroke) and joint replacement surgery. Out of the 197 births in New York State 136 or 69% occurred in New York City.

In 1972 The United States Congress passed Public Law 92-294, also known as "The Sickle Cell Anemia Control Act". If you were to read the law as it was written, you would find that it clearly states that sickle cell disease is the result of sickle cell trait carriers. This law created funding which was the equivalent of 1.9 billion in today's dollars for research and education. Within the fifty-one years of its passage there have been several repeated versions of this law as well as the updated version currently making its way through committees.

The law was to enable states, local governments, and institutions access to funds designated to fight this dreaded disease known as sickle cell anemia. I have yet to discover any state in the union or municipality that has an educational program for physicians as well as the public at large. It remains a challenge to fight historical mistrust of public health issues coupled with the enduring disparities in health care within most communities.

With passage of 968-A, New York City will become the first municipality in the nation to mandate a physician's educational program as part of its code and a community outreach initiative. Passage of this proposal would provide clarity to the community you serve without the need of incentivized programs to physicians [i] which gives the appearance of violating the Federal Anti-Kickback Statutes or the Stark Law.[ii] I would ask that the city council be provided with the findings of the Health & Hospital - Queens study after the September 29, 2023 deadline with the intent of using information towards policy implementation.

There is no wording in proposal 968-A that mentions SCT, however for a child to have sickle cell disease, both parents must have sickle cell trait. This inherited blood disorder affects approximately 3-4 million Americans in the United States. Whereas, majority of the population is African Americans, SCT can also affect Hispanics, South Asians, Caucasians from Southern Europe, and people from Middle Eastern countries. These individuals normally do not have SCD but can manifest symptoms such as blood clotting, sudden chronic chest pain, retinopathy, and kidney damage over the course of their lives.

Sickle Cell Disease affects all races and ethnic groups. In New York State, sickle cell disease occurs in approximately one out of every 260 Black or African American births, one out of 10,209 Caucasian birth and one out of 2,714 Hispanic births, according to the 2008 reporting of the CDC.

The importance of adding section 17-199.23 to the city code cannot be overstated as it is long overdue. However, I personally feel that the proposal in its current form needs to be modified as follows:

- Section A
    - Change sickle cell disease program to sickle cell program or add sickle cell trait in the wording.

- Section B
    - Genetic screening program…. establish a sickle cell genetic screening program to determine trait status of individuals who fall into an at-risk population.

- Section C
    - Education and outreach should include not only the public, but also the New York City Department of Education as it relates to its Athletic League.

There is relevancy for including the Department of Education in the overall outreach. The Public School Athletic League as well as New York States mandates that athletic coaches maintain AED, CPR, Concussion and First-Aid training. The PSAL medical form that is required of all 46,000 students who annually participate in a sport to include their SCT/SCD status. The PSAL website also provides information on the protocol for an athlete experiencing a health crisis due to a symptom of SCT called exertional sickling. However, the PSAL does not provide educational training for its coaches who are in more frequent contact with children more than a physician would be and could unknowingly create a harmful situation.

In summary, while SCT is usually not always as severe as SCD, it is not entirely benign. Understanding one's carrier status, taking appropriate precautions, and seeking genetic

counseling when planning a family are essential steps to ensure the well-being of individuals with SCT and their future children. Additionally, raising awareness about SCT in the community is crucial to prevent complications and promote informed decision-making. These initiatives can not be achieved without the implementation of proposal 968-A.

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[i] The initiative will be led by the New York City Health & Hospitals/Queen
s who will partner with the New York State Department of Health to test the hypothesis that physician incentives can drive the needed system change to increase hydroxyurea use in their patient population.
The Office of Minority Health expects the awarded project to generate data and assess the impact of incentive payments on hydroxyurea prescribing behavior and support the identification of best practices and lessons learned.

The project period for the grant is September 30, 2020 to September 29, 2023.

Grantee	**City**	**State**	**Award**
New York City Health & Hospitals/Queens	Jamaica	NY	$1,250,000

[ii] Anti-Kickback Statute (AKS) is a criminal statute, dating back to the 1970s, that prohibits the exchange (or offer to exchange), of anything of value, to induce (or reward) the referral of business reimbursable by federal health care programs. Penalties for violating the AKS include fines of up to $25,000, up to five years in jail, and exclusion from Medicare and Medicaid care program business. Investigation has been assigned to the HHS OIG with enforcement actions by the DOJ. A confusing factor is that there are alternative administrative authorities assigned to the OIG. Important is that the great majority of DOJ enforcement actions in health care arise from the AKS.

Stark Laws (physician self-referral laws) are federal civil laws that prohibit physician self-referral, specifically a referral by a physician to an entity providing “designated health services” (DHS) where the physician (or his/her immediate family member) has a financial relationship. Violations are non-criminal. Penalties for violations of Stark Law include (a) denial of payment for money received by physicians and facilities, (b) payment of civil penalties of up to $15,000 for each service provided in violation of the law, (c) three times the amount of improper payment the entity received from the Medicare program, and/or (d) exclusion from the Medicare/Medicaid programs. Although it is the primary agency responsible for enforcing the Stark Law, CMS has resulted in little government-initiated enforcement litigation. Instead, Whistleblowers (qui tam relators) have been the primary drivers of Stark enforcement actions through the DOJ.

Written Testimony.

My name is Rita Bellevue. I am a retired physician since 2015 and I am an active advocate for Sickle Cell Disease. I was trained in Internal Medicine and Hematology (both adult and pediatric hematology). I established a comprehensive program for newborns, children, adolescents and adults with a strong transition component and a Medical Home first at Brooklyn Jewish/Interfaith Medical Center(1978-1995), and at Brooklyn Methodist Hospital (1995-2015). I coordinated for 37 years in the 2 Institutions Newborn Screening in collaboration with the New York State Newborn Screening Program (comprehensive care for the newborns with sickle cell disease and education for the parents including parents of newborns with trait).

Sickle cell Disease is an inherited disorder of the red blood cells characterized by anemia, vaso-occlusion, pain , progressive tissue and organ damage. This is due to the distortion or polymerization of the hemoglobin S in the red blood cells in low oxygen environments. Chronic organ damage in sickle cell disease is responsible for the morbidity and mortality of most patients.

We have very few comprehensive programs in New York and many adult patients receive care in the emergency rooms when they are sick. Many sickle cell programs lack funding to provide services such as psycho-social support, counseling and some other essential medical and financial needs.

I am one of the Coordinators of SCAC an organization for physicians, nurses, other health professionals, patients and family, and the Sickle Cell Community base organizations; and I am Emeritus Chair of SCTPN the Sickle Cell Thalassemia Patient net work.

I support the proposal to develop/conduct general education, genetic screening for professionals and the public at large. We need comprehensive Centers in New York City, Long Island, Rochester, Westchester, Upstate New York. That is why I support also the Sickle cell Bill, which will provide resources for the formation of Sickle Centers.

Thank you very much,

From: Rita <bellevuer@aol.com>
Sent: Thursday, September 21, 2023 11:11 PM
To: Testimony
Subject: [EXTERNAL] NYC Council Joint Committee Hearing for Sickle Cell Disease

TO THE NYC COUNCIL JOINT COMMITTEE HEARING FOR SICKLE CELL DISEASE

My name is Dr Rita Bellevue and I was unable to be at the hearing yesterday because of health issues. I did send my testimony yesterday but my letter today is regarding the committee's report SECTION(5.)Health care Facility in New York State and New York City.
I want first to introduce myself properly. I am retired since 2015. I worked for 17 years at Brooklyn Jewish/Interfaith Medical Center from 1978 to 1995, and at New York Methodist Hospital from 1995 to 2015. In both Institution I established 2 strong Comprehensive Sickle Cell Programs for newborns, children adolescents and adults with a well organized newborn screening in collaboration with New York State with education for parents of children with trait and disease. Now I am Director Emeritus of the Sickle Cell Program at NYP Brooklyn Methodist Hospital. I am an Advocate and strong supporter of the CBOs in New York particularly SCTPN and I am Chairman Emeritus of their Advisory Board. I am one of the 3 Coordinators of SCAC , the Sickle Cell Advisory Consortium of New York.
SCAC was organized many years ago by Dr Doris Wethers and is the premiere organization of physicians, nurses, social workers, other health professionals, patients/families, community base organizations. We are committed to meeting the needs of those in the sickle cell community and to ensuring comprehensive, quality care. SCAC fulfills its mission through education, advocacy, outreach and coordination of all efforts. We have regular meeting now virtual since COVID.
Regarding the Committee's report, I was surprised to see 2 longstanding and well known programs among the very few programs in New York City providing comprehensive care for Pediatric and adult patients not listed. I am not sure how this information was obtained because 2 important hospitals, very well known in the community were some how excluded. I am talking about Interfaith Medical Center and Brookdale Medical Center (One Brooklyn Health):
I had my training in Hematology At Brooklyn Jewish/Interfaith Medical Center. Dr Harvey Dosik who was the chief of hematology started the first sickle cell clinic for children, adolescents and adults in 1972. In 1978 when I was hired as the director of the clinic I was able to organized progressively a very comprehensive program for newborns, children, adolescents and adults with a transition component.
Both Brookdale Hospital Medical Center and Interfaith Medical Center (One Brooklyn Health's) have a long history of providing coordinated, family-centered, and comprehensive and psychosocial care to children and adults with sickle cell disease for more than 50 years.

The Programs at One Brooklyn Health(OBH)- Brookdale and Interfaith currently follow over 700 patients with sickle cell disease for complete care and hospitalizations:
This involve regular care in the outpatient unit, emergency room visits, management of complications while hospitalized, education, counseling and referral for services based on the social determinants of health.
The OBH programs contribute to the regular SCAC meeting which are attended by members of the hospitals and the CBO's on your list. Those organization on the list regularly request SCAC for an opportunity to present during a meeting. SCAC provide the opportunity for every one including participants from Upstate and Downstate to come together in one forum and connect regularly.

So I do request that you also list the name of these 2 important programs in Brooklyn.

Respectfully Submitted,
Rita Bellevue MD

Testimony Before City Council on Sickle Cell Disease Care in NYC
September 20, 2023

My name is Thomas Moulton and I am a pediatric hematologist/oncologist with over 30 years of treating persons with sickle cell disease.

NYS is the second most populous state for persons with sickle cell disease, with approximately 80% of those living in the NYC area. The median life expectancy for severe sickle cell disease has gone from approximately 5 years old in the 1970s to approximately 45 years today. This improvement in life expectancy has not come from drugs specifically to treat sickle cell disease, but mostly by supportive care measures. While more than 90% of children will now reach the age of 18 due to the comprehensive care in pediatrics may die between the ages of 18-35 due to the poor, uncoordinated care by adult physicians. I don't know of any other disease where people die by age 40 where there is not outrage for this and a concerted effort by the healthcare system to improve this death rate, particularly when we know that having designated sickle cell centers with day hospitals can improve both the care of sickle cell patients as well as decrease costs.

Sickle cell disease is the most costly disease/patient to NYS Medicaid, yet little to no money is allocated for the improvement of care for sickle cell disease. Adult persons with sickle cell disease have to use the emergency room for their care as they cannot find a specialist to take care of them. This drives up the cost of the disease dramatically besides clogging our already busy emergency rooms, even though they will avoid the emergency room at all costs as they are treated so badly by the staff in most emergency rooms. Since they come to care so late, it almost ensures that they will have to be admitted and that they will have a prolonged stay in the hospital. Since many of the patients with sickle cell disease are poor, many seek care in our city hospitals.

We are asking that NYC step in providing better care for sickle cell disease persons, particularly adults. This can be easily done by designating at least one city hospital in each borough to be a sickle cell treatment center which includes an infusion center. They would have designated specialist and support staff, including nurse practitioners, for both the well care as well as a day hospital for when they are sick. With the improved care of these patients comes decreased costs of care and these decreased costs could very well offset any increase in cost for setting up the programs.

People with severe sickle cell disease are dying at a young age. If it were any other population we would not stand for this. Please move forward quickly in establishing these sickle cell treatment centers. Please help save their lives.

Facts on Sickle Cell Disease

Thomas Moulton, MD
Sickle Cell Thalassemia Patient's Network (SCTPN)
Joint Budget Hearing for Health/Medicaid

NYS and Sickle Cell Disease

For 12 years the sickle cell disease bill has languished with the Governor and the legislature. It is the major health care disparity in NYS which has continued to be ignored. There is minimal state funding specifically for sickle cell disease and has consistently been cut over the last 20 years, from $500,000 to $170,000 (66%). However, this funding is now completed and funding is only given on a yearly basis, but continues to be dismal. This despite the fact that the median age of death for severe sickle cell disease has decreased and in males is 38 and females is 42, the severe morbidity of sickle cell disease which prevents many from completing schooling and obtaining/maintaining jobs, that NYS has 10% of the nation's sickle cell disease population but NYS is the worst in providing funding for sickle cell disease and finally, most sickle cell disease patients are on NYS Medicaid and improving the care could save Medicaid at least $4-$5 million a year. In a year where the Medicaid budget is needing to be trimmed, improving the care of patients with sickle cell disease while decreasing the Medicaid budget should be obvious.

Finally, the Assembly graciously gave a one year increase in the sickle cell budget in April 2019. This went to the Dept. of Health to distribute but they did not notify groups of an increase in their funding until Nov. 2019, giving them only 4 months, instead of 12 months, to spend the money allocated. In addition, the senate gave an additional $250,000 in June 2019 to several sickle cell CBOs, but as of the writing of this testimony some of the groups still have not received this money from the Dept. of Health and will have less than 2 months to spend this money. This really is not the ideal way to help sickle cell patients and community organizations. When money is allocated, it should not take 8 or more months of a year of spending for the money to be sent to the organizations.

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.

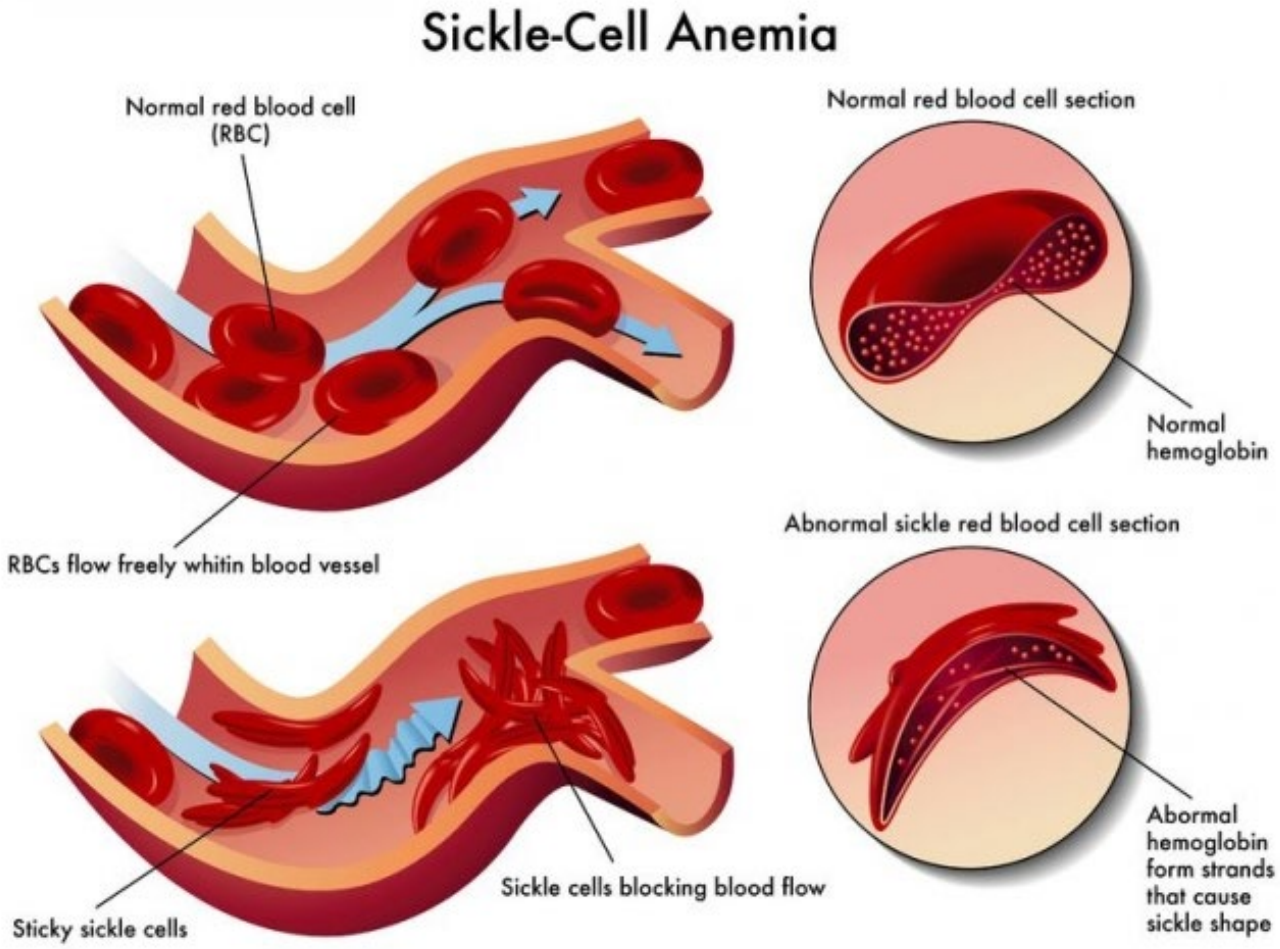
What is Sickle Cell Disease and What are its Complications?

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. 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.

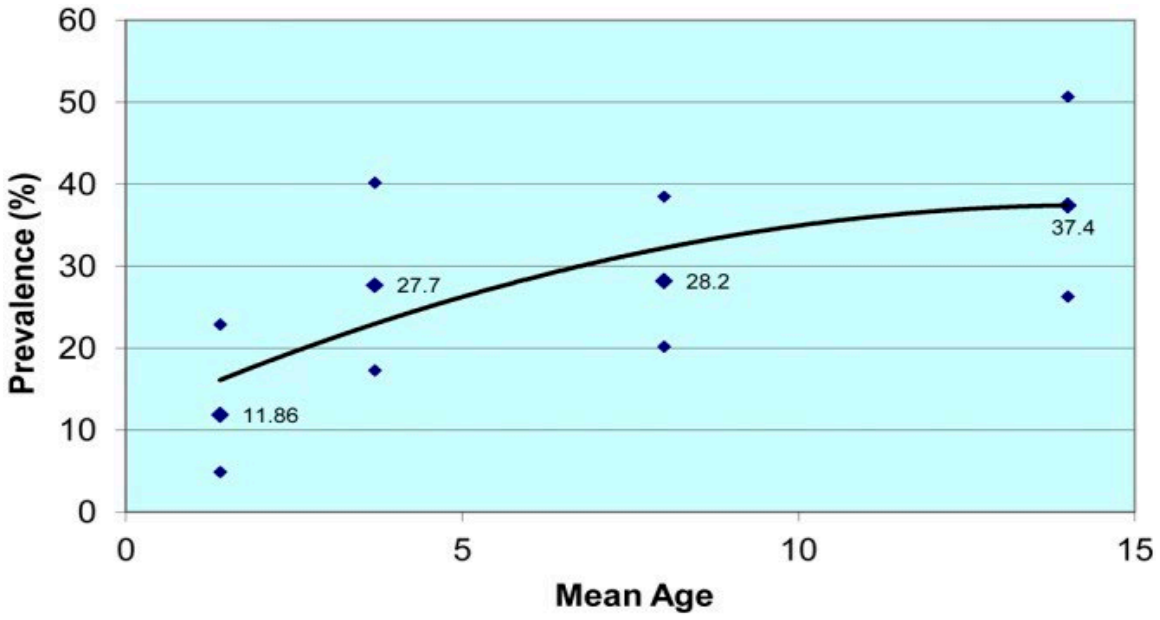
Silent Cerebral Infarct is defined as abnormal magnetic resonance imaging (MRI) of the brain in the setting of a normal neurologic examination without a history or physical findings associated with an overt stroke.

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;

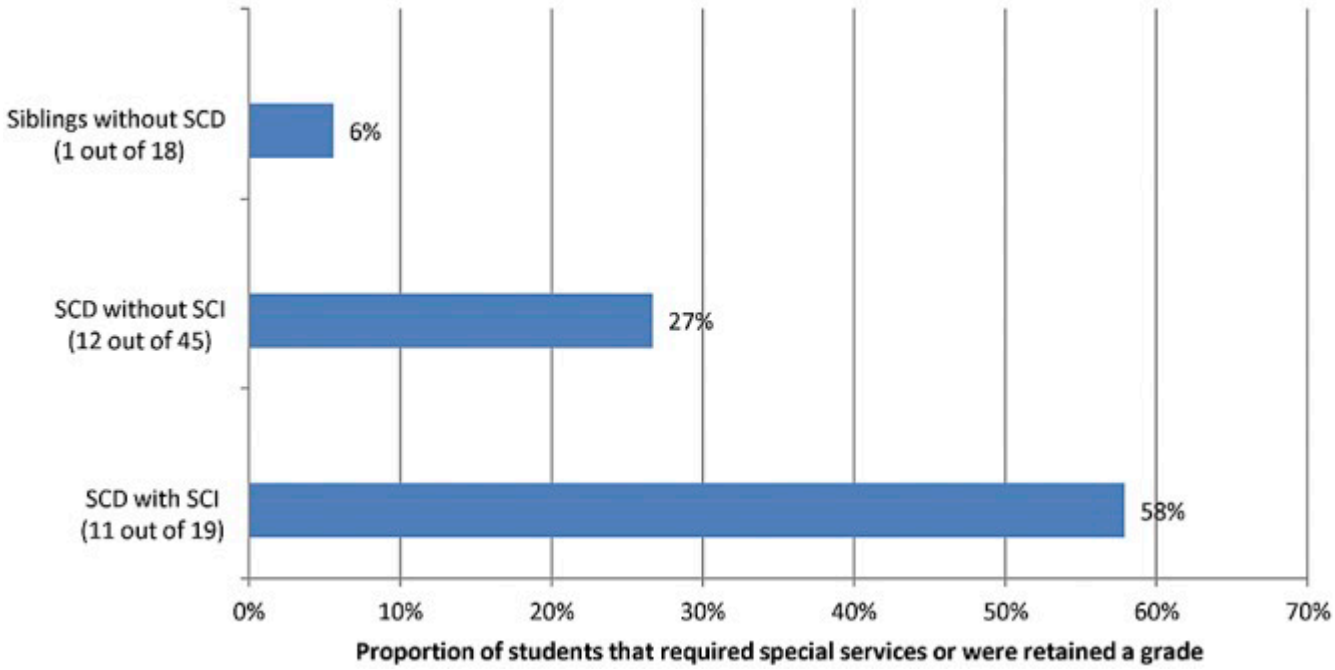
SCI is a risk factor for clinical stroke (14 fold higher) and progressive SCI

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]

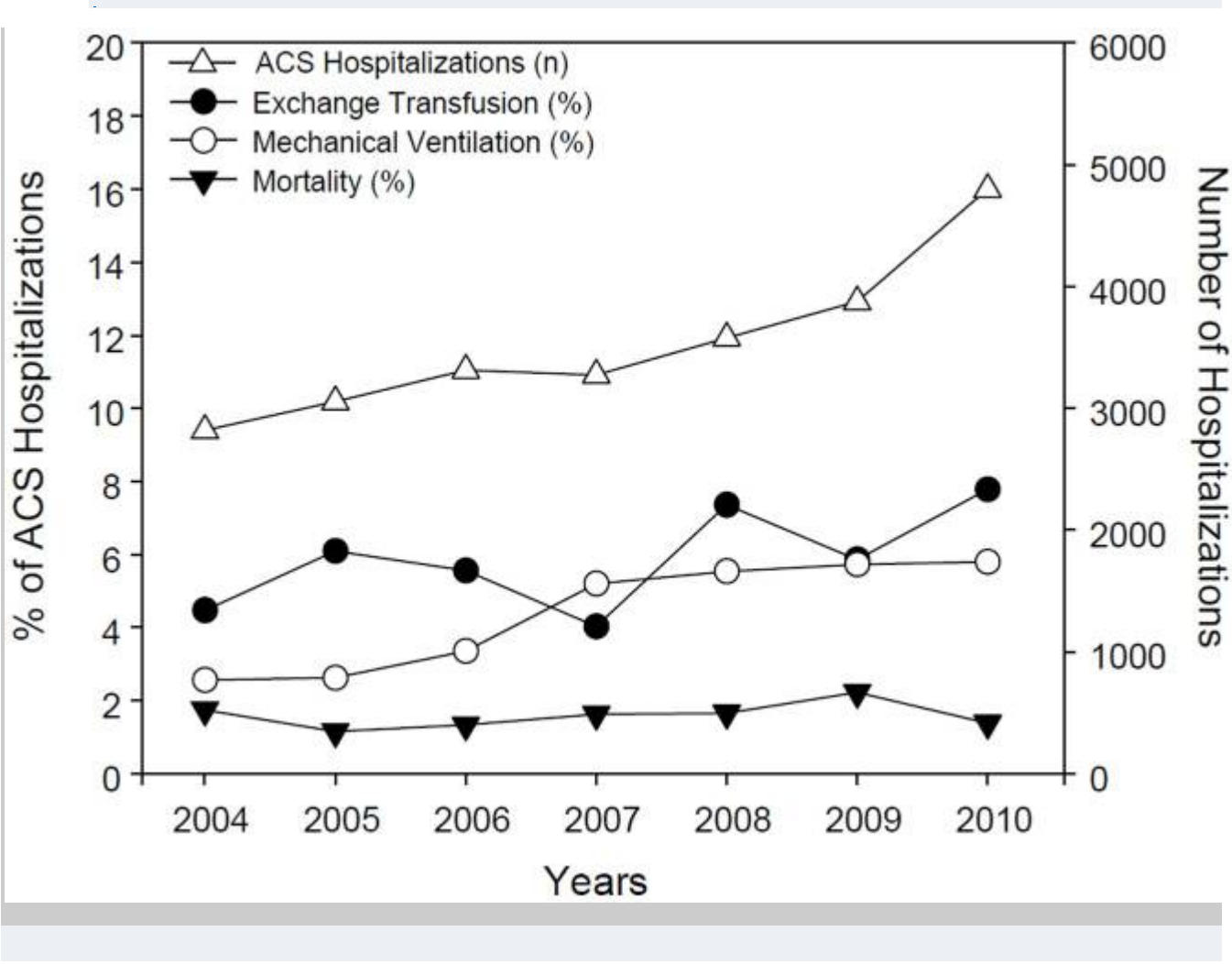
Silent cerebral infarcts: a review on a prevalent and progressive cause of neurologic injury in sickle cell anemia. Blood. 2012 May 17; 119(20): 4587–4596.

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 54 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	**>$4M**
Pennsylvania	**$1.26M**
Illinois	**$500,000 for one sickle cell program**

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.

I am a native New Yorker and sickle cell disease doctor; I completed pediatrics residency at the Children's Hospital at Montefiore in the Bronx and fellowship at Children's National Medical Center in Washington DC. I am an Assistant Professor of Medicine at Johns Hopkins University's Sickle Cell Center for Adults where I provide clinical care for young adults with sickle cell disease, support educational directives to reach clinicians around the country to care for people with SCD, and conduct NIH-funde sickle cell disease research. I am writing in strong support of efforts by New York City's City Council to improve care for people with sickle cell disease in the City. Sickle cell disease is a complex chronic illness that touches almost every part of the body. People with sickle cell disease are at risk for stroke, cognitive decline, blood clots, kidney and liver disease, vision and hearing loss, exceptionally high risk pregnancy, and early death. Life expectancy is 20 – 30 years lower than in healthy unaffected people. Over 60% of adults with sickle cell disease live with chronic pain and, perhaps unsurprisingly given this list of potential complications, adults with sickle cell disease have lower health related quality of life, more depression and more anxiety than unaffected adults. There are now four FDA-approved drugs to treat sickle cell disease and standards that define high quality pediatric and adult care. This care is not reaching most adults with sickle cell disease because there is a profound lack of experts to provide this care and a lack of resources to provide the comprehensive, multidisciplinary care to individuals living with this disease. High quality sickle cell disease care reduces reliance on emergency care systems and hospitalizations for sickle cell disease complications. Grave disparities in access to high quality care for people with sickle cell disease are a manifestation of structural racism. Most people with sickle cell disease in are Black (and in New York City, a sizeable proportion are Hispanic). The City Council can act to improve access to high quality sickle cell disease care. There is a practical and moral imperative to do so.

THE COUNCIL
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Appearance Card | 9

I intend to appear and speak on Int. No. ________ Res. No. 768-A

☑ in favor ☐ in opposition

Date: Sept 20, 2023

(PLEASE PRINT)

Name: Ginger Lanis

Address: 4 ~~Ele~~ St. Johns Place 1213

I represent: Sickle Cell Thalassemia Patients Ntwk

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: 09. 20 '23

(PLEASE PRINT)

Name: MICHAEL LANDRY

Address: 450 WEST END AVE

I represent: CTI LIFE HEALTH / CTI FOUNDATION

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: 9/20/23

(PLEASE PRINT)

Name: JASON CRITES

Address: N CLARK CHICAGO, IL 60614

I represent: Self

Address: Same

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Appearance Card

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

☐ in favor ☐ in opposition

Date: _____

(PLEASE PRINT)

Name: Brendan Fay

Address: 26 St Assistant

I represent: Community in Support

Address: _____

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Appearance Card

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☐ in favor ☐ in opposition

Date: _____

(PLEASE PRINT)

Name: Merlene Smith-Solito

Address: 164th Place Jamaica NY 11433

I represent: Sickle Cell Awareness Fdn Corp Inf

Address: _____

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☐ in favor ☐ in opposition

Date: 9/20/23

(PLEASE PRINT)

Name: THOMAS MOULTON

Address: 28th ST ASTORIA, NY 11105

I represent: SICKLE CELL DISEASE

Address: _____

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I intend to appear and speak on Int. No. 968-A Res. No. _____

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Date: 9/20/23

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Name: MILTON WADE

Address: 121 Kellery Ave Newark NJ 07106

I represent: Gregory B Gray

Address: _____

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

☐ in favor ☐ in opposition

Date: _____

(PLEASE PRINT)

Name: Dr. Kenneth Rivlin, MD, PhD

Address: Director of Division of Pediatric Hematology and Oncology

I represent: Health + Hospitals

Address: _____

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☐ in favor ☐ in opposition

Date: 9/20/23

(PLEASE PRINT)

Name: Yadira Navarro

Address: , Westbury, NY 11590

I represent: New York Blood Center

Address: 310 East 67th Street, NY, NY 10065

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Appearance Card

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

☐ in favor ☐ in opposition

Date: _____

(PLEASE PRINT)

Name: Dr. Toni Eyssallenne, MD, PhD

Address: Deputy Chief medical Office

I represent: DOHMH (Pediatrics, Internist)

Address: _____

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