

**A Comprehensive Review of Sickle Cell Disease Treatment and Research Centers in the
United States and Their Implication on Healthcare Access**

by

Nelly Kageha Kiriza

MD, Tumaini University- Kilimanjaro Christian Medical University College, 2012

Submitted to the Graduate Faculty of the

Department of Human Genetics

Graduate School of Public Health in Partial Fulfillment

of the requirements for the degree of

Master of Public Health

University of Pittsburgh

2020

UNIVERSITY OF PITTSBURGH
GRADUATE SCHOOL OF PUBLIC HEALTH

This essay was presented

by

Nelly K. Kiriza

It was defended on

December 1, 2020

and approved by

Laura M. De Castro, MD, MHSc, Associate Professor of Medicine, Clinical Chief Benign Hematology, Division of Hematology and Oncology, Department of Medicine

Emma Barinas-Mitchell, PhD, Associate Professor, Epidemiology; Associate Professor, Clinical Translation and Science; Director, Ultrasound Research Laboratory, Epidemiology Department

Essay Advisor: Candace Kammerer, PhD, Associate Professor of Human Genetics, Program Director, MPH in Public Health Genetics, Graduate School of Public Health, University of Pittsburgh

Essay Advisor: Dr. Andrea L. Durst, MS, DrPH, CGC Assistant Professor, Human Genetics Interim Director, Genetic Counseling Program, Human Genetics Co-Director, MPH in Public Health Genetics Program, Human Genetics.

Copyright © by Nelly K. Kiriza

2020

A Comprehensive Review of Sickle Cell Disease Treatment and Research Centers in the United States and Their Implication on Healthcare Access

Nelly K. Kiriza, MPH

University of Pittsburgh, 2020

ABSTRACT

Sickle Cell Disease is a collection of genetically inherited disorders of red blood cells affecting millions of people in the whole world. In the United States, it affects people of all ethnic/racial descent. It is usually diagnosed during early childhood. It is a significant public health concern for both the affected individuals and their surrounding community because it is expensive to manage and it has detrimental effects on people's lives and livelihood. Research on the best treatment for Sickle Cell Disease is still underway in several healthcare and research facilities. Currently, there is no up-to-date documentation of Sickle Cell Disease centers in the United States of America. This study aims to provide up-to-date information on the location and distribution of Sickle Cell Disease Centers in the US and to improve the public's healthcare access by providing resources that will ease referral and search for Sickle Cell Disease centers by both the healthcare workers and patients with sickle cell disease.

TABLE OF CONTENTS

ABREVIATIONS.....	x
1.0 INTRODUCTION.....	1
1.1.1 SPECIFIC AIMS.....	3
1.1.1.1 Specific Aim 1.....	3
1.1.1.2 Specific Aim 2.....	3
1.1.1.3 Specific Aim 3.....	3
2.0 REVIEW OF LITERATURE.....	4
2.1 HEALTHCARE ACCESS.....	8
2.2 FINANCES, FUNDING AND SUPPORT.....	9
2.3 TREATMENT OF SICKLE CELL DISEASE.....	11
2.3.1 Current Recommendations.....	11
2.3.2 Treatment Options.....	13
2.3.2.1 Blood and Bone marrow transplants.....	13
2.3.2.2 Gene Therapy for Sickle Cell Disease.....	13
2.4 MORTALITY AMONG SICKLE CELL DISEASE PATIENTS.....	14
3.0 MANUSCRIPT.....	16
3.1 DATASET DESCRIPTION.....	16
3.2 METHOD OF ANALYSIS.....	18
3.3 RESULTS.....	19
3.3.1 Number and distribution of Sickle Cell Disease centers in United States...19	
3.3.2 County- based Analyses of Sickle cell disease centers' distribution.....	23

3.3.3 Sickle Cell Disease Centers Resource Maps.....	24
3.4 DISCUSSION.....	29
3.4.1 Limitations.....	31
3.5 CONCLUSION.....	33
4.0 SIGNIFICANCE OF THE REVIEW TO PUBLIC HEALTH	34
APPENDIX A: DETAILED TABLES ON SICKLE CELL DISEASE CENTER IN US	35
APPENDIX B: SICKLE CELL DISEASE CENTERS/CLINICS IN THE US	51
APPENDIX C: DNA STRUCTURE IN SICKLE CELL DISEASE.....	127
BIBLIOGRAPHY.....	128

LIST OF TABLES

Table 1 Distribution of Sickle Cell Disease centers categorised by the number of centers per state..... 20

Table 2 State Per capita access of African American population to SCD centers 35

Table 3 Distribution of Sickle cell Disease Centres in USA 38

Table 4 Number of African Americans in counties with Sickle Cell Disease centers..... 41

Table 5 Number of African Americans in Counties without Sickle Cell Disease centers 48

LIST OF FIGURES

Figure 1 Types and Categorization of Sickle Cell Disease	7
Figure 2 Percentage representation of SCD centers by category as of October 01, 2020	19
Figure 3 Number of Sickle Cell Disease centers per state in the United States	21
Figure 4 African American per capita access to Sickle Cell Disease centers in the United States	22
Figure 5 Counties with Sickle Cell Disease centers or clinics in the United States.....	23
Figure 6 Snapshot of the map identifying pediatric Sickle Cell Disease centers in the United States	25
Figure 7 Snapshot of the map identifying adult Sickle Cell Disease centers in the United States	26
Figure 8 Snapshot of the map identifying centers offering both pediatric and adult Sickle Cell Disease care in the United States	27
Figure 9 Snapshot of an example of a map search in the SCD center pediatric map	28

PREFACE

I am grateful to God for the gift of life and His constant and unwaivered providence.

I am also thankful to Andrea, Candace, Emma, and Laura for serving in my essay committee. Your support, advice, guidance and editing of this essay made it possible for it to finally come to completion.

My experience at the department of Huma Genetics will forever be memorable to me. Candace and Andrea, since the beginning of my Human genetics studies you have been there to guide and advise in great ways. Thank you very much for taking the role of program director and mentor and for your constant support and always being there to offer advice anytime I reached out to you without tiring. You gave me the hope to keep pushing forward. Your encouragement, inspiration and constant reminder have taught me a lot and I am entirely grateful.

I would also like to thank my husband, Jacob Kigo, and our two beautiful daughters, Yaa and Mary, for their continued support and for cheering me on throughout my studies and essay writing. Thank you to my parents, Mr. & Mrs. Kiriza, for constantly checking on me and encouraging me every step of the way. I am who I am because you laid the foundation for me and in me. You all gave me the strength to keep pushing on.

“Feeling gratitude and not expressing it is like wrapping a present and not giving it.”

– William Arthur Ward.

ABBREVIATIONS

AA - African American

ACS - Acute chest syndrome

AKI - Acute Kidney Injury

CDC - Centers for Disease Control and Prevention

CF - Cystic fibrosis

DHHS - Department of Health and Human Services

DNA – Desoxyribonucleic Acid

ER - Emergency Room

HAS - Health Services Administration

HbA - Hemoglobin A

HbA2 - Hemoglobin A2

HbF - Hemoglobin F

HbS - Sickle Hemoglobin

NHLBI - National Heart, Lung, and Blood Institute

NIH - National Institute of Health

RBCs - Red blood cells

SCA - Sickle Cell Anemia

SCD - Sickle Cell Disease

SCDC – Sickle Cell Disease Coalition

SCT - Sickle cell trait

US – United States

1.0 INTRODUCTION

The Centers for Disease Control and Prevention (CDC) describes sickle cell disease (SCD) as a collection of inherited red blood cell disorders that cause the red blood cells (RBCs) that are normally round and smooth to become hard, sticky, and sickled.¹ These malformed cells clog small blood vessels, causing the patients with SCD significant pain and other problems like infection, end organ failure and stroke.^{1,2} Sickle cell disease exhibits an autosomal recessive mode of inheritance¹ and affects males and females equally.³ In the United States (US), it is usually diagnosed during early childhood, most often on newborn screening.⁴

The different genotypes of SCD are categorized based on the different combinations of abnormal hemoglobin. There are three types of hemoglobin in the human body that play a major role in gaseous exchange;⁵ Hemoglobin A (HbA), also known as the adult hemoglobin, is the most common type, and it accounts for about 97% of hemoglobin present in a normal adult. It is encoded by HBA1, HBA2 and HBB genes, and each of its four subunits consists of two alpha (α) and two beta(β) subunits.⁶ Hemoglobin A2 (HbA2), also known as minor variant of adult hemoglobin, accounts for about 2% of hemoglobin, and its subunits consist of two α and two delta (δ) subunits.⁶ Hemoglobin F (HbF), also known as fetal hemoglobin, is usually present at levels of 65 to 90% in a newborn baby but drops in concentration to less than 2% when the baby is 6 months to 12 months of age.^{6,7,8} It consists of two α and two gamma (γ) subunits. The two gamma subunits enable HbF to have higher affinity for oxygen compared to the other two types of Hb, HbA and HbA2.^{8,6}

Hemoglobin S (HbS) is the cause of sickle cell disease and an allelic variant of the β -globin gene whose formation occurs as a result of a point mutation on the β -globin gene on chromosome 11.² (See Appendix Figure 1 in Appendix D) The molecular basis of this disease is such that it

occurs in the first exon of the gene, resulting in glutamic acid being replaced by valine at the sixth codon position of the β -globin polypeptide chain body (Glu6Val).⁹

Signs and symptoms in people with SCD vary from one person to another and can be categorized in two groups: acute and chronic complications. Acute complications occur within a short time span, and the most common is an acute vaso-occlusive crisis that results from tissue ischemia caused by blockage of tiny blood vessels most commonly in bones and bone marrow. Other acute complications include infection that result in fever, acute kidney injury (AKI), acute anemia, acute chest syndrome (ACS), priapism, acute stroke, hepatobiliary complications, splenic sequestration and acute eye problems. Chronic complications affect almost any organ and are mostly because of prolonged acute complications.¹⁰ Patients with SCD who have high HbF levels have less severe clinical presentation and mild complications because higher levels of HbF inhibits polymerization of sickle Hemoglobin (HbS).⁷

Sickle cell trait (SCT) is a condition in which an individual inherits one sickle cell gene variant from one parent and one normal hemoglobin gene variant from the other parent. Most individuals with SCT do not exhibit any signs of SCD and they live a normal life, but in rare cases some experience some complications. Environmental conditions like high atmospheric pressure, dehydration, high altitude levels and low oxygen levels can trigger the complications in SCT.⁴

SCD is a significant public health concern for both the affected individuals and their surrounding community. Non-specialized care of patients with SCD exposes them to the possibility of inadequate management due to lack of up-to-date information on the management of the condition as compared to receiving care for their condition in SCD specialized healthcare facilities. This study will provide up-to-date information on location and distribution of SCD treatment and research centers in the US. The result of this study will be used to develop a resource

map to guide researchers and clinicians on where to refer patients with SCD and to aid patients living with SCD in locating centers offering services in their area.

1.1 SPECIFIC AIMS

1.1.1 Specific Aim 1

Identify the number and precise location of SCD centers in the US and the population they serve in each state.

1.1.2 Specific Aim 2

Use the results on the SCD centers distribution to evaluate the demographic characteristics of the counties where the centers are located and to identify the proportion of individuals with “ease of access” to the SCD centers.

1.1.3 Specific Aim 3

Develop a resource map to guide researchers and clinicians on where to refer patients with SCD and to aid patients living with SCD in locating centers offering services in their area.

2.0 REVIEW OF LITERATURE

Globally, people originating from regions that experience endemic malaria are more probable to have the sickle cell trait. These regions include Africa, India, the Mediterranean and Saudi Arabia.^{2,11} The sickle-cell trait enhances resistance to falciparum malaria in early childhood resulting in the sickle-cell gene being common in Africa; therefore, children with the SCT survive, promoting genetic transmission of the abnormal hemoglobin gene.² SCD, however, does not confer this type of protection, making Malaria a major cause of ill-health and death in children with sickle-cell anemia, the most severe type of SCD, in Africa.¹¹ The Sickle Cell Disease Coalition (SCDC) estimates that approximately 1,000 children are born with sickle cell disease daily in Africa,¹⁸ but unfortunately, more than half of them die before attaining the age of five years. In resource poor countries, 90% of the children suffering from sickle cell disease do not live to adulthood.¹² SCD has contributed a considerable proportion to the number of deaths in children below the age of 5 years, mainly following delayed diagnosis, educational gaps among service providers on best measures of managing the patients, and poor access to appropriate treatment and treatment facilities.¹³

The Sickle Cell Disease Coalition predicts that by 2050 there will be a 30% growth in the number of patients diagnosed with sickle cell disease globally,¹² due to a decrease in mortality suggested by the report received by CDC of a shift in the age at death in SCD patients in the year 2006.¹²

In the United States, more than 2 million people carry the sickle cell gene variant.³ African Americans are known to have a higher SCD prevalence with gene frequencies of 4% for HbS, 1.5% for HbC and 4% for beta thalassemia,¹⁴ as compared to other racial/ethnic groups.^{15,16,17}

Current population-based estimates suggest that 1 out of every 365 African American births and 1 out of every 16,300 Hispanic births have SCD.^{1,18} One in every 13 Black or African-American children (approximately 8%) is born with the sickle cell trait, and about 300,000 individuals in America have the sickle cell trait.¹⁸

Hassel KL (2010) estimated that SCD affects about 100,000 people in the USA¹⁹ with a majority of them being of African American descent,³ and more than 30,000 of them being homozygous for HbS disease.³ The American Society of Hematology states that approximately 2,000 incident cases of SCD are detected yearly through newborn screening.¹⁸ The severity of SCD largely depends on an individual patient's genotype.² Sickle cell anemia, which entails both genotypes HbSS and HbS β^0 , is the most severe and commonly occurring^{20,21} SCD genotype in the US with an expected prevalence of 1 in every 625 newborn babies.³ Patients with SCA have mutations that cause HbSS and HbS β^0 thal. All people who are either homozygous (HbSS) or compound heterozygous for an HbS allele and another variant hemoglobin type such as Hgb C, Hb D, Hb Oarab and β thal manifest some clinical symptoms of SCD which include hemolytic anemia, significant episodes of pain and multiple organ damage.²²

Patients with Sickle Hemoglobin-C (HbSC) Disease have an additional gene mutation that produces hemoglobin C in addition to hemoglobin S. The incidence ratio is 1:7386 newborn babies screened in the US.²⁰ Patients with HbSC disease experience less anemia compared to those with HbSS due to a higher red blood cell count. Individuals with West African, Mediterranean and Middle Eastern origin experience a high frequency of this SCD genotype.^{23,24}

In Sickle Beta Thalassemia, the severity of sickle cell disease depends on the amount of beta globin produced.²⁰ Patients with Sickle Beta-0 Thalassemia (HbS β^0 thal) do not produce beta globin, therefore resulting in no protein translation and symptoms resembling those of individuals

with HbSS with the presence of abnormally small erythrocytes. Those with Sickle Beta-plus Thalassemia (HbS β^+ thal) have a decreased amount of beta globin proteins, and symptoms are milder than Sickle Cell Anemia (SCA). Sickle Beta Thalassemia is seen most commonly in people of the Mediterranean and Caribbean origin.²²

Individuals of Asian and Latin American origins²⁵ more commonly have Sickle Hemoglobin D disease (HbSD) and they experience a moderately severe type of anemia with occasional pain episodes. Patients with Sickle Hemoglobin Oarab disease (HbSOarab) can have symptoms and complications similar to those with HbSS; the most common being joint pains, malaise, anemia and occasional jaundice with distinctive plasma proteins disturbances.²⁶ It mostly affects people with Arabian, North African and Eastern Mediterranean origin.²⁵ These and additional sickle cell disease types are summarized in Figure 1.

Type	Name	Genetics	Severity	Origin of highly affected individuals
HbSS	Sickle cell anemia	Combination of two β^S alleles (β^S/β^S)	Most severe	Africa and India
HbSC	Sickle Hemoglobin-C Disease	one β^S allele and one β^C allele	Milder form	West Africa, Mediterranean and Middle eastern
HbS β^0 thalassemia	β -0 thalassemia anemia(Also referred to as sickle cell anemia)	one β^S allele and β^0 (a null HBB allele)	Severe	Mediterranean and Caribbean
HbS β^+ thalassemia	Sickle Beta-plus Thalassemia	One β^S and one β^+ (a hypomorphic HBB allele)	Milder form	Mediterranean and Caribbean
HbSD	Sickle Hemoglobin D disease	One β^S and one β^D allele	Varies	Asia and Latin America
HbSOarab	Sickle Hemoglobin O disease	One β^S and one β^O allele	Varies	Arabia, North Africa, and East Mediterranean

Figure 1 Types and Categorization of Sickle Cell Disease

2.1 HEALTHCARE ACCESS

The SCD comprehensive centers are not supported with federal funding , as a result of low insurance payments for clinical services, they therefore often rely on financial support from hospital systems and other institutions.²⁷

Bemrich-Stolz CJ, et al (2015) assessed transition care in adult patients with SCD and stated that adult patients face challenges in attempting to establish access to care because of difficulty identifying new adult providers, and challenges concerning transportation due to the distance and expenses they incur to get to the healthcare facilities.²⁸ As per several other studies, a number of adult sickle cell disease patients opt to try different techniques at home in an attempt to treat themselves, mostly for pain crisis, in preference to going to health care facilities because of little confidence and diminished trust in the primary care and adult emergency departments.^{27,28} Several of the patients stated that the Emergency room (ER) physicians treated them as “drug seekers” and not patients. Other patients stated that following the opioid crisis, physicians were unwilling to prescribe them a sufficient amount of analgesic medications to treat their pain during a crisis at home and as a result they end up visiting the ER often for additional pain management.^{27,28,29,30,31}

Patients with SCD who live a significant distance away from the SCD specialty centers or live in rural areas or in areas with bad terrain, poor infrastructure and/or poor public transportation services have a hard time keeping up with their clinic appointments. The use of telehealth and telemedicine results in improvement in medication adherence, the number of clinic visits by the patients, and patient satisfaction.^{32,33}

2.2 FINANCES, FUNDING AND SUPPORT

The financial stability of patients with SCD is affected due to loss of jobs following frequent absenteeism from work caused by the patients developing frequent sickle cell disease complications, more especially the pain crisis. As a result of loss of jobs, they end up lacking insurance to be able to pay for their hospital visits and medication refills.²⁸ Even though a majority of people with SCD are able to obtain insurance through Medicaid, they still may not be able to access the healthcare services they need.^{27,34} The social life and relationships of patients with SCD, both at work and at home, are also affected. Patients with SCD feel like they receive less support from other members of their families, except their mothers, who they believe understand their pain and situation.²⁸

The National Sickle Cell Disease Control Act (Public Law 92-294), that allowed the establishment of programs to provide several services for patients with SCD was first passed by the US Congress in 1972. It provided the opportunity to start informational, educational, screening, research, testing, counseling and treatment programs.³⁵ Three major agencies were responsible for the program on the federal level: 1) The CDC developed hemoglobinopathy laboratories and training programs to provide proficiency testing and to serve as a reference laboratory, 2) The Health Services Administration (HSA) developed sickle cell screening and education clinics and 3) The National Institute of Health (NIH) developed comprehensive sickle cell centers whose main aim was to perform research and treatment of SCD.³⁵ In those initial years of establishment, the NIH was the body administering the sickle cell program in the sickle cell centers with well set and defined goals which were “1) to reduce the number of individuals getting sick and those dying

from sickle cell disease, 2) to educate the public about the disease and to increase knowledge about it, and 3) to invent and assess new ways of treatment of sickle cell disease.”³⁵

In 2004, after the approval of the American Jobs Creation Act of 2004 (Public Law 108-357) that included funding specifically for SCD, there was a great buildup of SCD research and treatment. Unfortunately the appropriations for the program lapsed in 2009 after a duration of five years and has never been reauthorized again.³⁶

Funding for both research and treatment centers is a big challenge for the institutions working on SCD. Farook Faheem et al in a cross-sectional study carried out in 2020 compared research funding for SCD and Cystic fibrosis (CF) from 2008 to 2017 using the NIH report database. They found that number of per annual PubMed publications was initially similar for CF and SCD, but later the CF research output expanded at a faster rate. Publications of CF remained greater than those of SCD between 2008 to 2018, (mean [SD] publications, 1594 [225] vs 926 [157]; $P < .001$) and benevolent disbursement of funds from foundations were significantly higher per individual with CF in comparison to funding per individual with SCD (mean [SD], \$ 7690 [\$3974] vs \$102 [\$13.7]; $P < .001$).²⁷ Cystic fibrosis (CF) is an inherited disease with an autosomal recessive mode of inheritance like SCD, but CF largely affects white individuals (1 in 2500) while SCD primarily affects black individuals (1 in 365). These are evidentially racially aligned diseases, and the fact that CF is receiving more funding and patients with the condition are receiving more financial support in relation to treatment than those with SCD expose health funding inequities that may be driven by social determinants such as race. There is need for change and equality.³¹

The 115th congress passed the [S.2465] Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018, and it was signed into law by the president on December 18, 2018. Therefore through this act, the Department of Health

and Human services is authorized to provide funding to support collection of data on SCD and other heritable blood disorders by government, educational and nonprofit organizations .³⁷ It had appeared in forms that were almost similar in the Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act of 2015 (HR 1807, 114th Congress) and the Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act of 2014 (HR 5124, 113th Congress).³⁶

2.3 TREATMENT OF SICKLE CELL DISEASE

Prompt recognition and consistent medical care to reduce and stop complications result in improvement of well-being in individuals with SCD. SCD is a lifelong illness that has widely varying severity from one individual to another.³⁸

2.3.1 Current Recommendations

The National Heart, Lung, and Blood Institute (NHLBI) states that “a patient with SCD in painful crisis should be treated as an emergency and should undergo a thorough history and physical examination to determine whether an illness might have precipitated the pain, so that the cause and symptom can be treated at the same time.”³⁹ Pain medication is given depending on an individual patient’s level of pain; with NSAIDs and Acetaminophen being used to manage mild to moderate pain while opioids, like morphine, have been used for management of moderate to severe pain. For better treatment results, it is important for patients, families and healthcare providers to be well educated on pain management.³⁹ Penicillin is used as a prophylactic medication in children from when they are newborns to 5 years of age.³⁹ All individuals with SCD have to get the

immunizations as per the Advisory Committee on Immunization Practices, which include additional recommendations for pneumococcal vaccines for individuals with SCD, unless there is a contraindication based on an individual's health. Due to increased risk of individuals with SCD getting invasive pneumococcal disease, it is recommended that all infants with SCD should receive a complete dose of the 13-valent conjugate pneumococcal vaccine (PCV13) shortly after being born and the 23-valent pneumococcal polysaccharide vaccine (PPSV23) at the age of 2 years and a second dose at the age of 5 years. Adults who are more than 19 years of age with asplenia and have not previously received the pneumococcal vaccine should be given one dose of the PCV13 followed by PPSV23 at least 8 weeks later.³⁹

Several tests are carried out in patients with SCD to rule out SCD complications like stroke and end organ failure. The tests include radiological and non-radiological imaging, pulmonary function tests and blood tests. The recommended neuroimaging test is Transcranial Doppler (TCD) ultrasound which is done annually in children with SCA starting at the age of 2 years and continuing until at least the age of 16 years. Computed tomography (CT) scans and magnetic resonance imaging (MRI) have very low supporting evidence of benefits in patients, of all ages, with SCD.¹⁰ Patients showing signs and symptoms of respiratory problems undergo the pulmonary function tests to establish the cause and preferred treatment for it. In patients with SCD experiencing Acute Renal Failure, a daily monitoring of renal function including serum creatinine and fluid intake/output is recommended.¹⁰ They also get blood tests like check of Hb S level and activated partial thromboplastin time (aPTT), and prothrombin time (PT).³⁹

2.3.2 Treatment Options

Some effective treatments exist that can reduce symptoms and prolong life.³⁸ Hydroxyurea and 5-azacytidine are two medications known for boosting the presence of HbF in the blood of patients with SCD.^{39,40} Hydroxyurea is given to stimulate HbF production, by releasing nitric oxide in adult patients with SCD, while 5-azacytidine inhibits DNA methylation, therefore preventing the switch from HbF to HbA synthesis.⁴⁰ HbF helps achieve higher oxygen concentration in the blood of these patients due to its high affinity for oxygen, and therefore reduces the number of times they become hypoxic.⁴⁰

2.3.2.1 Blood and Bone marrow transplants

Blood and bone marrow transplants are presently the only cure for sickle cell disease, and only a few of people with SCD being able to receive a transplant due to hardship in finding donors that match with them.³⁹ This also comes with a risk of death which the patients with SCD and their families have to decide upon. Blood transfusion is not recommended in patients with SCD unless there are other indications because it may result in iron overload in the patients.¹⁰

2.3.2.2 Gene Therapy for Sickle Cell Disease

The utilization of gene therapy in the treatment of SCD is still being explored.⁴¹ Genetic related treatments that change an individual's hematopoietic stem cells may provide alternative treatment and probably a cure for patients with SCD who are not able to find a well matched bone marrow donor.¹⁷ When introduced to the bloodstream, the refashioned stem cells travel to the bone marrow where they make healthy non-sickling red blood cells.¹⁷

There are several gene- editing studies that are being conducted to further study this method of treatment. A number of clinical trials have recruited SCD patients and are working on using CRISPR and stem cell therapy in modifying the affected cells.⁴² Some considerable achievements have been made at the basic level to successfully attain the genetic correction of hemoglobinopathies⁹ but there is still significant research that needs to be completed.⁴²

As studies and research continue, it continues to be important to offer genetic testing and counseling to individuals or couples with or at risk for having a child with SCD, to enable them to make well informed decisions on marriage and childbearing.

2.4 MORTALITY AMONG SICKLE CELL DISEASE PATIENTS

In the 1980s, SCD related hospitalizations and deaths were high in comparison to the late 1990s and early 2000s where there was a remarkable decrease in early childhood mortality. In 1975, New York was the first state to enact newborn screening for sickle cell disease^{43,44} and in 2006 the Recommended Uniform Screening Panel (RUSP) that included SCD was published.⁴⁴

This mortality decrease is attributed to the recommendation of newborn screening for SCD that enabled early detection and management of the young patients, improved health of patients with sickle cell disease following the availability of penicillin prophylaxis, and administration of Hemophilus influenzae type B and Streptococcus pneumoniae vaccinations.^{2,30} Despite the improvement, patients with SCD of African-American ethnicity still continue to bear a high burden of the disease given their high prevalence at birth (1 in every 365 live births) in comparison to the other ethnic/racial groups that are affected.

About 95% of patients with SCD in the USA live well over the age of 18 to 22 years and need to transition to an adult healthcare facility. This age group has been associated with considerable increase in the use for healthcare and an increase in the risk of death in individuals with SCD because of few knowledgeable primary and specialty care providers, poor access to facilities offering management, and poor economic status of the majorly affected population.^{28,30}

In this analysis, I will describe per capita distribution of SCD centers in every state within the US and their precise locations in specific counties in relation to the most affected group of individuals, African Americans.

3.0 MANUSCRIPT

This study utilized data that is available publicly online and as a result did not require IRB review.

3.1 DATASET DESCRIPTION

The CDC's SCD National Resource Directory⁴¹ was used as a starting list to identify SCD centers in the US. Another directory that was also used is available at this [link](#)⁴⁵ and was used to compare and confirm that all centers were recorded, that contacts and center details were added, and that links to the websites updated. From this list, a comprehensive and systematic search via Google from the SCD centers' websites was conducted. Additional searches for SCD Centers not on the list were completed by searching per state using the following search terms; Sickle cell disease treatment and research centers in "Name of state", Sickle cell disease centers in "Name of state", and sickle cell centers in "Name of state".⁴⁶ Newly found centers that were not included and specified in the SCD National resource Directory⁴⁶ and [link](#)⁴⁵ were added, and those that no longer existed were omitted. Not all of the centers had direct individual websites because some were stated as branches or clinics of other major hospitals and centers.

Center addresses were grouped by state location and www.mapchart.net was used to generate visual representation to show the distribution of the SCD centers by state. This website was also used to create an additional map showing the precise distribution of the SCD centers by

county since the state map only indicated the presence of the centers but was not dependable in assessment of the accessibility by the population they serve.

Concurrently, 3 custom maps were created with each location of the centers using this [link](#).⁴⁷ Centers were categorized into 3 groups, with their respective maps; pediatric centers ([map](#))⁴⁸, adult centers ([map](#))⁴⁹ and centers that offer services to both adult and pediatric patients with SCD ([map](#))⁵⁰.

Population estimates from U.S. Census Bureau QuickFacts (population, census, April 01, 2010)⁵¹ per state and of county-wide population numbers was used to create tables that helped identify the number of SCD centers per state and the proportion of majorly affected ethnic/racial groups without ready access to SCD Centers and clinics at the county level.

Population estimates of the most affected ethnic/racial group, African-Americans,³ was used in analyzing per capita and county access to SCD centers since the number of affected individuals from other ethnic/racial groups is minimal. The estimated number of African American individuals living in the counties that have ≥ 1 SCD center/clinic were categorized as individuals with “ease of access” and this was determined by calculating the number of AA in the particular counties in comparison to the total number of AA in all the counties in a particular state. This was done for all the 50 states and District of Columbia.

3.2 METHOD OF ANALYSIS

With a majority of the estimated 100,000 patients in the US with SCD being African - American, I analyzed the association between the number of SCD centers per state and the population size of the group, which was identified using the U.S. Census Bureau QuickFacts (population, census, April 01, 2010).⁵¹ I used this data to estimate the general average per capita access to SCD centers for this population.

I also assessed the access to SCD centers at the county level by the majorly affected population. Population data for counties that have the SCD centers was identified using the U.S. Census Bureau QuickFacts (population, census, April 01, 2010).⁵¹ The proportion of African-American population with “ease of access” to the centers was obtained by summing across all counties with SCD centers and comparing it to the total population of African-American in the US from the 2010 population census.

3.3 RESULTS

3.3.1 Number and distribution of Sickle Cell Disease centers in United States

The sum total of SCD centers and clinics around the US is 311 with most being pediatric centers (71% n= 220) followed by adult centers (22%, n= 68) and lastly centers that offer services to both adult and pediatric patients with SCD (7%, n=23). (Figure 2) Several SCD centers have branches and clinics in several parts of a city, state, or neighboring states. Thirty-seven SCD centers offer services as comprehensive centers with 15 of them offering services to adult patients with SCD. For a more detailed list of the sickle cell disease centers found see **Appendix B**.

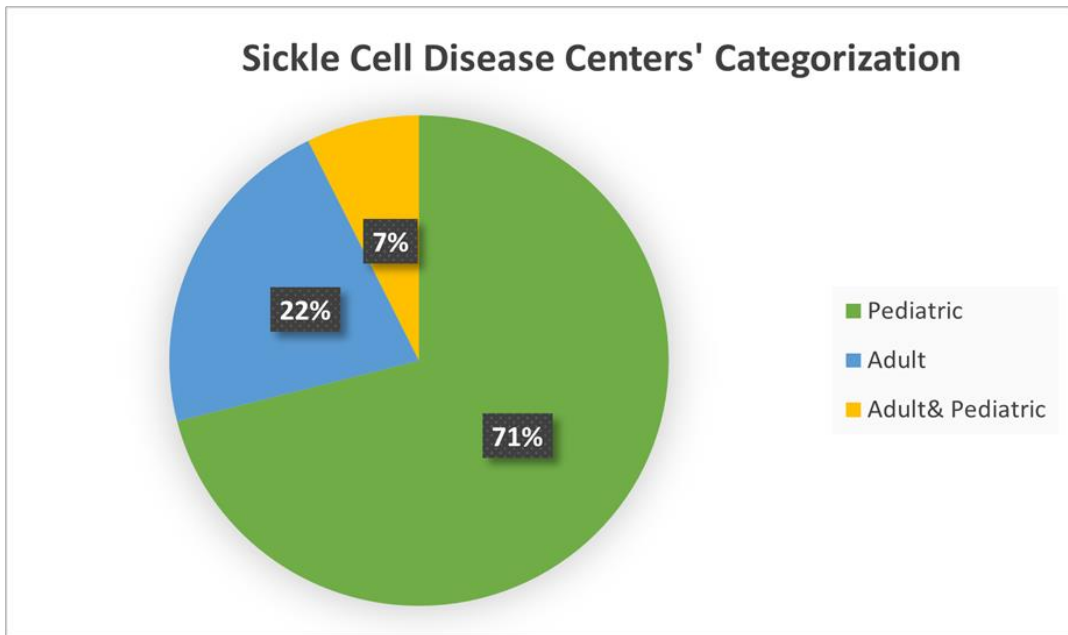


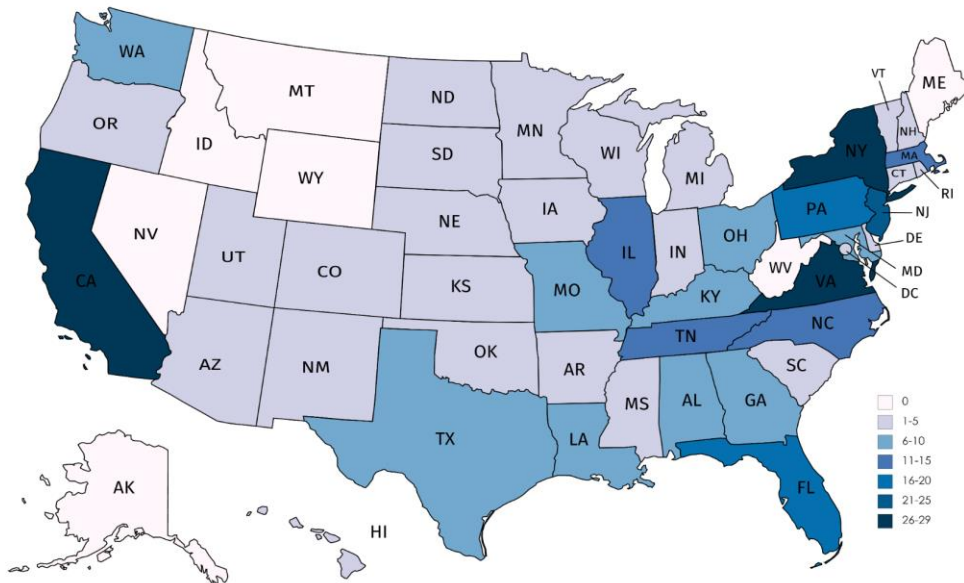
Figure 2 Percentage representation of SCD centers by category as of October 01, 2020

Table 1 Distribution of Sickle Cell Disease centers categorised by the number of centers per state

Number of Sickle Cell Disease Centers	Number of States represented	Percentage representation
0	7	13.73
1	10	19.61
2	5	9.8
3	6	11.76
4	3	5.88
5	1	1.96
6	1	1.96
7	1	1.96
8	5	9.8
9	2	3.92
11	2	3.92
12	2	3.92
17	2	3.92
21	1	1.96
27	1	1.96
28	1	1.96
29	1	1.96

The seven states that do not have an established Sickle cell disease center are Alaska, Nevada, Idaho, Wyoming, Montana, Maine, and West Virginia (Figure 2). In the remaining 43 states and Washington D.C, the number of SCD centers' distribution ranges between 1- 29 per state with an average of 7 centers per state.

Of the 50 states and Washington D.C., 7 states (13.73%) do not have any SCD center identifies through this search, 10 states (19.61%) have only 1 SCD center each and 4 states have more than 20 centers each (Table 1). A details documentation of the SCD centers per state can be found in Table 4 in **Appendix A**.



Created with mapchart.net

Figure 3 Number of Sickle Cell Disease centers per state in the United States

The 7 States lacking SCD centers have a small number of AA living in them as per the population estimates of the 2010 census data⁵¹ (Table 6) and are represented in Figure 4 as grey shaded states. For the AA individuals in the remaining 43 states and D.C, the per capita access is represented with color intensity indication decreasing with availability of access, light blue representing the states with better access and darker blue representing states with limited access to SCD centers/clinic. The average per capita access for every one SCD center is 134,800 AA individuals per center, with a maximum of 394,772 AA in Georgia and a minimum of 8,760 AA in Vermont. (Figure 4).

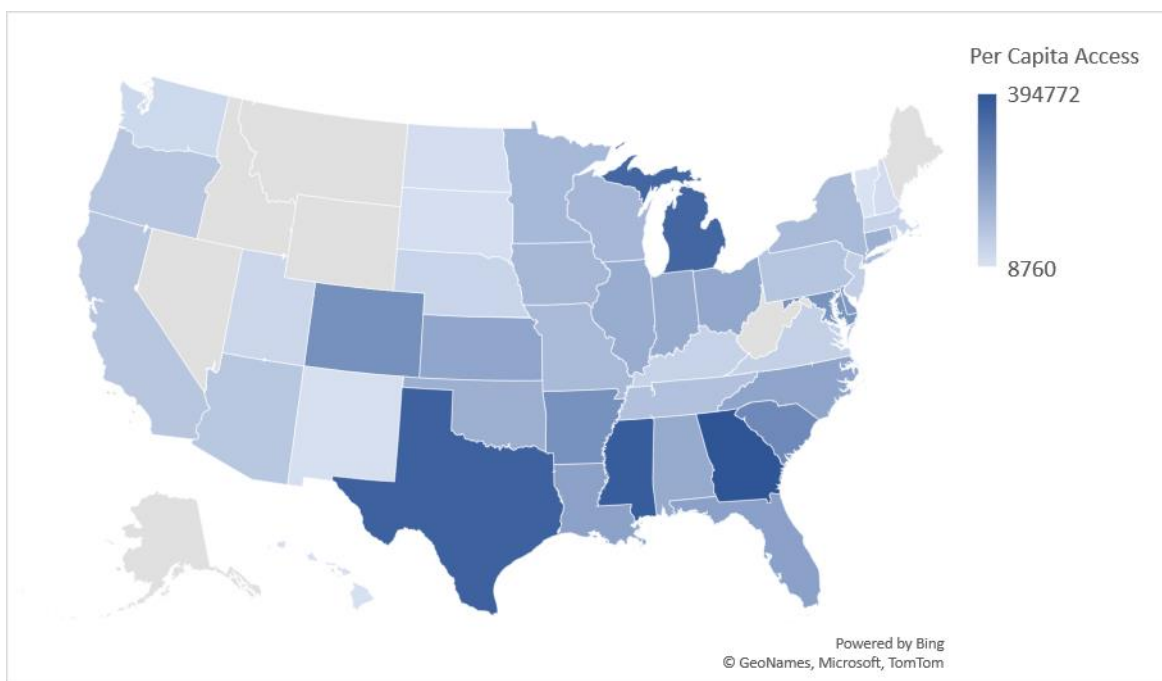


Figure 4 African American per capita access to Sickle Cell Disease centers in the United States

3.3.2 County- based Analyses of Sickle cell disease centers' distribution

The location of SCD centers at the state level was crude, therefore the number of SCD centers by county was investigated and it was found that only 155 out of the 3133 counties in the US have more than one SCD center/clinic. Despite them being sparsely distributed, there was visible absence of SCD centers in counties in the Northwest region of USA. A bigger proportion of SCD centers and clinics is in the Northeast, Mid-Atlantic, Southeast, and part of the Mid-West regions of USA. (Figure 5). For details on the specific counties with the centers, see Table 4 in **Appendix A**.

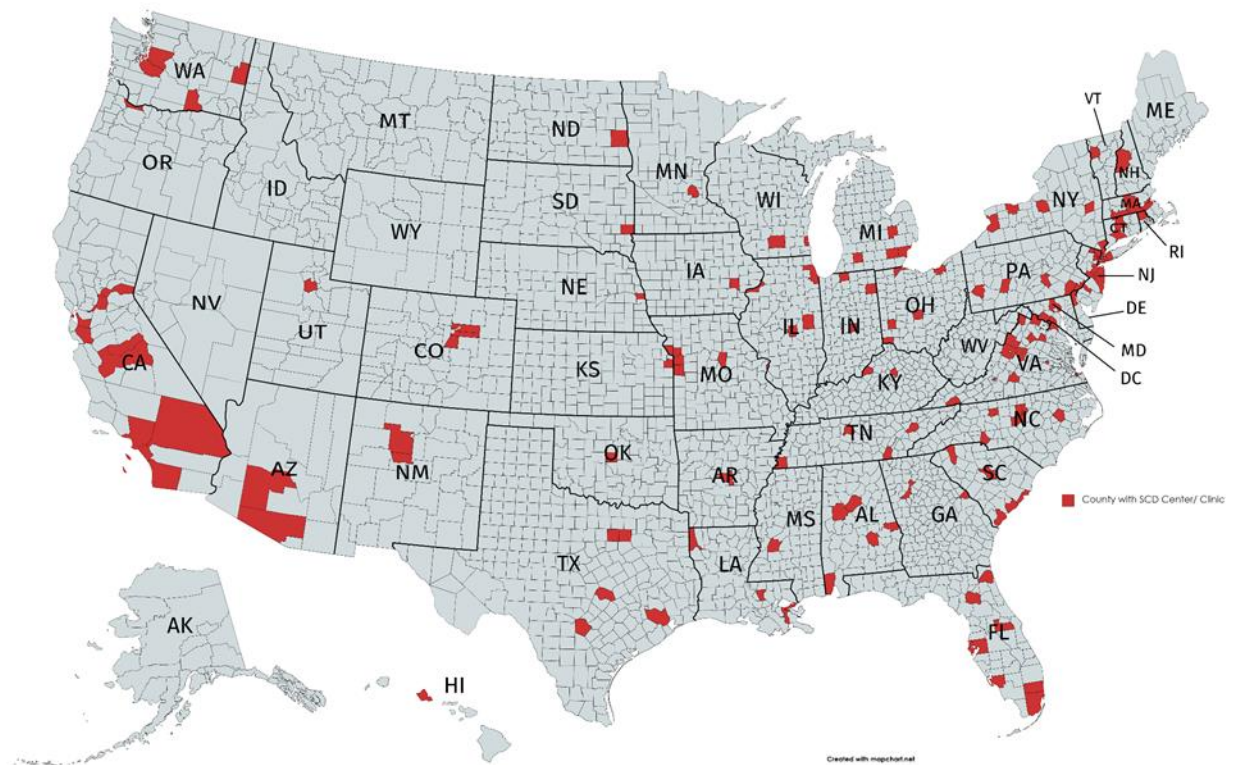


Figure 5 Counties with Sickle Cell Disease centers or clinics in the United States

The estimated total number of African American individuals who lack “ease of access” to SCD centers in the remaining 2978 counties was categorized per state. “Ease of access” was defined as having a SCD center in the county. All counties in Alaska, Idaho, Maine, Montana, Nevada, West Virginia, and Wyoming had the highest level of inaccessibility to SCD centers of 100% each since there are no SCD centers located in those states. On the contrary Washington D.C had the lowest rate of inaccessibility of 0% for the AA individuals given that the number of centers were more than sufficient to serve the estimated number of individuals in the District. The average inaccessibility across states was 53%. For more details see Table 5 in **Appendix A**.

3.3.3 Sickle Cell Disease Centers Resource Maps

Information gathered on the SCD Centers in the US was used to develop resource maps (Figure 6, Figure 7, and Figure 8) to be used by researchers and clinicians as a guide on where to refer patients with SCD and to aid patients living with SCD in locating centers offering services in their area. For ease of access and to simplify the ability of researchers, clinicians, patients and their relatives to search for centers in their preferred location, the maps are categorized into three groups: pediatric SCD centers, Adult SCD centers and SCD centers offering services to both pediatric and adult patients.

The 220 pediatric SCD centers are presented in the map with blue indicators. There is a visible absence of pediatric SCD centers in most parts of the Northwest, and some parts of the West and Southwest regions (Figure 6).

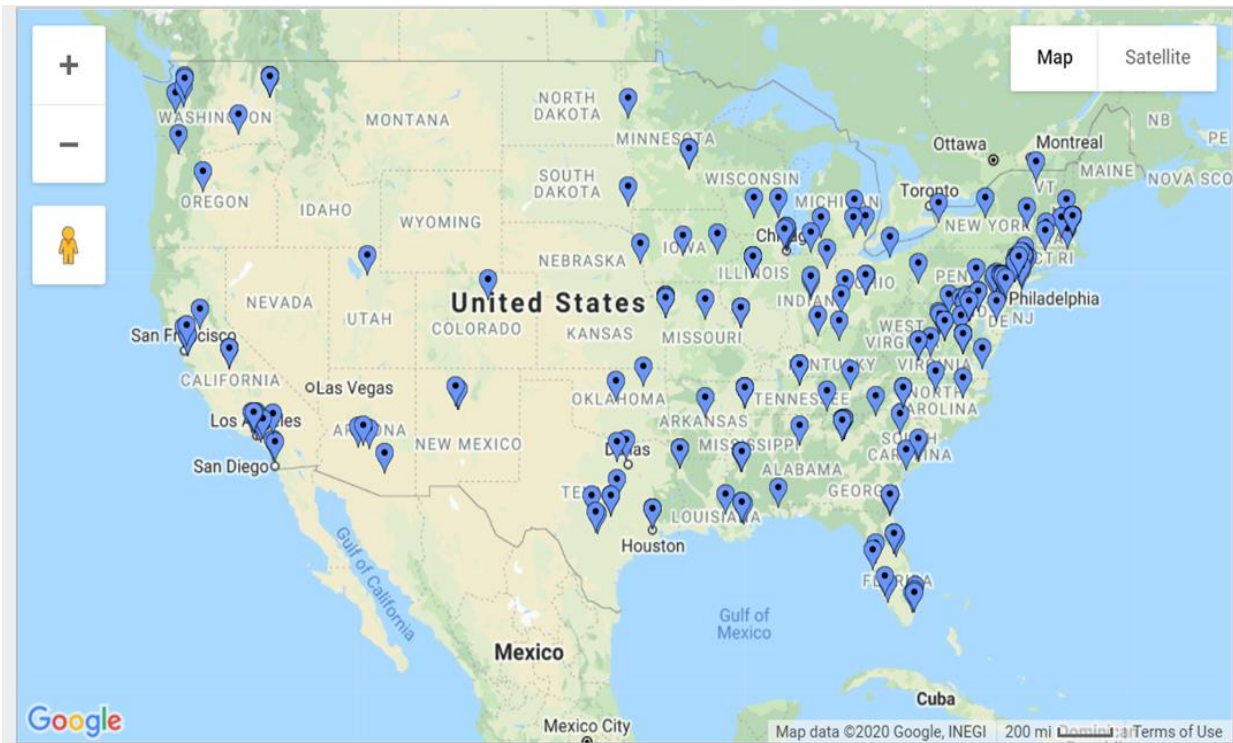


Figure 6 Snapshot of the map identifying pediatric Sickle Cell Disease centers in the United States

The map with the 68 Adult centers shows a total absence of the centers in the North West and South West regions. The SCD centers are represented in the map with green (target) indicators (Figure 7).

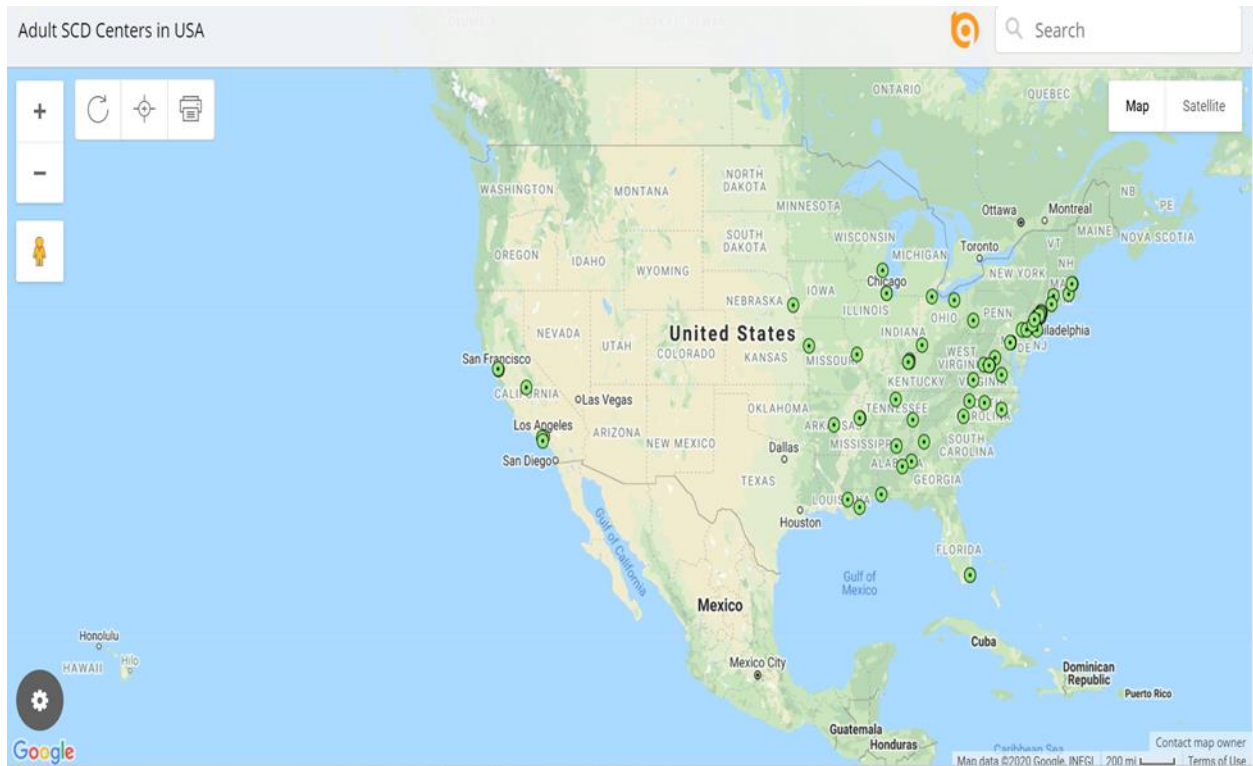


Figure 7 Snapshot of the map identifying adult Sick Cell Disease centers in the United States

The 23 SCD centers offering services to both pediatric and adult patients are represented in the map with purple indicators and are evidently very few. There is also an evident absence of these centers in the North West and South West regions of USA. (Figure 8).

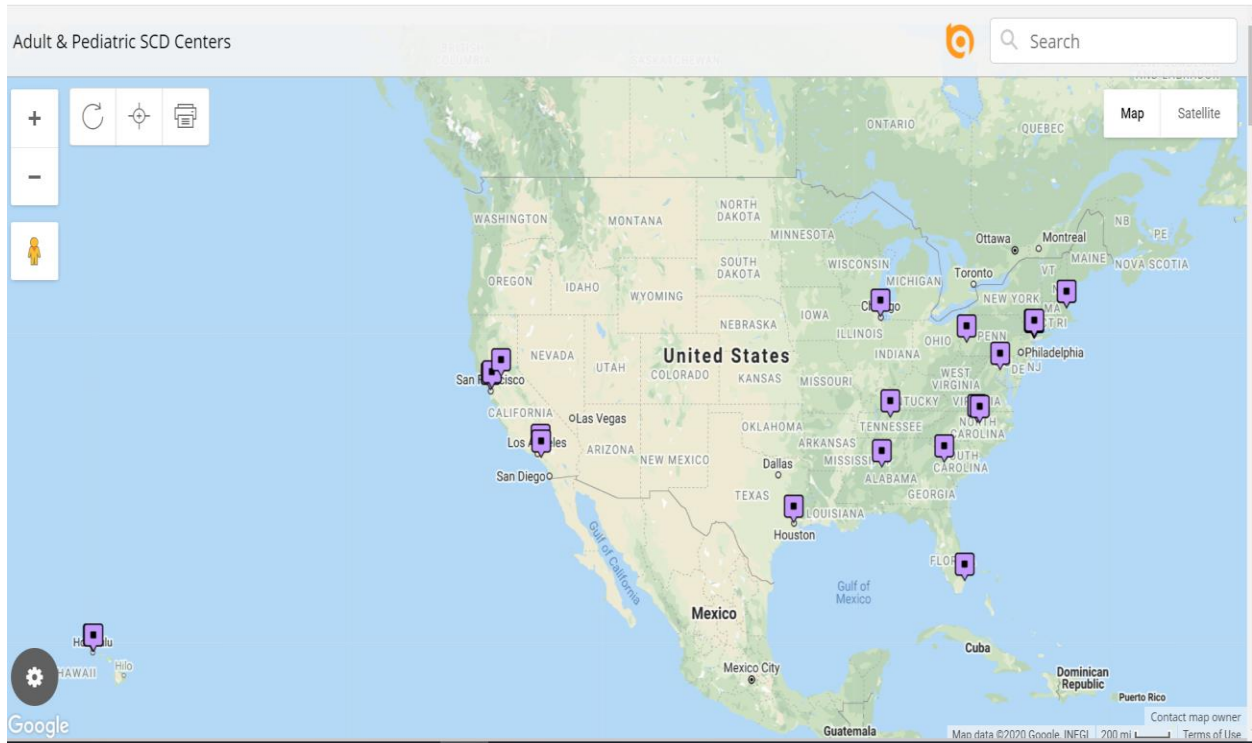


Figure 8 Snapshot of the map identifying centers offering both pediatric and adult Sickle Cell Disease care in the United States

These maps allow for a detailed search and give the name of the center in the search area, the contacts of the center and a link that enables an individual to open the center’s website to get more information on the center and services they offer. An example of one of the searches is shown in Figure 9.

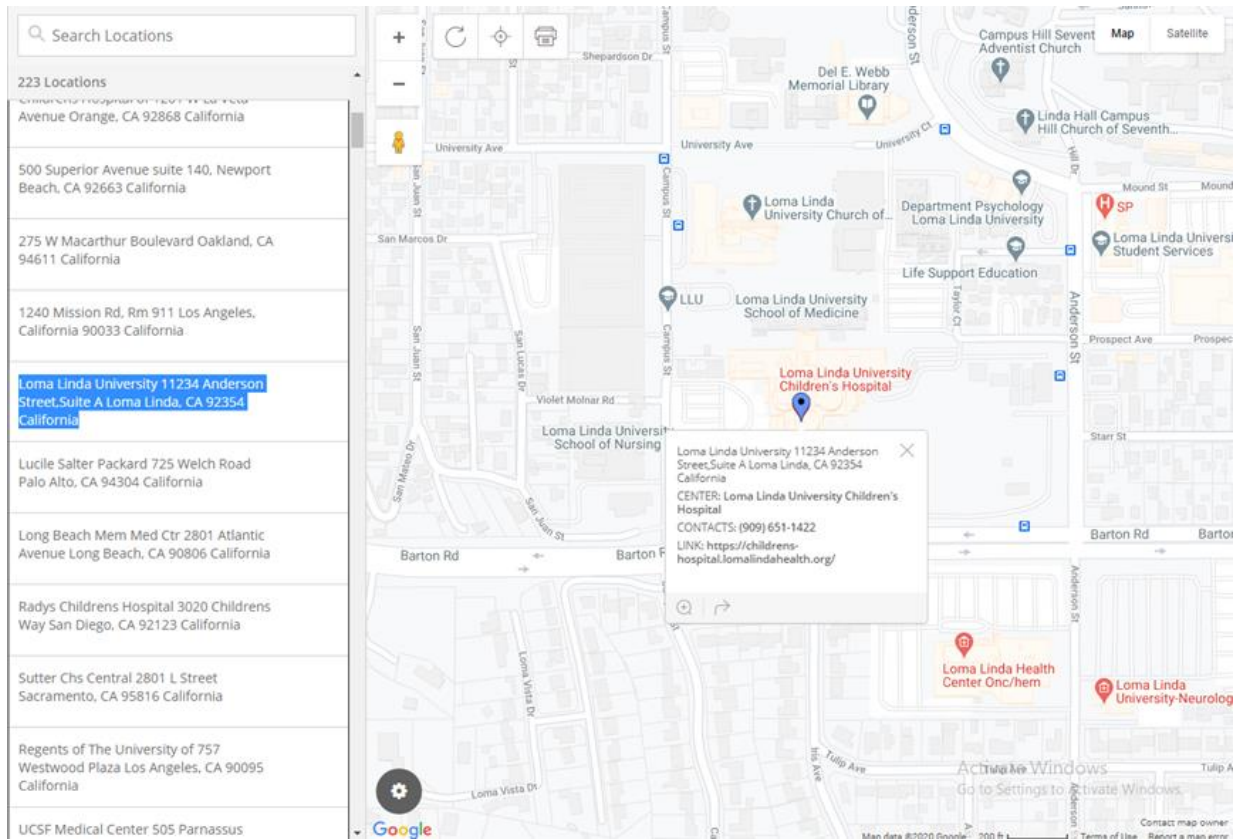


Figure 9 Snapshot of an example of a map search in the SCD center pediatric map

3.4 DISCUSSION

The developed custom map shows the distribution of SCD centers by county in the US (Figure 5) and indicates the geographic distribution of SCD centers, revealing that majority of SCD centers are in the West, Mid-Atlantic, and South East regions of the United States. SCD centers in the North West, South West, and Mid-west regions of the US are very few and sparsely distributed. (Figure 3) The seven states that do not have an established SCD center are all either rural and /or mountainous and have a small number of African Americans living in the state in comparison to other states. Some states with high numbers of AA do not appear to have sufficient SCD centers to offer services to individuals living in them. Most of these states, for example Mississippi, are known to have high poverty rates. This therefore means that starting and maintaining a SCD center in these areas may be difficult from a funding perspective given the fact that SCD centers are not federally sponsored and that they depend on institutional support, donations and third party reimbursement for clinical services, which can be low in rural areas.²⁷ African Americans living in these states may receive care from other qualified providers who are not part of the SCD centers, but at some point they may have to travel or be emergently transferred to neighboring states that have SCD centers to receive more advanced treatment or tests. As per the access per capita results, Washington D.C has sufficient SCD centers to offer care to individuals in its territory and possibly serve the neighboring states like Virginia and Maryland. It is therefore also important to increase funding towards developing the centers and maintaining the ones that already exist to ensure that individuals with SCD can easily access and receive quality healthcare services.³¹

Telemedicine clinic sites could be one among the possible solutions to the inaccessibility and absence of SCD centers in these areas. This helps families save money and are therefore able

to afford the purchase of required medicine and food for their members with SCD. Telehealth would also play an important role in educating the public, especially the majorly affected African American community, on the presentation of the disease and ways of reducing and possibly preventing occurrence of complications among these patients with SCD. This will help cut down on the costs and expenditure of the families and also improve their quality of life.³⁴ Teleconsults and/or telementoring, like Project ECHO which is an all teach all learn initiative,⁵² could allow healthcare providers in the areas lacking SCD centers with no specialization in management of SCD patients to be able to obtain guidance through online communication or educational models and mentoring from healthcare providers with expertise in managing patients with SCD.³² Additionally, states that have a center in ≥ 1 county could organize to have satellite clinics set up in other counties without SCD centers, that would work on a certain number of days to have SCD healthcare professional specialists visit the clinics to see the patients with SCD. This would aid in cutting down on the number of individuals with SCD, especially adult patients, who miss important visits/ appointments due to bad terrain, poor infrastructure and transportation services or lack of ample time to travel to and from the center without interfering with their work schedule.

Even though there has been an evident decrease in mortality of patients with SCD over the years³⁸, the burden of SCD is still weighing heavily on the African American community.^{14,15,16,17} There is need to advocate for more funding and to channel the funding towards the care of individuals diagnosed with SCD as well as research studies and clinical trials tailored specifically towards individuals diagnosed with SCD from all the affected races/ethnic groups.

Given the difficulty in estimating the locations of patients with SCD in each state, it is important that states continue to assess the needs of this population in their states and ensure that high quality services are accessible to individuals with SCD.

3.4.1 Limitations

This study, looking at distribution of SCD Centers in the US, had several limitations. The search strategy was complicated because not all centers used common or expected titles that include SCD center or program in their name. Some used names of individuals or different names that required a lot more effort in searching for the state. We used key words to search the internet but also had to compare what we found with the previously published informational links and addresses in the CDC SCD directory (last updated in 2011) and the [link](#) (last updated in 1998). Therefore, there is a possibility that some centers have been missed in this collection and compilation. Given that the SCD center directory that was utilized may have been out of date, attempts to contact the CDC publication office to inquire if they had a latest version of the directory were not successful.

Information on the precise representation of SCD patients in the USA was not obtained because not all states have readily accessible estimations of SCD patients in their areas of jurisdiction. Similarly, the catchment area of the centers may in some areas be larger than the counties where they were located, for example, the adult Comprehensive Sickle cell center located in Allegheny county, PA regularly manages individuals with SCD from more than 10 counties in Pennsylvania as well as a significant number of individuals residing in neighboring states such as Ohio and West Virginia. Therefore, the results of this study may not be accurately representative of the healthcare access of patients with SCD in the US.

In the estimation of ease of access, being in a county with more than one SCD center does not necessarily mean that an individual with SCD could easily access it. Other factors like infrastructure, transportation system, healthcare insurance and financial ability of the individuals contribute to the healthcare access. Example, if an individual with SCD does not live on a bus line

or is living in a county without a bus line to the SCD center, the SCD center might not be accessible to them. Additionally, individuals with SCD living in a neighboring county might be closer to a SCD center if it is located at the border of two counties than others who are in the county with the SCD center but living on the extreme end of the county. Cross state borders were also not taken into account in this study. This therefore is only an estimate and is not entirely representative of the measure of ease of access.

This study evaluated geographical location but did not entertain or discuss the overall structure, capacity and resources that each of the Sickle cell center identified has to care for the population they offer services to, thus a follow-up study evaluating their capacity, resources, institutional support and presence of, or lack of, standardized approaches for patient care between these centers will be complementary to our findings.

The information used in this study analysis mainly targeted African-Americans, but individuals of other racial and ethnic backgrounds can also have SCD. It is therefore not representative of all affected individuals and ethnic groups. In addition, we also do not have information on outreach SCD centers and centers currently offering telemedicine and telegenetics, therefore there may be a wider coverage than what is shown in this study.

3.5 CONCLUSION

This study indicated that there are likely inequalities in access to SCD centers in the US based on the regional location of an individual and the state they live in. It also indicates that a comprehensive up-to-date resource listing all currently functional SCD centers does not exist. There is no centralized SCD registry/database that contains demographics and/or health-related outcome of all individuals with SCD in all states in the US, though some states do maintain some of this information.

4.0 SIGNIFICANCE OF THE REVIEW TO PUBLIC HEALTH

The results of this study point out the fact that the monitoring of a SCD patient's status is not equal to all individuals in the US because it depends on the availability and proximity of a SCD center or a healthcare facility offering the services in the area of residence of the affected individuals. With the only available directories on SCD centers and facilities being outdated, an up-to-date directory on the SCD centers, clinics, and support groups will assist physicians in directing patients with SCD for more advanced and expertise management. The resource maps and updated directory created in this review are meant make it easier for patients and their families to know where to go for healthcare and support services if they are researching centers or if they have just moved to a new state and are looking for SCD centers.

APPENDIX A: DETAILED TABLES ON SICKLE CELL DISEASE CENTER IN US

Table 2 State Per capita access of African American population to SCD centers

STATE	AA population Estimate	No. of SCD centers	Per Capita Access
Alabama	1,280,969	8	160,121
Alaska	26,279	0	-
Arizona	332,385	4	83,096
Arkansas	457,799	2	228,900
California	2,421,507	28	86,482
Colorado	231,343	1	231,343
Connecticut	436,040	3	145,347
Delaware	208,321	1	208,321
Florida	3,177,421	17	186,907
Georgia	3,158,175	8	394,772
Hawaii	29,927	2	14,963
Idaho	14,108	0	-
Illinois	1,873,272	12	156,106
Indiana	641,896	4	160,474
Iowa	124,901	1	124,901

Kansas	174,040	1	174,040
Kentucky	368,846	7	52,692
Louisiana	1,486,946	8	185,868
Maine	22,582	0	-
Maryland	1,795,575	8	224,447
Massachusetts	589,287	11	53,572
Michigan	1,393,593	4	348,398
Minnesota	371,275	3	123,758
Mississippi	1,121,638	3	373,879
Missouri	706,693	6	117,782
Montana	5,936	0	-
Nebraska	94,970	2	47,485
Nevada	278,157	0	-
New Hampshire	23,696	1	23,696
New Jersey	1,327,576	21	63,218
New Mexico	53,539	3	17,846
New York	3,410,546	29	117,605
North Carolina	2,116,877	12	176,406
North Dakota	22,868	1	22,868
Ohio	1,511,282	9	167,920

Oklahoma	292,605	2	146,303
Oregon	84,284	1	84,284
Pennsylvania	1,524,285	17	89,664
Rhode Island	89,468	2	44,734
South Carolina	1,248,848	5	249,770
South Dakota	18,726	1	18,726
Tennessee	1,085,184	11	98,653
Texas	3,243,777	9	360,420
Utah	41,458	1	41,458
Vermont	8,760	1	8,760
Virginia	1,592,204	27	58,971
Washington	295,880	8	36,985
West Virginia	66,708	0	-
Wisconsin	381,028	3	127,009
Wyoming	7,327	0	-
Washington DC	276,793	3	92,264

Table 3 Distribution of Sickle cell Disease Centres in USA

STATE	Total counties per state	No. of counties with centers	No. of SCD centers per State
AL	67	5	8
AK	20	0	0
AZ	15	2	4
AR	75	1	2
CA	58	11	28
CO	64	3	1
CT	8	2	3
DE	3	1	1
FL	67	8	17
GA	159	2	8
HI	5	1	2
ID	44	0	0
IL	102	4	12
IN	92	3	4
IA	99	1	1
KS	105	1	1
KY	120	2	7
LA	64	4	8
ME	16	0	0

MD	24	3	8
MA	14	4	11
MI	83	4	4
MN	87	1	3
MS	82	1	3
MO	115	6	6
MT	56	0	0
NE	93	1	2
NV	17	0	0
NH	10	1	1
NJ	21	9	21
NM	33	3	3
NY	62	11	29
NC	100	6	12
ND	53	1	1
OH	88	5	9
OK	77	1	2
OR	36	1	1
PA	67	8	17
RI	5	1	2
SC	46	4	5
SD	66	1	1
TN	95	4	11

TX	254	6	9
UT	29	1	1
VT	14	1	1
VA	133	13	27
WA	39	4	8
WV	55	0	0
WI	72	2	3
WY	23	0	0
DC	1	1	3
TOTAL	3133	155	311

Table 4 Number of African Americans in counties with Sickle Cell Disease centers

STATE	Counties with SCD Centers	Population Of AA	No. of SCD centers
Alabama	Jefferson	286,433	3
	Montgomery	136,012	1
	Lee County	32,117	1
	Tuscaloosa	63,069	1
	Mobile	149,503	2
Arizona	Maricopa	244,295	3
	Pima	41,171	1
Arkansas	Pulaski	145,061	2
California	Alameda	166,130	4
	Los Angeles	883,674	9
	Orange	63,215	2
	Placer	6,620	1
	San Bernardino	191,310	1
	Santa Clara	49,886	2
	San Diego	170,242	2
	Fresno	53,966	1
	Sacramento	154,648	2
	San Francisco	45,093	2
	Madera	6,336	2
Colorado	Adams, Arapahoe, Douglas	88,297	1

Connecticut	Hartford	141,254	2
	New Haven	131,097	1
Delaware	New Castle	142,158	1
Florida	Orange	261,278	3
	Pinellas	101,736	1
	Hillsborough	221,261	1
	Alachua	50,951	1
	Miami-Dade	441,869	5
	Duval	266,193	2
	Broward	527,916	3
	Lee	56,307	1
Georgia	Fulton	409,659	7
	Richmond	115,717	1
Hawaii	Honolulu	26,690	2
Illinois	Cook	1,236,333	9
	Macon	19,717	1
	Rock Island	16,378	1
	Champaign	27,749	1
Indiana	Marion	262,887	2
	Allen	42,639	1
	St. Joseph	36,836	1
Iowa	Johnson	9,816	1
Kansas	Johnson	26,665	1

Kentucky	Jefferson	166,006	6
	Lexington-Fayette	42,596	1
Louisiana	Orleans Parish	206,641	3
	Jefferson Parish	122,412	1
	Caddo Parish,	127,485	2
	East Baton Rouge Parish	207,761	2
Maryland	Baltimore	243,924	6
	Prince George's	556,042	1
	Montgomery	195,327	1
Massachusetts	Norfolk	53,668	1
	Hampden	50,520	1
	Suffolk	175,452	8
	Worcester	48,712	1
Michigan	Washtenaw	42,409	1
	Wayne	704,566	1
	Genesee	86,435	1
	Kalamazoo	29,539	1
Minnesota	Hennepin	159,035	3
Mississippi	Hinds	179,303	3
Missouri	Jackson, Clay, Platte, and Cass counties	187,341	2
	Boone	15,939	1
	St. Louis	249,739	3

Nebraska	Douglas	59,468	2
New Hampshire	Grafton	1,159	1
New Jersey	Essex	328,483	5
	Bergen	66,979	1
	Camden	110,950	2
	Monmouth	47,279	3
	Middlesex	97,183	3
	Hudson	93,871	2
	Mercer	78,800	1
	Passaic	74,683	1
	Ocean	20,756	2
	Union	127,687	1
New Mexico	Bernalillo	23,852	2
	Sandoval	3,552	1
New York	New York	282,285	9
	Queens	461,759	3
	Kings	846,589	5
	Richmond	54,373	1
	Westchester	158,502	1
	Bronx	603,907	4
	Erie	128,666	1

	Monroe	120,584	1
	Nassau	175,479	1
	Albany	42,893	1
	Onondaga	56,043	1
North Carolina	Durham	98,740	1
	Chatham	7,875	1
	Orange	15,789	3
	Forsyth	96,434	1
	Pitt	60,365	2
	Mecklenburg	303,477	4
North Dakota	Cass	9,586	1
Ohio	Hamilton	213,431	2
	Franklin	276,893	2
	Cuyahoga	390,437	3
	Montgomery	115,058	1
	Lucas	89,688	1
Oklahoma	Oklahoma	113,544	1
	Tulsa	65,168	1
Oregon	Multnomah	44,120	1
Pennsylvania	Philadelphia	665,339	8
	Allegheny	163,929	3
	Chester	30,931	4
	Delaware	5,316	1

	Dauphin	126,888	1
Rhode Island	Providence	51,475	2
South Carolina	Charleston	78,333	2
	Richland	92,105	1
	Beaufort	187,253	1
	Greenville	29,040	1
South Dakota	Minnehaha	83,025	1
Tennessee	Shelby	10,338	5
	Knox	503,711	1
	Hamilton	38,468	2
	Davidson	64,937	3
Texas	Harris	171,711	2
	Tarrant	818,492	1
	Dallas	323,817	3
	Williamson	558,881	1
	Bexar	31,278	1
	Jackson	147,470	1
Utah	Salt Lake	943	1
Vermont	Chittenden	22,652	1
Virginia	Norfolk	3,914	1
	Richmond	102,220	5
	Stafford	2,739	2
	Washington	25,792	1

	Fairfax	823	3
	Loudoun	114,663	1
	Albemarle	25,297	5
	Augusta	9,600	1
	Culpeper	3,466	1
	Rockingham	6,817	1
	Frederick	1,908	1
	Roanoke	3,680	3
	Campbell	5,912	1
Washington	King	8,117	2
	Spokane	135,187	3
	Benton	9,424	1
	Pierce	3,153	2
Wisconsin	Milwaukee	257,784	2
	Dane	26,844	1
Washington DC	Washington D.C.	282,208	3

Table 5 Number of African Americans in Counties without Sickle Cell Disease centers

STATE	Number of AA in all Counties	Number of AA in counties without SCD Centers	Percentage of AA without close access to SCD Center
Alabama	1,280,969	613,836	48
Alaska	26,279	26,279	100
Arizona	332,385	46,918	14
Arkansas	457,799	312,738	68
California	2,421,507	630,386	26
Colorado	231,343	143,046	62
Connecticut	436,040	163,689	38
Delaware	208,321	66,162	32
Florida	3,177,421	1,249,911	39
Georgia	3,158,175	2,632,800	83
Hawaii	29,927	3,237	11
Idaho	14,108	14,108	100
Illinois	1,873,272	573,096	31
Indiana	641,896	299,533	47
Iowa	124,901	115,084	92
Kansas	174,040	147,375	85
Kentucky	368,846	160,245	43
Louisiana	1,486,946	822,647	55
Maine	22,582	22,582	100

Maryland	1,795,575	800,281	45
Massachusetts	589,287	260,935	44
Michigan	1,393,593	530,644	38
Minnesota	371,275	212,240	57
Mississippi	1,121,638	942,335	84
Missouri	706,693	253,675	36
Montana	5,936	5,936	100
Nebraska	94,970	35,501	37
Nevada	278,157	278,157	100
New Hampshire	23,696	22,538	95
New Jersey	1,327,576	280,906	21
New Mexico	53,539	26,134	49
New York	3,410,546	479,466	14
North Carolina	2,116,877	1,534,198	72
North Dakota	22,868	13,282	58
Ohio	1,511,282	425,774	28
Oklahoma	292,605	113,894	39
Oregon	84,284	40,164	48
Pennsylvania	1,524,285	480,408	32
Rhode Island	89,468	11,135	12
South Carolina	1,248,848	857,425	69
South Dakota	18,726	8,389	45
Tennessee	1,085,184	306,357	28

Texas	3,243,777	1,362,896	42
Utah	41,458	18,806	45
Vermont	8,760	4,847	55
Virginia	1,592,204	1,281,169	80
Washington	295,880	86,882	29
West Virginia	66,708	66,708	100
Wisconsin	381,028	96,400	25
Wyoming	7,327	7,327	100
Washington DC	276,793	0	0
TOTAL	41,547,602	18,893,898	53

APPENDIX B: SICKLE CELL DISEASE CENTERS/CLINICS IN THE US

STATE	CENTER	ADDRESS, CONTACT AND LINK
Alabama	Comprehensive Sickle Cell Center - UAB	1802 6th Avenue, South North Pavilion, Room 2512 Birmingham, AL 35294 (205) 996-1735, email: ewarner@uabmc.edu. https://www.uab.edu/medicine/hemonc/about/comprehensive-sickle-cell-center
Alabama	Children’s of Alabama/UAB Pediatric Hematology Clinic	1600 7th Ave. S. Birmingham, AL 35233 (205) 638-9100 https://www.childrensal.org/hematology
Alabama	Montgomery Site at UAB Montgomery	2055 East South Boulevard Suite 202 Montgomery, AL 36116 (334) 284-5211 https://www.uabmedicine.org/locations/uab-medicine-montgomery

Alabama	Opelika Site at East Alabama Medical Center Clinic	2501 Village Professional Dr Opelika, AL 36801 (334) 528-1070
Alabama	Tuscaloosa Site at University of Alabama Health Sciences Campus	850 Peter Bryce Boulevard Tuscaloosa, AL 35401 (205) 348-1770 https://umc.ua.edu/university-medical-center/
Alabama	The Kirkland Clinic (TKC) UAB	2000 6th Avenue South Birmingham, AL 35233 (205) 934-3411 https://www.uabmedicine.org/locations/the-kirclin-clinic-of-uab-hospital
Alabama	USA Comprehensive Sickle Cell Center	https://www.southalabama.edu/colleges/com/research/sickle-cell.html
Alabama	Strada Patient Care Center	Suite 1F 1601 Center Street AL 36604 (251) 410-5437 https://www.usahealthsystem.com/services/pediatric-sickle-cell-care

Alabama	Mastin Patient Care Center	Suite 102 2451 University Hospital Dr. AL 36617;(251) 470-5890 https://www.usahealthsystem.com/services/sickle-cell-care
Alaska	No Center	
Arizona	Sickle Cell Program - Phoenix Children's Hospital	(602)-933-0920 https://www.phoenixchildrens.org/centers-programs/sickle-cell
Arizona	Phoenix Children's Hospital - Main	1919 E. Thomas Rd Phoenix, Arizona 85016 (602)-933-1000 http://www.phoenixchildrens.org/locations/phoenix-childrens-hospital-main
Arizona	Phoenix Children's Specialty Care - Tucson	5983 E. Grant Rd. Suite 201, Tucson, Arizona 85712 (520)-320-7999 http://www.phoenixchildrens.org/locations/phoenix-childrens-east-valley-specialty-care-center
Arizona	Phoenix Children's East Valley Specialty Care Center	5131 E. Southern Ave. Mesa, Arizona 85206 (602)-933-0002

		http://www.phoenixchildrens.org/locations/phoenix-childrens-east-valley-specialty-care-center
Arizona	Phoenix Children's Southwest Valley Specialty Care Center	1665 N. Avondale Blvd., Avondale, Arizona 85392;(602)-933-0005; http://www.phoenixchildrens.org/locations/phoenix-childrens-southwest-valley-specialty-care-center
Arkansas	Sickle Cell Disease Program Arkansas Children's	1 Children's Way Little Rock, AR 72202 (501)364-1494 email :mullangelab@uams.edu https://www.archildrens.org/programs-services/a-to-z-services-list/sickle-cell-clinic/sickle-cell-clinic
Arkansas	UAMS Adult Sickle Cell Clinical Program	4301 W. Markham Little Rock, AR 72205 - Slot # 519 1-855-SIC-CELL (1-855-742-2355) email: sicklecell@uams.edu https://sicklecell.uams.edu/
California		https://www.dhcs.ca.gov/services/ccs/scc/Pages/SickleCell.aspx
California	Alta Bates Summit Medical Center	2450 Ashby Avenue, Berkeley, CA 94705; (510) 204-4444;

	Sutter Bay Hospitals	https://www.sutterhealth.org/absmc
California	Cedars-Sinai Medical Center	8700 Beverly Boulevard Los Angeles, CA 90048; (310) 855-5000; https://www.cedars-sinai.org/programs/pediatrics/conditions/hematology.html
California	Children's Hospital Los Angeles	4650 Sunset Boulevard Los Angeles, CA 90027; (213) 660-2450; ars-sinai.org/programs/pediatrics.html?_ga=2.251315073.686791604.1595616070-157137035.1595616070
California	CHOC Children's Main Campus - Orange	Childrens Hospital of 1201 W La Veta Avenue Orange, CA 92868; (714) 997-3000; https://www.choc.org/programs-services/hematology/
California	Harbor-UCLA Medical Center	Los Angeles County Harbor 1000 W Carson Street Torrance, CA 90502; (310) 222-2345; https://dhs.lacounty.gov/harbor/

California	Kaiser Permanente Oakland Medical Center	Kaiser Foundation Hosp 275 W Macarthur Boulevard Oakland, CA 94611; (510) 752-1000;
California	Kaiser Permanente Roseville Medical Center	Kaiser Foundation Hospitals 1600 Eureka Road Roseville, CA 95661; (916) 784-5727; https://healthy.kaiserpermanente.org/northern-california/health-wellness/maternity/find-hospital/roseville
California	Kaiser Permanente West Los Angeles Medical Center	Kaiser Found Hosp Wla 6041 Cadillac Avenue Los Angeles, CA 90034; (213) 857-2000; https://thrive.kaiserpermanente.org/care-near-you/southern-california/west-los-angeles/locations/west-los-angeles-medical-center/
California	LAC+USC Medical Center	Lacusc Med Ctr 1200 N State Street Los Angeles, CA 90033; (323) 409-3343; https://dhs.lacounty.gov/lacusc/
California	LAC+USC Medical Center	1240 Mission Rd., Rm. 911 Los Angeles, California 90033

California	Loma Linda University Children's Hospital	Loma Linda University 11234 Anderson Street, Suite A Loma Linda, CA 92354; (909) 651-1422; https://lluch.org/services/specialty-team-centers
California	Lucile Packard Children's Hospital Stanford	Lucile Salter Packard 725 Welch Road Palo Alto, CA 94304; (650) 725-6557; https://www.stanfordchildrens.org/
California	Miller Children's & Women's Hospital Long Beach	Long Beach Mem Med Ctr 2801 Atlantic Avenue Long Beach, CA 90806; (652) 933-8001; https://www.millerchildrenshospitallb.org/search/search&keywords=sickle+cell
California	Rady Children's Hospital San Diego	Radys Childrens Hospital 3020 Childrens Way San Diego, CA 92123; (858) 576-1700; https://www.rchsd.org/programs-services/cancer-blood-disorders/services/comprehensive-sickle-cell-center/
California	Saint Agnes Medical Center	Saint Agnes Medical Center 1303 E Herndon Avenue Fresno, CA 93720; (559) 450-3000;

		https://www.samc.com/
California	Sutter Medical Center, Sacramento	Sutter Chs Central 2801 L Street Sacramento, CA 95816; (916) 455-2661; https://www.sutterhealth.org/smcs/services/pediatric/pediatric-sickle-cell-disease-clinic-smcs
California	UC Davis Medical Center	UC Davis Medical Center 2315 Stockton Boulevard Sacramento, CA 95817; (916) 734-2011; https://health.ucdavis.edu/medicalcenter/
California	U.C. Irvine Medical Center	101 City Drive South Bldg. 29A, Rt. 81 Orange, California 92668; (714) 456-6615 OR (714)-880-7812; http://www.ucihealth.org/medical-services/blood-disorders
California	UCLA Mattel Children's Hospital at Ronald Reagan	Regents of The University of 757 Westwood Plaza Los Angeles, CA 90095; (310) 825-8021; https://www.uclahealth.org/mattel/about-mattel-childrens-hospital-ucla
California	UCSF Benioff Children's Hospital Oakland	Childrens Hospital Medical 747 52nd Street Oakland, CA 94609; (510) 428-3885x5130;

		https://www.childrenshospitaloakland.org/main/home.aspx
California	UCSF Benioff Children's Hospital San Francisco	UCSF Medical Center 505 Parnassus Avenue San Francisco, CA 94143; (415) 476-1000; http://www.ucsfmissionbayhospitals.org/children/
California	Valley Children's Hospital	Valley Childrens Hospital 9300 Valley Childrens Place Madera, CA 93636; (559) 353-3000; https://www.valleychildrens.org/#
California	Zuckerberg San Francisco General Hospital and Trauma Center	San Francisco Gen Hosp 1001 Potrero Avenue San Francisco, CA 94110; (415) 821-8200; https://zuckerbergsanfranciscogeneral.org/
California	Stanford Children's Hospital	Stanford Children's Hospital Sickle Cell Disease Center 735 Welch Rd. Palo Alto, California 94303 ; (415) 497-8238 ; https://www.stanfordchildrens.org/en/topic/default?id=sickle-cell-disease-in-children-90-P02327
California	Valley Children's Hospital of Central California	9300 Valley Children's Place Madera, CA 93636; (559) 353-3000; https://www.valleychildrens.org/

California	Highland Hospital Sickle Cell Disease Center	1411 E. 31st St. Oakland, California 94602; (510) 437-4251;
California	University of California, San Diego University Hospital	UC San Diego Health 200 West Arbor Drive San Diego, CA 92103; (858) 657-7000 OR (800) 926-8273; https://health.ucsd.edu/Pages/default.aspx
California	City of Hope Medical Center	1500 East Duarte Road Duarte, CA 91010; (626) 256-4673; https://www.cityofhope.org/patients/departments-and-services/benign-hematology/sickle-cell-disease-program
Colorado	Colorado Sickle Cell Treatment and Research Center	CU Anschutz Education II South 13121 East 17th Avenue Aurora, CO 80045; (303) 724-9070; https://medschool.cuanschutz.edu/sickle-cell-center#:~:text=The%20Colorado%20Sickle%20Cell%20Treatment,expertise%20and%20facilitation%20of%20comprehensive
Connecticut	Connecticut Children's Medical Center	Connecticut Children's Hartford 282 Washington Street Hartford, CT 06106; (860) 545-9000;

		https://www.connecticutchildrens.org/health-library/en/parents/sickle-cell-anemia/
Connecticut	Yale New Haven Health Adult Sickle Cell Clinic	Yale New Haven Hospital 20 York Street New Haven, CT 06510-3202; (203)-200-4363; https://www.ynhh.org/services/hematology/adult-sickle-cell-clinic.aspx
Connecticut	New England Sickle Cell Institute (NESCI)	Carole and Ray Neag Comprehensive Cancer center Uconn Health Main Building 300 Uconn Health Boulevard Farmington, CT 06030; (800) 579-7822; https://health.uconn.edu/cancer/patient-services/centers-and-interdisciplinary-clinics/new-england-sickle-cell-institute/
Delaware	Delaware Comprehensive Sickle cell Research Center	Nemours/Alfred I. duPont Hospital for Children 1600 Rockland Road Wilmington, DE 19803; (302) 651-4000 info@grantome.com ; https://sicklecellcobrede.org/
Florida	Sickle Cell Disease Program - Arnold Palmer Hospital	92 W Miller St, Orlando, FL 32806; (321) 841-8588;

		https://www.arnoldpalmerhospital.com/pediatric-specialties/sickle-cell-disease-program
Florida	Sickle Cell Program - Johns Hopkins All Children's Hospital	501 6th Ave S, St. Petersburg, FL 33701; (727) 767-4176; https://www.hopkinsallchildrens.org/Services/Cancer-Institute/Programs-and-Services/Benign-Hematology/Sickle-Cell-Program
Florida	Comprehensive Sickle Cell Program Morsani College of Medicine USF Health - University of South Florida	12901 Bruce B Downs Blvd, Tampa, FL 33612; (813) 250-2262; https://health.usf.edu/medicine/pediatrics/hematology/sickle-cell
Florida	Pediatric Sickle Cell Program University of Florida	1600 SW Archer RD Gainesville, FL 32608; (352) 273-9120; https://ufhealthjax.org/pediatric-sickle-cell/
Florida	Sickle cell program-University of Miami Miller school of medicine	1601 N.W. 12th Ave. Miami, FL 33136; E-mail: pedsinformation@med.miami.edu ; http://pediatrics.med.miami.edu/hemonc-stemcell-transplant/clinical-services/sickle-cell-program

Florida	Pediatric Sickle Cell Program UF Health C.B. McIntosh Center - University of Florida Jacksonville	555 West 11th Street Jacksonville, FL 32206; (904) 244-4472; https://ufhealthjax.org/pediatric-sickle-cell/
Florida	Foundation for Sickle Cell Disease Research	3858 Sheridan St. Suite S, Hollywood, FL 33021; (954) 397-3251 info@fscdr.org ; https://fscdr.org/we-help/
Florida	Golisano Children’s Hospital of Southwest Florida	9981 S. HealthPark Drive, Fort Myers, FL 33908; 239-343-KIDS(5437); https://www.leehealth.org/find-a-location/golisano-children-s-hospital-of-southwest-florida
Florida	Holtz Children’s Hospital (Pediatric care)	1611 NW 12th Avenue Miami, FL 33136; (305) 585-5437; https://jacksonhealth.org/holtz/oncology/
Florida	Jackson Memorial Hospital (Adult care)	1611 NW 12th Avenue Miami, FL 33136; (305) 585-6602 OR (305) 585-5196; https://jacksonhealth.org/services/oncology/?open#jackson-memorial-hospital

Florida	Memorial Healthcare sickle cell day hospital Memorial Healthcare System	3501 Johnson Street Hollywood, Florida 33021; (954) 265-4325; https://www.mhs.net/services/cancer/types/sickle-cell
Florida	Sickle Cell/Hemoglobinop athies Comprehensive care Program Miami Children's Hospital - Nicklaus Children's Hospital Main Hospital Campus	3100 SW 62nd Avenue Miami, FL 33155; (800) 432-6837; https://www.nicklauschildrens.org/medical-services/cancer-center/programs/sickle-cell-hemoglobinopathies
Florida	Nemours Children's Clinic Specialty Care, Orlando	1717 S. Orange Ave. Orlando, FL 32806; (407) 650-7715; https://www.nemours.org/locations/florida-pediatric-specialty-care-orlando.html
Florida	Nemours Children's Clinic	807 Children's Way Jacksonville, FL 32207; (904) 697-3600;

	Specialty Care, Jacksonville	https://www.nemours.org/locations/florida-pediatric-specialty-care-jacksonville.html
Florida	Nemours Children's Hospital, Orlando	6535 Nemours Parkway Orlando, FL 32827; (407) 567-4000; https://www.nemours.org/locations/orlando-nemours-childrens-hospital.html
Florida	Sylvester Comprehensive Cancer Center University of Miami School of Medicine Sickle Cell Center	1475 NW 12th Ave 1st Floor Miami, FL 33136; (305) 243-1000; https://umiamihealth.org/en/locations?specialties=hematology
Georgia	Georgia Comprehensive Sickle Cell Center Grady Memorial Hospital	80 Jesse Hill Jr Drive SE Atlanta, GA 30303; (404) 616-1000; https://www.gradyhealth.org/care-treatment/sickle-cell-disease-center/
Georgia	Sickle Cell Disease Program Aflac Cancer and Blood Disorders Center -	35 Jesse Hill Jr. Drive SE Atlanta GA 30303; (404) 785-9800; https://www.choa.org/locations/hughes-spalding-hospital#services-at-this-location

	Hughes Spalding Hospital - Children's Healthcare of Atlanta	
Georgia	Sickle Cell Disease Program Aflac Cancer and Blood Disorders Center - Egleston Hospital - Children's Healthcare of Atlanta	1405 Clifton Road NE Atlanta, GA 30322; (404) 785-1200; https://www.choa.org/locations/egleston-hospital#location
Georgia	Sickle Cell Disease Program Aflac Cancer and Blood Disorders Center - Scottish Rite Hospital - Children's Healthcare of Atlanta	1001 Johnson Ferry Road NE Atlanta, GA 30342-1605; (404) 785-1112; https://www.choa.org/locations/scottish-rite-hospital#location

Georgia	Sickle Cell Center - Medical College of Georgia Augusta University	Walter L. Shepard Building 989 St. Sebastian Way Augusta, GA 30912; (706) 721-2171- Adult OR 706-721-0174- Pediatric; https://www.augusta.edu/centers/blood-disorders/sickle-cell/
Georgia	Sickle Cell Disease Research - Emory University	100 Woodruff Circle Atlanta, GA 30322 USA; (404) 712-4822; https://med.emory.edu/departments/pediatrics/divisions/hematology/research/sickle-cell-disease.html
Georgia	Morehouse Healthcare - Pediatric department	1513 Cleveland Avenue, Bldg. 500 East Point, GA. 30344; (404) 752-1000; http://morehousehealthcare.com/specialties/pediatrics.html
Georgia	Winship Cancer Institute Emory University Clifton Campus	1365-C Clifton Road NE Atlanta, Georgia 30322; (404) 778-1900; https://winshipcancer.emory.edu/patient-care/cancer-types/blood-disorders.html
Hawaii	Hawaii Sickle cell Disease Project - State of Hawaii, Department of Health	741 Sunset Avenue Honolulu, HI 96816; (808) 733-9055 https://health.hawaii.gov/genetics/projects/sicklecell/

Hawaii	Hawaii Community Genetics Kapiolani Medical Center for women and Children	1319 Punahou Street Honolulu, HI 96826; (808) 973-3403; https://www.hawaiipacifichealth.org/kapiolani/services/genetics/
Idaho	No Center	
Illinois	Sickle cell program UI Health(Comprehensive care program)	
Illinois	Acute Care Center at the UI Health	University of Illinois Hospital 1740 W. Taylor St. Suite 5E Chicago IL, 60612; (312) 413-8666; https://hospital.uillinois.edu/primary-and-specialty-care/sickle-cell/acute-care-center
Illinois	Pediatric Sickle Cell Program at UI Health	Outpatient Care Center 1801 W. Taylor St. Suite 2E Chicago IL, 60612; (312) 413-8667; https://hospital.uillinois.edu/primary-and-specialty-care/sickle-cell/pediatric-care
Illinois	The S.T.A.R. Clinic at UI Health - Transitional Care	University of Illinois Hospital 1740 W. Taylor St. Suite 5E Chicago IL, 60612; (312) 413-8666; https://hospital.uillinois.edu/primary-and-specialty-care/sickle-cell/transitional-care

Illinois	Adult Care Center at the UI Health	University of Illinois Hospital 1740 W. Taylor St. Suite 5E Chicago IL, 60612; (312) 413-8666; https://hospital.uillinois.edu/primary-and-specialty-care/sickle-cell
Illinois	Sickle Cell Disease Program Ann & Robert H. Lurie Children's Hospital of Chicago	225 E. Chicago Ave., Chicago, Illinois 60611; (800) 543-7362; https://www.luriechildrens.org/en/specialties-conditions/sickle-cell-disease-program/
Illinois	Rush University Children's Hospital	1725 W. Harrison St. Suite 710 Chicago, IL 60612; (312) 942-3034; https://www.rush.edu/kids/services-conditions/sickle-cell-anemia-children
Illinois	Rush University Medical Center	1620 W. Harrison St. Chicago, IL 60612; (888) 352-RUSH (7874)
Illinois	Comer Children's Uchicago Medicine	5841 S. Maryland Avenue Chicago, IL 60637; (773) 702-6169; https://www.uchicagomedicine.org/comer/conditions-services/anemias-blood-diseases/conditions-services/sickle-cell

Illinois	OSF Children's Hospital of Illinois - Sickle Cell Clinic	1221 E. Condit Street Decatur, Illinois 62521; (309) 624-4945; https://www.osfhealthcare.org/practices/31/1471/osf-childrens-hospital-of-illinois-sickle-cell-clinic/
Illinois	OSF Children's Hospital of Illinois - Sickle Cell Clinic	2112 25th Avenue Rock Island, IL 61201; (309) 624-4945; https://www.osfhealthcare.org/practices/40/1472/osf-childrens-hospital-of-illinois-sickle-cell-clinic/
Illinois	OSF Children's Hospital of Illinois - Sickle Cell Clinic	1405 W. Park Street Urbana, IL 61081; (309) 624-4945; https://www.osfhealthcare.org/practices/48/1473/osf-childrens-hospital-of-illinois-sickle-cell-clinic/
Illinois	Pediatric Sickle Program La Rabida Children's Hospital	6501 South Promontory Drive Chicago, IL 60649; (773) 256-5759; https://larabida.org/program/sickle-cell-disease/
Indiana	The Indiana Hemophilia & Thrombosis Center	8326 Naab Road Indianapolis, IN 46260; (317) 871-0000; https://www.ihtc.org/
Indiana	Lutheran Children's Hospital	7950 West Jefferson Boulevard Fort Wayne, Indiana 46804;(260) 435-2501 OR (800) 444-2001;

		https://www.lutheranchildrenshosp.com/hematology-oncology
Indiana	Riley Pediatric Sickle Cell Center- Riley Hospital for Children Riley Outpatient Center	702 Barnhill Drive, 3rd Floor Indianapolis, Indiana 46201; (317) 944-2143 OR (800) 248-1199; https://www.rileychildrens.org/health-info/sickle-cell-disease
Indiana	Beacon Memorial Children's Hospital Pediatric Hematology/Oncology Clinic	615 North Michigan Street, 6th Floor South Bend, Indiana 46601; (574) 647-6892 OR 800-284-6892; https://www.beaconhealthsystem.org/beacon-childrens-hospital/pediatric-hematology-oncology/
Iowa	Iowa Hemoglobinopathy Screening and Comprehensive Care Program UI Health Care Department of Pediatrics - Stead Family Children's Hospital	200 Hawkins Drive, 2518 JCI Iowa City, Iowa 52242-1083; (319) 356-1400; https://uichildrens.org/health-library/iowa-hemoglobinopathy-screening-and-comprehensive-care-program

Kansas	University of Kansas Cancer care center	2650 Shawnee Mission Pkwy. Westwood, Kansas 66205; (913) 588-1227; https://www.kucancercenter.org/cancer/cancer- types/sickle-cell-disease
Kentucky	Sickle Cell Disease Program Norton Children's Louisville, Ky.	231 E Chestnut St, Louisville, KY 40202; (502) 588-3600; https://nortonchildrens.com/services/hematology/programs /sickle-cell-disease/
Kentucky	Sickle Cell Treatment Program UL school of Medicine	571 S. Floyd St., Suite 432 Louisville, KY 40202; (502) 852-8600 https://louisville.edu/medicine/departments/pediatrics/divis ions/hematology-oncology/programs/sickle-cell-treatment- program
Kentucky	Adult Comprehensive Sickle Cell Program Norton Healthcare	(502) 629-HOPE(4673) https://nortonhealthcare.com/services-and- conditions/hematology/services/sickle-cell/
Kentucky	Norton Cancer Institute Downtown	676 S. Floyd Street, lower level Louisville, KY 40202; (502) 629-2500;

Kentucky	Norton Women's & Children's Hospital campus	Norton Medical Plaza 2, Suite 405 3991 Dutchmans Lane Louisville, KY 40207; (502) 899-3366;
Kentucky	Norton Audubon Hospital campus	Norton Medical Plaza West, Suite 405 2355 Poplar Level Road Louisville, KY 40217; (502) 636-7845;
Kentucky	Norton Cancer Institute – Brownsboro	4950 Norton Healthcare Blvd. Louisville, KY 40241; (502) 394-6350;
Kentucky	Hematology/Oncology Clinic - Pediatric DanceBlue Kentucky Children's Hospital	UK Chandler Hospital - Pavilion HA 800 Rose St. Lexington, KY 40536; (859) 257-4554; https://ukhealthcare.uky.edu/kentucky-childrens-hospital/services/cancer/hematology-oncology-pediatric
Louisiana	Tulane Sickle Cell Center of Southern Louisiana	https://medicine.tulane.edu/tulane-doctors/sickle-cell-center
Louisiana	Tulane Sickle Cell Center of Southern Louisiana- Adult & Transitional Sickle Cell Clinic at the	150 South Liberty Street New Orleans, LA 70112; (504) 988-6300; https://medicine.tulane.edu/tulane-doctors/sickle-cell-center/adult-clinic

	Tulane Cancer Center	
Louisiana	Pediatric Sickle Cell Clinic Tulane Lakeside Hospital for Women & Children - 4th floor	4720 S. I-10 Service Road West Metairie, LA 70001; (504) 988-6253; https://medicine.tulane.edu/find-doctor/sickle-cell-center/pediatric-clinic
Louisiana	Sickle Cell Disease Program at Feist-Weiller Cancer Center LSU Health Shreveport, Main Campus	1405 Kings Highway, Shreveport, LA 71103 (use for GPS) MAILING ADDRESS: 1501 Kings Highway, Shreveport, LA 71103; (318) 813-1405; https://www.lsuhs.edu/centers/feist-weiller-cancer-center/patients/patient-guide/sickle-cell-disease
Louisiana	Hematology & Oncology Children's Hospital New Orleans	200 Henry Clay Avenue New Orleans, LA 70118; (504) 899-9511; https://www.chnola.org/our-services/hematology-oncology/hematology-services/
Louisiana	St. Jude Children's Resesarch hospital Baton Rouge Affiliate Clinic at Our Lady of the	8300 Constantin Blvd., Suite 300 Baton Rouge, LA 70809; (225) 374-1485; https://www.stjude.org/treatment/affiliate-clinics/baton-rouge-louisiana.html

	Lake Children's Health	
Louisiana	The St. Jude Shreveport Affiliate Clinic Ochsner LSU Health Shreveport	1501 Kings Highway Shreveport, LA 71103; (318) 626-0772; https://www.stjude.org/treatment/affiliate-clinics/shreveport-louisiana.html
Louisiana	Louisiana Hematology Oncology Associates Our Lady of the Lake	4950 Essen Lane, Suite 500, Baton Rouge LA 70809; (225) 767-1311; https://ololrhc.com/services/cancer-care/cancer-treatment-options/hematology-and-oncology
Louisiana	Ochsner Foundation Hospital	1315 Jefferson Hwy. New Orleans, LA 70121; (504) 842-3900; https://www.ochsner.org/services/pediatric-hematology-and-oncology
Maine	No Center	
Maryland	University of Maryland Medical Center Marlene and Stewart Greenebaum	22 S. Greene St, Baltimore, MD 21201; (410) 328-7904 OR (410) 328-7609.; https://www.umms.org/ummc/health-services/hematology/sickle-cell-anemia

	Comprehensive Cancer Center	
Maryland	University of Maryland Children's Hospital Cancer (Pediatric Hematology and Oncology)	22 S. Greene St, Baltimore, MD 21201; (410) 328-5887; https://www.umms.org/childrens/health-services/pediatric-cancer-hematology-oncology
Maryland	Johns Hopkins Children's Center Pediatric Hematology Oncology Unit	600 North Wolfe Street Baltimore, MD 21287; (410) 955-5000- Maryland (855) 695-4872 Outside of Maryland OR +1-410-502-7683 International; https://www.hopkinsmedicine.org/health/conditions-and-diseases/sickle-cell-disease
Maryland	The Sickle Cell Infusion Center Sickle Cell Center for Adults at John Hopkins Hospital	1800 Orleans Street- Park 1 Baltimore, MD 21287; (410) 614-0676; https://www.hopkinsmedicine.org/hematology/sicklecell/
Maryland	Kennedy Krieger Institute	707 North Broadway, Baltimore, MD 21205; (888) 554-2080;

		https://www.kennedykrieger.org/patient-care/conditions/sickle-cell-disease-scd
Maryland	Children's National Comprehensive Sickle Cell Disease Program	
Maryland	Children's National Prince George's County Blood Disorders(Hematology)	2900 North Campus Way Lanham, MD 20706; (301) 276-9100; https://childrensnational.org/visit/locations-and-directions/outpatient-centers/prince-georges-county
Maryland	Children's National Montgomery County	9850 Key West Avenue Rockville, Maryland 20850; (301) 765-5400 OR (800) 787-0243; https://childrensnational.org/visit/locations-and-directions/outpatient-centers/montgomery-county
Maryland	The Sidney Kimmel Comprehensive Cancer Center John Hopkins Medicine	401 N Broadway St, Baltimore, MD 21287; (410) 955-8964; https://www.hopkinsmedicine.org/kimmel_cancer_center/types_cancer/sickle_cell_anemia.html
Massachusetts	Boston Medical Center Hematology(Sickle cell disease)	830 Harrison Avenue Boston, MA 0211 Moakley Building 3rd Floor; (617) 638-6428; https://www.bmc.org/sickle-cell-disease

Massachusetts	Brigham and Women's Hospital Sickle Cell Disease Clinic	450 Brookline Avenue Brookline, MA 02215; (617) 732-6089; https://www.brighamandwomens.org/medicine/hematology/sickle-cell-disease-clinic
Massachusetts	Mass. Gen Hospital Sickle cell disease clinic	55 Fruit Street Boston, MA 02114; (617) 726-2737; https://www.massgeneral.org/condition/sickle-cell-disease
Massachusetts	Boston Children's Hospital sickle cell Disease Program	300 Longwood Avenue, Boston, MA 02115; (617) 355-6000; http://www.childrenshospital.org/centers-and-services/programs/o--z/sickle-cell-disease-program#
Massachusetts	Sickle Cell Disease Program at Dana-Farber/Boston Children's Cancer and Blood Disorders Center	450 Brookline Avenue 3rd Floor, Dana Building Boston, MA 02215; (617) 355-8246; http://www.danafarberbostonchildrens.org/centers-and-programs/blood-disorders-center/programs/sickle-cell-program.aspx
Massachusetts	BU Center of Excellence in Sickle Cell Disease	72 East Concord Street, R-304, Boston, MA 02118; (617) 358-1226; https://www.bu.edu/sicklecell/

Massachusetts	Sadowsky Center for Children pediatric hematology and oncology Bay state Health	759 Chestnut Street Suite SW 3500 Springfield, MA 01199; (413) 794-9338; https://www.baystatehealth.org/services/pediatrics/specialties/hematology-oncology
Massachusetts	Benign Hematology Program at Tufts Medical Center	800 Washington Street. Boston MA 02111; (617) 636-6227; https://www.tuftsmedicalcenter.org/patient-care-services/Departments-and-Services/Cancer-Center/Clinical-Care-Services/Benign-Hematology-Program
Massachusetts	UMass Memorial Medical Center Sickle Cell Disease Clinic	119 Belmont Street Worcester, MA 01655; (855) 862-7763; https://www.umassmemorialhealthcare.org/umass-memorial-medical-center/services-treatments/childrens-medical-center/z-list-pediatric-services/pediatric-hematology-and-cancer-care/pediatric-cancer-specialized-clinics
Massachusetts	Boston Medical Center Pediatric Hematology	850 Harrison Ave Boston, MA 0218 Yawkey Ambulatory Care Center 6th Floor; (617) 414-4841;

		https://www.bmc.org/pediatrics-hematology
Michigan	C.S Mott Children's Hospital university of Michigan	1540 East Hospital Drive Ann Arbor, MI 48109; (734) 936-9814; https://www.mottchildren.org/conditions-treatments/sickle-cell-disease
Michigan	Sickle Cell Center at the Children's Hospital of Michigan Detroit Medical Center	3950 Beaubien Boulevard Detroit, MI 48201; (313)-745-KIDS ; https://www.childrensdmc.org/services/sickle-cell-center
Michigan	Hurley Medical Center Pediatric Sickle Cell Clinic	One Hurley Plaza Flint, MI 48503; (810) 262-4970; https://www.hurleymc.com/services/pediatric-hematology-oncology/
Michigan	Bronson Pediatric Hematology/Oncology	601 John St. M-005 Kalamazoo, MI 49007; (269) 341-6350; https://www.bronsonhealth.com/locations/locations-profile/bronson-pediatric-oncology-hematology-specialists/
Minnesota	Hemoglobinopathy and Sickle Cell Program Children's Minnesota	2525 Chicago Avenue South Minneapolis, MN 55404; (612) 813-5940; https://www.childrensmn.org/services/care-specialties-departments/cancer-blood-disorders/conditions-and-

		services/blood-disorders-services/hemoglobinopathy-sickle-cell/sickle-cell/
Minnesota	University of Minnesota Masonic Children's Hospital Hematology/Oncology Unit	2450 Riverside Ave. Minneapolis, MN 55454 Floor 9; (612) 365-8100; https://www.mhealth.org/childrens/care/conditions/sickle-cell-disease#related-care
Minnesota	University of Minnesota Masonic Children's Hospital Blood and Marrow Transplant (BMT) Unit	2450 Riverside Ave. Minneapolis, MN 55454 Floor 4, Unit 4; (612) 626-5768; https://bmt.umn.edu/hemoglobinopathies
Mississippi	Children's of Mississippi Center for Cancer and Blood Disorders- (inside Batson Children's Hospital)	2500 N. State St. Jackson, MS 39216; (601) 984-2700 (Option 1) OR (601) 984-5220; https://www.umc.edu/Childrens/Childrens%20Cancer%20and%20Blood%20Disorders/Childrens-Cancer-and-Blood-Disorders.html
Mississippi	University of Mississippi Medical	2500 N. State St. Jackson, MS 39216 ;;

	Center Sickle Cell Center	
Mississippi	Jackson Hinds Comprehensive Health Center	3502 West Northside Drive Jackson, MS 39213; (601) 362-5321; https://www.jackson-hinds.com/adult-med
Missouri	Sickle Cell Disease Program Children's Mercy	2401 Gillham Road, Kansas City, MO 64108; (816) 302-6808; https://www.childrensmercy.org/departments-and-clinics/division-of-pediatric-hematology-oncology-and-blood-and-marrow-transplantation/hematology/sickle-cell-disease-program/
Missouri	Designated Sickle Cell Center Cardinal Glennon Children's Hospital	1465 S. Grand Blvd. St. Louis, MO 63104; (314) 268-4000; https://www.ssmhealth.com/cardinal-glennon/pediatric-hematology/sickle-cell-disease
Missouri	St. Louis Children's Hospital	One Children's Place St. Louis, MO 63110; (314) 454-6000 OR (800) 678-5437; https://www.stlouischildrens.org/conditions-treatments/sickle-cell-disease-program
Missouri	Truman Medical Centers/University	2301 Holmes Street Kansas City, MO 64108; (816) 404-4290;

	Health Sickle Cell Center	https://www.trumed.org/services/sickle-cell-center/
Missouri	University of Missouri School of Medicine Child Health Divisions	One Hospital Drive Columbia, MO 65212; (573) 219-3920; https://www.muhealth.org/conditions-treatments/pediatrics/pediatric-cancer-care
Missouri	Barnes-Jewish Hospital Washington University Physicians- Hematology services	1 Barnes-Jewish Hospital Plaza St. Louis, MO 63110; (314) 362-7216.;
Montana	No Center	
Nebraska	Children's Hospital and Medical Center Omaha - Hematology & Oncology	111 N. 84th St. Omaha, NE 68114; (402) 955-3950; https://www.childrensomaha.org/department/hematology-and-oncology/
Nebraska	University of Nebraska Medical Center Oncology	986840 Nebraska Medical Center Omaha, NE 68198-6840; (402) 559-5600;

	and Hematology Division	https://www.unmc.edu/intmed/divisions/onchem/index.htm 1
Nevada	No Center	
New Hampshire	Children's Hospital at Dartmouth- Hitchcock	One Medical Center Drive Lebanon, New Hampshire 03756; (603) 650-5000; https://www.chadkids.org/internal-medicine- pediatrics/treatments-and-services
New Jersey	Valerie Fund Center for Childhood Cancer and Blood Disorders - Sickle Cell Anemia Center Children's Hospital of New Jersey at Newark Beth Israel Medical Center	201 Lyons Avenue at Osborne Terrace Newark, NJ 07112; https://www.rwjbh.org/childrens-hospital-of-nj-at-newark- beth-israel/treatment-care/cancer-blood-disorders/sickle- cell-anemia-center/
New Jersey	Pediatric Hematology at the Children's Cancer	30 Prospect Ave, Hackensack, NJ 07601; (844) 464-9355 OR 551-996-5614;

	Institute Hackensack Meridian - Children's Health at Joseph M. Sanzari Children's Hospital	https://www.hackensackumc.org/services/pediatrics/pediatric-services/childrens-cancer-institute/pediatric-hematology/
New Jersey	Children's Hospital of Philadelphia, New Jersey Section of Hematology/Oncology Specialty Care Center	1012 Laurel Oak Road Voorhees, NJ 08043; (856) 435-1300; https://www.chop.edu/centers-programs/division-hematology
New Jersey	Frederick B. Cohen, MD, Comprehensive Cancer and Blood Disorder Center - Newark Beth Israel Medical Center	201 Lyons Avenue at Osborne Terrace Newark, NJ 07112; (973) 926-7000; https://www.rwjbh.org/newark-beth-israel-medical-center/treatment-care/cancer-blood-disorders/
New Jersey	Pediatric Hematology -	HOPE Tower 19 Davis Avenue 5th Floor Neptune, NJ 07753;

	Neptune at the Rutgers Cancer Institute of New Jersey (CINJ)	(732) 776-4860; https://www.hackensackmeridianhealth.org/locations/pediatric-hematology-and-oncology-neptune/
New Jersey	Regional Comprehensive Sickle Cell Center Robert Wood Johnson University Hospital	1 Robert Wood Johnson Place New Brunswick, NJ 08901; (732) 235-7223; https://www.onescdvoice.com/place/regional-comprehensive-sickle-cell-center-robert-wood-johnson-medical-school/
New Jersey	Pediatric hematology Program Cooper University Health Care	Three Cooper Plaza Camden, NJ 08103; (856) 342-2001 OR (800) 826-6737; https://www.cooperhealth.org/services/pediatric-hematology
New Jersey	pediatric cancer and hematology centers Jersey City Medical Center	355 Grand Street Jersey City, NJ 07302; (888) 724-7123 OR (201) 915-2000; https://www.rwjbh.org/treatment-care/pediatrics/conditions-treatments/pediatric-cancer/
New Jersey	hematology centers Jersey City Medical Center	355 Grand Street Jersey City, NJ 07302; (201) 915-2000; https://www.rwjbh.org/treatment-care/blood-disorders/

New Jersey	Valerie Fund Children's Center The Unterberg Children's Hospital at Monmouth Medical Center.	300 Second Avenue Long Branch, NJ 07740; (844) 226-2376; https://www.rwjbh.org/unterberg-childrens-hospital-at-monmouth-medical/treatment-care/cancer-blood-disorders/
New Jersey	Robert Wood Johnson (RWJ) University Hospital Hamilton	1 Hamilton Health Place Hamilton, NJ 08690; (888) 724-7123 OR (609) 586-7900; https://www.rwjbh.org/treatment-care/pediatrics/conditions-treatments/pediatric-cancer/
New Jersey	Children's Hospital of New Jersey at Newark Beth Israel Medical Center The Valerie Fund Children's Centers for Cancer and Blood Disorders	201 Lyons Avenue at Osborne Terrace Newark, NJ 07112; (973) 926-7161; https://www.thevaleriefund.org/sickle-cell-patient-program
New Jersey	K. Hovnanian Children's Hospital at Jersey Shore Medical Center	1945 Route 33 Neptune, NJ 07753; (732) 775-5500; https://www.khovnanianchildrenshospital.com/services/hematology-oncology/

	Pediatric Hematology and Oncology Program	
New Jersey	St. Barnabas Medical Center Valerie Fund Children's Centers for Cancer and Blood Disorders	94 Old Short Hills Road Livingston, NJ 07039; (973) 322-5000; https://www.rwjbh.org/treatment-care/pediatrics/conditions-treatments/pediatric-cancer/
New Jersey	University of Medicine and Dentistry of New Jersey, The University Hospital Division of Pediatric Hematology/Oncology	150 Bergen St, Newark, NJ 07103; (973) 972-0658; http://www.uhnj.org/directory/pediatrics/hema_onco.htm
New Jersey	Pediatric Hematology/ Oncology Program- Rutgers Cancer	195 Little Albany Street New Brunswick, New Jersey 08901; (732) 235-5437; https://cinj.org/patient-care/pediatric

	Institute of New Jersey RWJ Barnabas Health	
New Jersey	Pediatric Hematology/Oncology Program The Children’s Hospital at Saint Peter’s University Hospital	254 Easton Avenue New Brunswick, NJ 08901; (732) 745-6674; https://www.saintpetershcs.com/Services/Pediatric-Hematology-Oncology
New Jersey	Valerie Fund Center at St. Joseph’s Children’s Hospital	703 Main Street Paterson, NJ 07503; (973) 754-2500; https://www.stjosephshealth.org/pedshemonc
New Jersey	Pediatric Cancer & Blood Disorder Treatments at Community Medical center	99 Highway 37 West Toms River, NJ 08755; (732) 557-8000 OR (888) 724-7123; https://www.rwjbh.org/treatment-care/pediatrics/conditions-treatments/pediatric-cancer/
New Jersey	J. Phillip Citta Regional Cancer Center at	99 Highway 37 West Toms River, NJ 08755; (844) 226-2376; https://www.rwjbh.org/community-medical-center/treatment-care/cancer/

	Community Medical Center	
New Mexico	University of New Mexico Comprehensive Cancer Center	2211 Lomas Blvd. NE Albuquerque, NM 87106; (505) 272-4461; https://hsc.unm.edu/health/patient-care/pediatrics/blood-disorders-cancers.html
New York	Weill Cornell Medicine- Pediatric Hematology/Oncol ogy Division	525 East 68th Street, Payson-695 New York, NY 10065; (212) 746-3400; https://weillcornell.org/services/pediatric-hematology-and-oncology
New York	Jack Martin Division of Pediatric Hematology- Oncology at Mount Sinai Kravis Children’s Hospital	1468 Madison Avenue Annenberg Building, 4th Floor New York, NY 10029; (212) 241-7022; https://www.mountsinai.org/care/pediatrics/services/hematology-oncology/hematology/conditions-treatments
New York	Hematology and Medical Oncology service at The Blavatnik Family – Chelsea Medical	325 West 15th Street New York, NY 10011; (212) 604-6010 OR 1-(844) MD- CANCER; https://www.mountsinai.org/locations/chelsea/services/hematology-oncology

	Center at Mount Sinai	
New York	Derald H. Ruttenberg Treatment Center, part of The Tisch Cancer Institute at The Mount Sinai Hospital	1470 Madison Avenue (between 101st and 102nd Streets); (212) 241-6756; https://www.mountsinai.org/locations/ruttenberg-treatment-center/about
New York	Mount Sinai Queens Hematology/Oncology	2715 30th Avenue Astoria, NY 11102; (718) 932-1000; https://www.mountsinai.org/locations/queens/care/cancer
New York	Mount Sinai West Infusion Center Hematology-Oncology Infusion Center	425 West 59th Street 8th Floor New York, NY 10019; (212) 523-5559; https://www.mountsinai.org/locations/west/care/infusion-center
New York	Mount Sinai-Union Square	10 Union Square East Suites 4A, 4B, 4C, 4D New York, NY 10003; (212)-844-8288 OR 1-(844) MD- CANCER;

		https://www.mountsinai.org/locations/union-square/services/cancer
New York	NYC Health + Hospitals/Harlem Pediatric center	506 Lenox Avenue (RHB 1) New York, NY 10037; 212-939-8005; https://www.nychealthandhospitals.org/harlem/services/children-adolescents/
New York	NYC Health + Hospitals/Harlem Adult care	506 Lenox Avenue (RHB 3) New York, NY 10037; 212 939-8226; https://www.nychealthandhospitals.org/harlem/services/adult-primary-care/
New York	NYC Health + Hospitals/Kings County	451 Clarkson Avenue Brooklyn, NY 11203; (718) 245-3325 OR 718-245-3131; https://www.nychealthandhospitals.org/kingscounty/our-services/specialties/
New York	NYC Health + Hospitals/Queens Pediatric Clinic Sickle Cell Comprehensive Care Program	82-68 164th Street Jamaica, New York 11432, Pavilion, First Floor – Suite P151 Jamaica, New York 11432; (718) 883-3300; https://www.nychealthandhospitals.org/queens/our-services/pediatric-specialties/
New York	Division of Hematology/Oncol	269-01 76th Avenue, Suite 255 Queens, New York 11040; (718) 470-3460;

	ogy and Stem Cell Transplantation at Cohen Children's Northwell Health	https://pediatrics.northwell.edu/departments-services/pediatric-hematology-oncology/programs-services/comprehensive-hemoglobinopathy-programs
New York	Sanford R. Nalitt Institute for Cancer and Blood Related Diseases (Ambulatory Oncology) A division of Staten Island University Hospital	256 Mason Avenue, A Staten Island, NY 10305; (718) 226-6400; https://pediatrics.northwell.edu/find-care/locations/northwell-health-sanford-r-nalitt-institute-for-cancer-blood-related-diseases
New York	Sickle Cell Transplant Program NewYork-Presbyterian/Morgan Stanley Children's Hospital	3959 Broadway, New York, NY 10032; 212-305-2466; https://www.nyp.org/morganstanley/clinical-services/cancer-blood-disorders/sickle-cell-disease
New York	Comprehensive Pediatric Sickle	One Brookdale Plaza Suite 346 CHC Brooklyn, NY 11212-3198;

	Cell Program The Brookdale University Hospital and Medical Center - Division of Pediatric Hematology/Oncol ogy	(718) 240-5904; http://www.sicklecellbrooklyn.org/sicklecellcenter.html
New York	Sickle Cell Disease (SCD) program at Maria Fareri Children’s Hospital Westchester Medical Center Health Network	100 Woods RoadValhalla, NY 10595; (914) 493-7000; https://www.mariafarerichildrens.org/sickle-cell-disease
New York	Montefiore Sickle Cell Center for Adults (SCCA)- Division of Hematology at Montefiore Medical Center	Family Care Center 4th Floor, Clinic 460 3444 Kossuth Avenue Bronx, NY 10467; (718) 920-2273; https://www.montefiore.org/hematology

New York	Sickle Cell & Hemoglobinopathy Center of WNY at John R. Oishei Children's Hospital	Roswell Park Comprehensive Cancer Center Elm & Carlton Streets Buffalo NY 14263; (716) 845-4447; https://www.ochbuffalo.org/care-treatment/sickle-cell-hemoglobinopathy-center-wny
New York	Golisano Children's Hospital Pediatric Hematology/Oncology	601 Elmwood Avenue Rochester, NY 14642; (585) 275-2981; https://www.urmc.rochester.edu/childrens-hospital/hemonc/sickle-cell-disease.aspx
New York	Children's Hospital of Montefiore (CHAM) Sickle Cell Anemia Program	3415 Bainbridge Avenue Bronx, NY, zip code 10467; (718) 741-2426; https://www.cham.org/programs-centers/sickle-cell-program/sickle-cell-anemia
New York	Sickle Cell Disorders and the Sickle Cell Program Montefiore and Albert Einstein College of Medicine-Family Care Center	3444 Kossuth Avenue 4th Floor, Clinic 460 Bronx N.Y 10467; (718) 405-8505; http://www.einstein.yu.edu/departments/medicine/division/hematology/patient-care/clinical-services-treatment-programs/sickle-cell-program.aspx

New York	Sickle Cell Disorders and the Sickle Cell Program Montefiore and Albert Einstein College of Medicine-Montefiore Practice	1695 Eastchester Road 2nd Floor, Oncology/Hematology Clinic Bronx N.Y 10461; (718) 405-8505; http://www.einstein.yu.edu/departments/medicine/divisions/hematology/patient-care/clinical-services-treatment-programs/sickle-cell-program.aspx
New York	NYU Winthrop Hospital Division of Pediatric Hematology/Oncology,	259 First Street Mineola, NY 11501; (516) 663-9400; https://nyuwinthrop.org/services/center-for-cancer-care/cancer-center-for-kids/services/
New York	Pediatric Hematology and Oncology - Children's Hospital at SUNY Downstate SUNY Downstate Health Sciences University	450 Clarkson Avenue, MSC 49 Brooklyn, NY 11203; (718) 270-1625; https://www.downstate.edu/peds/services/services.html

New York	Melodies Center for Childhood Cancer and Blood Disorders Children's Hospital at Albany Medical Center	43 New Scotland Avenue Albany, NY 12208; (518)262-5513; https://www.amc.edu/patient/services/childrens_hospital/pediatric_hematology_oncology/index.cfm
New York	Sickle Cell Program at Interfaith Medical Center	1545 Atlantic Avenue Brooklyn, NY 11213; (718) 613-4000; http://www.interfaithmedical.com/departments-and-services/pediatrics/index.html
New York	Sickle Cell/Thalassemia Program at NewYork-Presbyterian Brooklyn Methodist Hospital Adult center)	1910 Nostrand Ave Brooklyn, NY 11226; (718) 284-4440;
New York	Sickle Cell/Thalassemia Program at	263 Seventh Ave Brooklyn, NY 11215; (718) 246-8515;

	New York- Presbyterian Brooklyn Methodist Hospital (Pediatric center)	https://www.nyp.org/brooklyn/services/pediatric-services/pediatric-sickle-cell-and-thalassemia-diseases
New York	Waters Center for Children's Cancer and Blood Disorders at Upstate Cancer Center	750 East Adams Street Syracuse, NY 13210; (315) 464-5294; https://www.upstate.edu/cancer/cancer-care/treatment-options/child-cancerblood/
North Carolina	Duke Adult Comprehensive Sickle Cell Center Duke University Hospital	40 Duke Medicine Cir Clinic 2N Durham, NC 27710-4000; (919) 684-0628 OR 919-620-5300; https://www.dukehealth.org/locations/duke-adult-comprehensive-sickle-cell-center-clinic-2n
North Carolina	Community Care of North Carolina Sickle Cell Program	1000 CentreGreen Way, Suite 300 Cary, NC 27513; (877) 566-0943; https://www.communitycarenc.org/what-we-do/care-management/population-health-outreach-and-care-coordination/sickle-cell-program

North Carolina	UNC Comprehensive Sickle Cell Program at the University of North Carolina Division of Hematology and Oncology	Haupt Building, 3rd Floor 170 Manning Drive, CB# 7305 Chapel Hill, NC 27599; (919) 966-4431; https://www.med.unc.edu/medicine/hemonc/patient-care/clinical-services/sickle-cell-program/
North Carolina	UNC Lineberger Comprehensive Cancer Center's Pediatric Hematology- Oncology Program UNC Children's Hospital	101 Manning Drive in Chapel Hill Chapel Hill, NC 27514 (pediatric clinic); (984) 974-1000 OR (984) 974-0000; https://www.uncchildrens.org/uncmc/unc-childrens/care-treatment/hematology/sickle-cell/
North Carolina		6011 Farrington Road in Chapel Hill - Adult clinic;;
North Carolina	Wake Forest Baptist Medical Center	Medical Center Boulevard Winston-Salem, NC 27157; (336) 716-9253 OR (888) 716 9253(toll free); https://www.wakehealth.edu/Locations/Facilities/Comprehensive-Cancer-Center

	Comprehensive Cancer Center	
North Carolina	East Carolina University Comprehensive Sickle Cell Center	600 Moye Blvd Greenville, NC 27834 USA ; (252) 744-4676; https://www.ecu.edu/cs-dhs/sicklecell/index.cfm
North Carolina	Comprehensive sickle cell treatment center at James and Connie Maynard Children’s Hospital at Vidant Medical Center	2102 Stantonsburg Road Greenville, NC 27834; (252) 744-4676; https://www.vidanthealth.com/Services-Treatments/Services/Childrens/For-Parents/Patient-Care/Sickle-Cell
North Carolina	Novant Health Presbyterian Medical Center Adult center	200 Hawthorne Ln, Charlotte, NC 28204; (704) 316-3297; https://www.novanthealth.org/presbyterian-medical-center/services/sickle-cell.aspx
North Carolina	Presbyterian Blume Pediatric Hematology/Oncol ogy Clinic - Sickle Cell Program	1712 East 4th Street Charlotte, North Carolina 28233; (704) 384-1900; https://www.phs.org/doctors-services/services-centers/childrens-health/pediatric-hematology-oncology/Pages/default.aspx#

North Carolina	Levine Cancer Institute at Atrium Health(formerly Carolina Healthcare System)	1021 Morehead Medical Drive, suite 5300 Charlotte, NC 28204; (980) 442-4363; https://atriumhealth.org/medical-services/specialty-care/cancer-care/hematology-oncology-blood-disorders
North Carolina	Levine Children's Cancer & Blood Disorders, a facility of Atrium Health at Levine Children's Hospital	1001 Blythe Blvd. Suite 601 Charlotte, NC 28203; (704) 381-9900; https://atriumhealth.org/medical-services/childrens-services/childrens-specialty-care/pediatric-cancer-and-blood-disorders/sickle-cell-disease
North Carolina	PMG Hematology / Oncology at Presbyterian Rust Medical Center Ted and Margaret Jorgensen Cancer Center (Rio Rancho)	2400 Unser Blvd SE Rio Rancho, NM 87124; (505) 559-6100; https://www.phs.org/doctors-services/services-centers/cancer-care/oncology-hematology/Pages/rio-rancho.aspx
North Carolina	PMG Hematology / Oncology at Presbyterian	8300 Constitution Ave. NE Albuquerque, NM 87110; (505) 559-6100;

	Kaseman Hospital Physician Office Building (Albuquerque)	https://www.phs.org/doctors-services/services-centers/cancer-care/oncology-hematology/Pages/kaseman.aspx
North Dakota	Meritcare Roger Maris Cancer Center	820 Fourth St. N. Fargo, North Dakota 58102; (701) 234-6161; https://www.sanfordhealth.org/medical-services/pediatrics/pediatrics-specialized-care/pediatric-hematology-and-oncology
Ohio	Comprehensive Sickle Cell Center at Cincinnati Children's	3333 Burnet Avenue, Cincinnati, Ohio 45229-3026; (513) 636-4200 OR (800) 344-2462; https://www.cincinnatichildrens.org/service/s/sickle-cell
Ohio	Ohio State University Comprehensive Cancer Center- James	460 W. 10th Avenue Columbus, OH 43210; (800) 293-5066 Email: jamesline@osumc.edu ; https://cancer.osu.edu/for-patients-and-caregivers/learn-about-cancers-and-treatments/cancers-conditions-and-treatment/benign-blood-diseases/sickle-cell-anemia
Ohio	Comprehensive Hemophilia and Bleeding Disorder	700 Childrens Drive Columbus, OH 43205; (614) 722-3250;

	Treatment Center Nationwide Children's Hospital	https://www.nationwidechildrens.org/specialties/hematology-oncology-bmt
Ohio	Seidman Cancer Center - Adult Sickle Cell Disease Clinic University Hospitals	11100 Euclid Avenue Cleveland, OH 44106; (216) 844-1582 ; https://www.uhhospitals.org/services/cancer-services/benign-hematologic-disorders/adult-sickle-cell
Ohio	University of Cincinnati Medical Center - Adult Sickle Cell Center	234 Goodman Street, Cincinnati, OH 45219; (513) 584-2088; https://www.uhealth.com/university-of-cincinnati-medical-center/services/adult-sickle-cell-center/
Ohio	Dayton Children's comprehensive care for kids with sickle cell disease	1 Childrens Plaza, Dayton, OH 45404; (937) 641-3111; https://www.childrensdayton.org/patients-visitors/services/hematology-oncology/sickle-cell-disease
Ohio	Cleveland Clinic - Sickle cell Disease	9500 Euclid Avenue, Cleveland, Ohio 44195; (800) 223.2273; https://my.clevelandclinic.org/health/diseases/12100-sickle-cell-disease
Ohio	Department of Pediatric	9500 Euclid Ave, Cleveland, OH 44106; (216) 444.5437;

	Hematology, Oncology, and Blood and Marrow Transplantation Cleveland Clinic Children's	https://my.clevelandclinic.org/pediatrics/departments/hematology-oncology/benign-hematology#what-we-treat-tab
Ohio	ProMedica Comprehensive Adult Sickle Cell Clinic ProMedica Toledo Hospital	2142 N. Cove Blvd. Toledo, Ohio 43606; (419) 291-4327; https://www.promedica.org/pages/OHAM/OrgUnitDetails.aspx?OrganizationalUnitId=1302
Oklahoma	Jimmy Everest Center for Cancer and Blood Disorders in Children Children's Hospital at OU Medicine	O.U. Children's Physicians Building 1200 Childrens Ave Oklahoma City, OK 73104; (405) 271-4412; https://www.oumedicine.com/ou-physicians/locations-of-care/ou-children-s-physicians-building/jimmy-everest-center
Oklahoma	Hematology/oncology clinic at The Children's Hospital at Saint Francis	6161 South Yale Avenue Tulsa, Oklahoma 74136; (918) 502-6760; https://www.saintfrancis.com/services/hematology/

Oregon	Doernbecher Children's Hospital - Pediatric Blood Disorders	700 S.W. Campus Drive Portland, Oregon 97239;503-346-0640 OR 877-346-0640; https://www.ohsu.edu/doernbecher/pediatric-blood-disorders
Pennsylvania	Jefferson's Comprehensive Sickle Cell Program Jefferson University Hospitals	(215) 955-6180; https://hospitals.jefferson.edu/diseases-and-conditions/sickle-cell-disease.html
Pennsylvania	Buerger Center for Advanced Pediatric Care Comprehensive Sickle Cell Center at Children's Hospital of Philadelphia	3500 Civic Center Blvd. Philadelphia, PA 19104; (215) 590-1000 OR (215) 590-3423; https://www.chop.edu/centers-programs/sickle-cell-center
Pennsylvania	UPMC Adult Sickle Cell Disease Program	Hillman Cancer Center William Pavilion, 2nd Floor 5115 Centre Ave., Second floor Pittsburgh, PA 15232; (412) 692-4724; https://www.upmc.com/services/sickle-cell

Pennsylvania	Pediatric Sickle Cell Program - Children's Hospital Pittsburgh	4401 Penn Avenue, Floor 9 Pittsburgh, PA 15224; (412) 692-5055; https://www.chp.edu/our-services/cancer/conditions/sickle-cell
Pennsylvania	Penn Comprehensive Sickle cell Disease Program - Penn Medicine	https://www.pennmedicine.org/for-patients-and-visitors/find-a-program-or-service/hematology/sickle-cell-disease-program
Pennsylvania	Abramson Cancer Center Perelman 4th Floor West - Hospital of the University of Pennsylvania	3400 Civic Center Boulevard Philadelphia, PA 19104 Perelman Center for Advanced Medicine West Pavilion, 4th Floor; (800) 789-7366; https://www.pennmedicine.org/practices/abramson-cancer-center-perelman-4th-floor?fadf=pennmedicine
Pennsylvania	Penn Blood Disorders Center Perelman Center for Advanced Medicine- Hospital of University of Pennsylvania	3400 Civic Center Boulevard Philadelphia, PA 19104 Perelman Center for Advanced Medicine South Pavilion, 1st Floor; (800) 789-7366; https://www.pennmedicine.org/practices/penn-blood-disorders-center?fadf=pennmedicine

Pennsylvania	Penn Hematology/Oncology West Chester Chester County Hospital	440 East Marshall Street West Chester, PA 19380 Suite 201; (800) 789-7366; https://www.pennmedicine.org/practices/hematology-oncology-west-chester?fadf=pennmedicine
Pennsylvania	Penn Hematology/Oncology Exton Chester County Hospital	720 West Lincoln Highway The Commons at Oaklands Exton, PA 19341; (800) 789-7366; https://www.pennmedicine.org/practices/hematology-oncology-exton?fadf=pennmedicine
Pennsylvania	Penn Hematology/Oncology Kennett Square of Chester County Hospital	400 McFarlan Road Kennett Square, PA 19348 Suite 300; (800) 789-7366; https://www.pennmedicine.org/practices/hematology-oncology-kennett-square?fadf=pennmedicine
Pennsylvania	Penn Hematology/Oncology Pennsylvania Hospital- Abramson Cancer Center, Farm	230 West Washington Square Philadelphia, PA 19106; (800) 789-7366; https://www.pennmedicine.org/practices/hematology-oncology-pennsylvania-hospital?fadf=pennmedicine

	Journal Building, 2nd Floor	
Pennsylvania	Abramson Cancer Center Radnor of the Hospital of the University of Pennsylvania Penn Medicine Radnor	145 King of Prussia Road Radnor, PA 19087 Floor 2, Suite 200 North; (800) 789-7366; https://www.pennmedicine.org/practices/abramson-cancer-center-radnor?fadf=pennmedicine
Pennsylvania	Abramson Cancer Center Penn Presbyterian of Penn Presbyterian Medical Center	51 N. 39th Street Cupp Building, 1st Floor Philadelphia, PA 19104; (800) 789-7366; https://www.pennmedicine.org/practices/abramson-cancer-center-penn-presbyterian?fadf=pennmedicine
Pennsylvania	Abramson Cancer Center Valley Forge	Penn Medicine Valley Forge 1001 Chesterbrook Boulevard Berwyn, PA 19312; (800) 789-7366; https://www.pennmedicine.org/practices/abramson-cancer-center-valley-forge?fadf=pennmedicine
Pennsylvania	Marian Anderson Comprehensive Sickle Cell Care and Research	160 E Erie Ave Philadelphia, PA 19134; (215) 427-5096 or (215) 427-5336; https://www.stchristophershospital.com/SitePages/our-services/hematology/sickle-cell-anemia.aspx

	Center at St. Christopher's Hospital for Children	
Pennsylvania	Pediatric Comprehensive Sickle Cell Anemia Program at Penn State Children's Hospital Pediatric Hematology	600 University Drive Hershey, PA 17033; (717) 531-6807; https://childrens.pennstatehealth.org/hematology-oncology/patient-care-and-treatment/sickle-cell-anemia
Pennsylvania	Sickle Cell Center of Excellence - University of Pittsburgh and UPMC	200 Lothrop Street Pittsburgh, PA 15213; (412) 648-3181; https://sicklecell.pitt.edu/about-the-center/
Pennsylvania	Nemours duPont Pediatrics, Philadelphia	833 Chestnut St. E., Suite 300 - Specialty Care Philadelphia, PA 19107; (800) 416-4441; https://www.nemours.org/locations/pennsylvania-pediatric-specialty-care-philadelphia.html

Rhode Island	pediatric hematology/oncology at Hasbro Children's Hospital	593 Eddy Street Suite 105 Providence, RI 02903; (401) 444-5241; https://www.lifespan.org/centers-services/pediatric-hematology-oncology/programs/sickle-cell-program
Rhode Island	Sickle Cell Multidisciplinary Clinic of the Lifespan Cancer Institute	Ambulatory Patient Center (APC Building) 593 Eddy Street Providence, RI 02903; 1-844-222-2881; https://www.lifespan.org/centers-services/sickle-cell-multidisciplinary-clinic
South Carolina	MUSC Children's Health Sickle cell Center	10 McClellan Banks Drive Charleston, SC 29425; (843) 876-0444; https://musckids.org/our-services/sickle-cell-center
South Carolina	Prisma Health Children's Hospital–Midlands - Sickle Cell Clinic	7 Richland Medical Park Dr. Columbia, SC 29203; (803) 434-3656 OR 803-296-KIDS (5437); https://www.palmettohealthchildrens.org/pediatric-specialties/hematology-oncology
South Carolina	Beaufort Memorial Sickle Cell Clinic Beaufort Memorial Campus	989 Ribaut Road, Suite 103 (with Infusions Services) Beaufort, South Carolina 29902; (843) 522-5351; https://www.bmhsc.org/location/beaufort-memorial-sickle-cell-clinic?utm_source=local-

		listing&utm_medium=organic&utm_campaign=website-link
South Carolina	Comprehensive Sickle Cell Disease Program of Prisma Health (located within the BI-LO Charities Children's Cancer Center)	900 W. Faris Road, 2nd Floor Greenville, SC 29605; (864) 455-5680; https://www.ghs.org/healthcareservices/cancer/clinical-programs/comprehensive-sickle-cell-disease-program/
South Carolina	MUSC Health Sickle cell Care	171 Ashley Avenue, Charleston, SC 29425; (843) 792-1414; https://muschealth.org/health-professionals/progressnotes/2016/year-in-review/share/sickle-cell-care
South Dakota	Sanford Children's Hematology and Oncology Sanford Children's Hospital Sioux Falls	1600 W. 22nd St. Sioux Falls, South Dakota 57117; (605) 312-1000; https://www.sanfordhealth.org/medical-services/pediatrics/pediatrics-specialized-care/pediatric-hematology-and-oncology
Tennessee	St. Jude Children's Pediatric Sickle Cell Program	262 Danny Thomas Place Memphis, TN 38105; (866) 278-5833; https://www.stjude.org/disease/sickle-cell-disease.html

Tennessee	Center for Sickle Cell Disease at UTHSC	College of Medicine 956 Court Avenue, Suite D324 Memphis, TN 38163; (901) 448-3181; https://uthsc.edu/sickle-cell/
Tennessee	Methodist Comprehensive Sickle Cell Center Methodist Le Bonheur Healthcare	1325 Eastmoreland, Suite 101 Memphis, TN 38104; (901) 516-8785 OR (901) 516-8188; https://www.methodisthealth.org/healthcare-services/sickle-cell-center/
Tennessee	East Tennessee Children's Hospital Pediatric hematology/Oncology	2018 W Clinch Avenue Knoxville, TN 37916; (865) 541-8266; https://www.etch.com/medical-services/hematology-oncology/
Tennessee	Erlanger Health System Medical Oncology/Hematology	979 East 3rd Street Suite A540/A550 Chattanooga, TN 37403; (423) 778-9250; https://www.erlanger.org/centers-of-excellence/cancer-services/cancer-services/medical-oncology-hematology
Tennessee	T.C Thompson Children's Hospital - Erlanger Health	910 Blackford Street 5th Floor Massoud Building Chattanooga, TN 37403; (423) 778-7289;

	System Childhood Cancer and Blood Disorders Center	https://www.childrensaterlanger.org/childrens-hospital/the-childhood-cancer-and-blood-disorders-center/pediatric-cancer-and-blood-disorder-center
Tennessee	Le Bonheur Children’s Hospital Division of Hematology	848 Adams Avenue Memphis, TN 38103; (866) 870-5570; https://www.lebonheur.org/services/hematology
Tennessee	Diggs-Kraus Sickle Cell Center - Regional One Health Affiliated medical center of UTHSC	877 Jefferson Avenue, Memphis, TN 38103; (901) 545-7100; https://www.regionalonehealth.org/outpatient-center/sickle-cell/
Tennessee	Meharry Comprehensive Sickle cell center	
Tennessee	Vanderbilt-Meharry Center of Excellence in Sickle Cell Disease	(615) 340-1280; https://www.vanderbilthealth.com/service-line/sickle-cell-disease

Tennessee	Meharry Sickle Cell Center - Adult Sickle Cell Clinic	(615) 341-4383 Email: sicklecell@mmc.edu; https://home.mmc.edu/research/office-for-research/research-centers/sickle-cell-center/
Tennessee	Vanderbilt Children's Center of Excellence in Sickle Cell Disease	2200 Children's Way, 6th Floor Nashville, TN 37232; (615) 936-1762; https://www.childrenshospitalvanderbilt.org/program/sickle-cell-disease-center-excellence
Texas	Texas Children's Hospital Cancer and Hematology Centers - Sickle Cell Program	6621 Fannin St, Houston, TX 77030; (800) 226-2379; https://www.texaschildrens.org/departments/sickle-cell-program
Texas	UT Physicians Comprehensive Sickle Cell Center	Plaza Medical Center 1200 Binz, Suite 850 Houston, TX 77004; (713) 486-5660 OR (713) 486-8876 (24-Hour Nurse Help Line); https://www.utphysicians.com/clinic/ut-physicians-comprehensive-sickle-cell-center/
Texas	Sickle Cell Program at Cook Children's Sickle	801 7th Ave, Fort Worth, TX 76104; (682) 885-4007;

	Cell Center Cook Children's Medical Center	https://cookchildrens.org/hematology-oncology/conditions/Pages/Sickle-Cell.aspx
Texas	UT Southwestern Medical Center Comprehensive Sickle cell Center	5323 Harry Hines Blvd. Dallas, TX 75390; (214) 645-8300 OR (817) 882-2700; https://utswmed.org/conditions-treatments/sickle-cell/
Texas	Children's Health Pediatric Sickle Cell Disease Program	1935 Medical District Drive Dallas, Texas 75235; (844) 424-4537; https://www.childrens.com/specialties-services/specialty-centers-and-programs/cancer-and-blood-disorders/programs-and-services/hematology/sickle-cell-disease
Texas	Children's Blood & Cancer Center (CBCC) Dell Children's Medical Center	1000 Hesters Crossing Road Round Rock, TX 78681; (512) 628-1900; https://www.dellchildrens.net/childrens-blood-and-cancer-center/what-we-treat/blood-disorders/sickle-cell-disease/
Texas	Baylor Scott & White McLane Children's Pediatric	3500 Gaston Ave., Dallas, TX 75246-2017; (254) 724-2006;

	Hematology Oncology	https://www.bswhealth.com/mclane-childrens/specialties/Pages/pediatric-hematology-oncology.aspx
Texas	Children's Hospital of San Antonio Cancer and Blood Disorders Center Christus Health - Baylor College of Medicine	333 North Santa Rosa Street, San Antonio, Texas 78207; (210) 704-2011; https://www.christushealth.org/childrens/services-treatments/cancer-care/conditions-we-treat
Texas	University of Kansas Health System- Pediatric Hematology and Oncology	3901 Rainbow Blvd. Kansas City, KS 66160; (913) 588-1227; https://www.kansashealthsystem.com/care/specialties/pediatric-hematology-oncology
Utah	Intermountain Primary Children's Hospital - Cancer, Blood and Marrow Clinic	100 N Mario Capecchi Dt Salt Lake City, UT 84113; (801) 662-4700 OR (801) 662-1000(After hour contact); https://intermountainhealthcare.org/primary-childrens/programs-specialties/cancer
Vermont	University of Vermont Children's	111 Colchester Avenue Main Campus, Specialty Center Burlington, Vermont 05401;

	Hospital - Pediatric hematology and oncology	(802) 847-2850; https://www.uvmhealth.org/medcenter/pages/departments-and-programs/pediatric-hematology-and-oncology.aspx
Virginia	Children's Hospital of The King's Daughters Comprehensive Sickle cell program	601 Children's Ln, Norfolk, VA 23507; (757) 668-7243; https://www.chkd.org/our-services/specialty-care-and-programs/cancer-and-blood-disorders-center/about-sickle-cell-anemia/
Virginia	VCU Health Sickle Cell Program	57 N 11th St, Richmond, VA 23298; (800) 762-6161; https://www.vcuhealth.org/services/sickle-cell-program
Virginia	Children's Hospital of Richmond (CHoR) at VCU ASK Pediatric Hematology and Oncology Clinic	Children's Pavilion 1000 East Broad Street Richmond, VA 23219; (804) 828-CHOR (2467); https://www.chrichmond.org/services/hematology-and-oncology/hematology-and-oncology
Virginia	Fredericksburg Multispecialty Center	10528 Spotsylvania Avenue Fredericksburg, VA 22408; (540) 891-3173; https://www.chrichmond.org/locations/location-details?practice=76

Virginia	VCU Massey Cancer Center	401 College Street, Box 980037 Richmond, Virginia 23298-0037; (804) 828-0450 E-mail: AskMassey@vcu.edu ; https://www.massey.vcu.edu/
Virginia	VCU Medical Center North Hospital	1300 E. Marshall Street Richmond, VA 23219; https://www.vcuhealth.org/locations/location-details?id=16
Virginia	Ambulatory Care Center VCU Health	417 N. 11th Street Richmond, VA 23219; https://www.vcuhealth.org/locations/location-details?id=10
Virginia	Comprehensive Sickle Cell Disease Program at Children's National	111 Michigan Avenue NW, Washington, D.C., 20010; (202) 476-2140; https://childrensnational.org/departments/center-for-cancer-and-blood-disorders/programs-and-services/blood-disorders/programs-and-services/sickle-cell-disease-program
Virginia	Fredericksburg	1300 Hospital Dr Suite 201 Fredericksburg, VA 22401; (540) 681-2353; https://childrensnational.org/visit/locations-and-directions/outpatient-centers/fredericksburg

Virginia	INOVA Pediatric Comprehensive Sickle Cell Program	Fairfax CCBD 8081 Innovation Park Dr, Suite 765, Building B, Fairfax, Virginia, 22031; (571) 472-1717; https://psvcare.org/specialty/cancer-and-blood-disorders
Virginia	Inova Hematology Oncology - Fairfax	8081 Innovation Park Dr 4th, Fl, Skyline Clinic Fairfax, VA 22031; (571) 472-4724; https://www.inova.org/locations/inova-hematology-oncology-fairfax
Virginia	Inova Hematology Oncology - Fair Oaks	3580 Joseph Siewick Dr #403 Fairfax, VA 22033; (703) 391-4395; https://www.inova.org/locations/inova-hematology-oncology-fair-oaks
Virginia	Pediatric Specialists of Virginia - Ashburn	Ashburn 22505 Landmark Court, Suite 225, Ashburn, Virginia, 20148; (703) 876-2788; https://www.inova.org/locations/pediatric-specialists-virginia-ashburn
Virginia	UVA Cancer Center - comprehensive	1215 Lee Street Charlottesville, VA 22903; (434) 924-9333;

	Adult Sickle Cell Clinic	https://uvahealth.com/services/blood-disorders/sickle-cell-disease
Virginia	Emily Couric Clinical Cancer Center	1240 Lee St. Charlottesville, VA 22903; (434) 924-9333; https://uvahealth.com/locations/profile/emily-couric-clinical-cancer-center
Virginia	UVA Cancer Center Pantops	Suite 175 590 Peter Jefferson Pkwy. Charlottesville, VA 22911; (434) 982-6900; https://uvahealth.com/locations/profile/uva-cancer-center-pantops
Virginia	UVA Cancer Center Augusta	Third Floor, Suite 300 57 Beam Ln. Fishersville, VA 22939; (540) 213-2220; https://uvahealth.com/locations/profile/uva-cancer-center-augusta
Virginia	UVA Cancer Care a Department of Novant Health UVA Health System Culpeper Medical Center	545 Sunset Ln. Culpeper, VA 22701; (540) 829-4352; https://uvahealth.com/locations/profile/uva-culpeper-medical-center-cancer-care

Virginia	Stem Cell Transplant Clinic	Emily Couric Clinical Cancer Center Third Floor 1240 Lee St. Charlottesville, VA 22903; (434) 924-9333; https://uvahealth.com/locations/profile/Stem-Cell-Transplant-Clinic
Virginia	UVA Children's comprehensive sickle cell clinic	
Virginia	UVA Pediatric Hematology/Oncology	Battle building Fifth Floor 1204 W. Main St. Charlottesville, VA 22903; (434) 924-8499; https://childrens.uvahealth.com/services/pediatric-blood-disorders
Virginia	UVA Pediatrics Harrisonburg McGaheysville	9982 Spotswood Trail McGaheysville, VA 22840; (540) 437-3740; https://uvahealth.com/locations/profile/pediatrics-harrisonburg-mcgaheysville
Virginia	UVA Pediatrics Harrisonburg	1947 Medical Avenue Harrisonburg, VA 22801; (540) 434-3004; https://uvahealth.com/locations/profile/pediatrics-harrisonburg

Virginia	UVA Pediatrics Specialty Care Winchester	Suite B 629 Cedar Creek Grade Winchester, VA 22601; (540) 678-3950; https://childrens.uvahealth.com/locations/profile/uva-childrens-hospital-specialty-clinic-winchester
Virginia	Carilion Children's Comprehensive Care	https://www.carilionclinic.org/specialties/pediatric-hematology-oncology
Virginia	Carilion Children's Pediatric Hematology/Oncology	1906 Belleview Ave, 4 North Roanoke, VA 24014; (540) 981-7376; https://www.carilionclinic.org/locations/carilion-childrens-hematologyoncology
Virginia	Carilion Children's Hospital	1906 Belleview Ave Roanoke, VA 24014; (540) 266-5437; https://www.carilionclinic.org/locations/carilion-childrens-hospital
Virginia	Carilion Children's Pediatric Hematology & Oncology - Lynchburg	1620 Graves Mill Rd Lynchburg, VA 24502; (434) 316-5495; https://www.carilionclinic.org/locations/carilion-childrens-pediatric-hematology-oncology-lynchburg
Virginia	Carilion Roanoke Memorial Hospital	1906 Belleview Ave Roanoke, VA 24014;

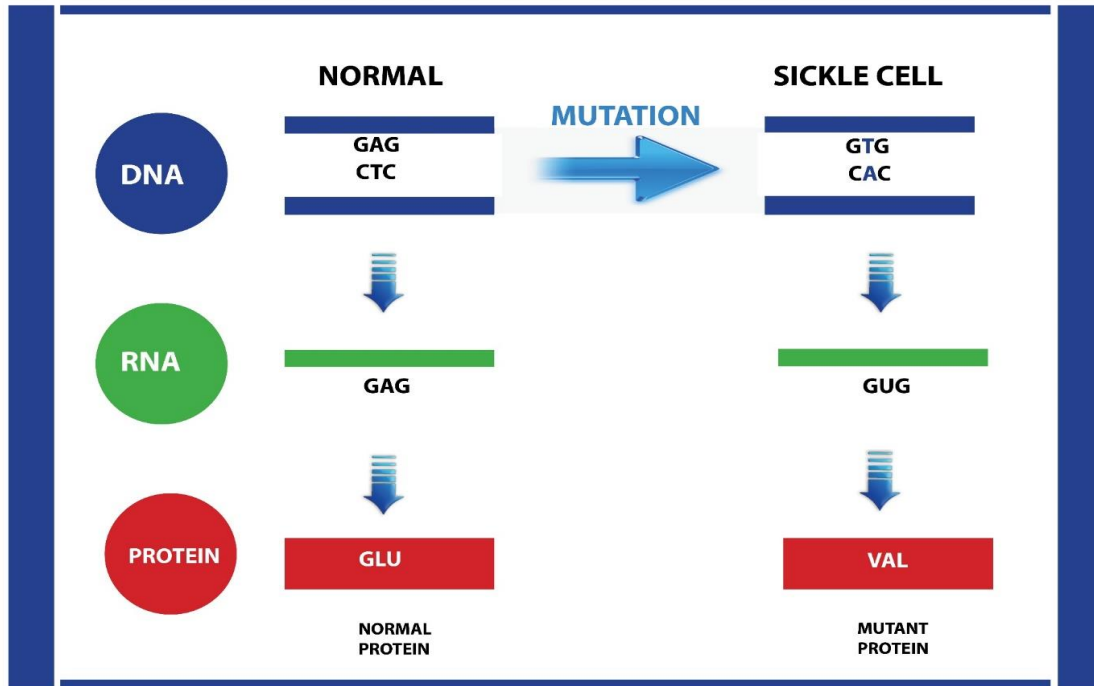
		(540) 981-7000; https://www.carilionclinic.org/locations/carilion-roanoke-memorial-hospital
Washington	Sickle cell program Seattle Children's - Odessa Brown Children's Clinic	2101 E. Yesler Way Seattle, WA 98122; (206) 987-7263; https://www.seattlechildrens.org/clinics/cancer/services/sickle-cell-program/
Washington	Seattle Cancer Care Alliance (SCCA)	825 Eastlake Ave E PO Box 19023 Seattle WA 98109-1023; (855) 557-0555 ; https://www.seattlecca.org/diseases/sickle-cell-disease
Washington	Providence Health and Services Washington	https://washington.providence.org/services-directory/services/p/pediatric-oncology-and-hematology/related-services
Washington	Providence Pediatric Hematology Oncology - Spokane Sacred Heart Children's Hospital	Third Floor, 101 W. 8th Avenue Spokane, WA 99204; (509) 474-2777; https://washington.providence.org/locations-directory/p/pediatric-hematology-and-oncology

Washington	Providence Pediatric Specialty Clinic - Richland	112 Columbia Point Dr, Suite 103 Richland, WA 99352; (509) 942-2766; https://washington.providence.org/locations-directory/r/richland-specialty-clinic
Washington	Sacred Heart Children's Hospital	101 West 8th Ave. Spokane, WA 99204; (509) 474-3131; https://washington.providence.org/locations-directory/s/sacred-heart-childrens-hospital
Washington	Providence Sacred Heart Medical Center	101 West 8th Ave. Spokane, WA 99204; (509) 474-3131; https://washington.providence.org/locations-directory/s/sacred-heart-medical-center
Washington	Mary Bridge Children's Hospital	317 Martin Luther King Jr Way Tacoma, WA 98405; (253)403-1400; https://www.marybridge.org/services/cancer/conditions-we-treat/blood-disorders/
Washington	Mary Bridge Children's Hematology/Oncology Mary Bridge Children's Outpatient Center	311 South L Street West Wing, First Floor Tacoma, WA 98405; (253) 403-3481 OR (800) 552-1419; https://www.marybridge.org/locations/mary-bridge-childrens-health-center/

West Virginia	No Centers	
Wisconsin	MACC Fund Center for Cancer and Blood Disorders Children's Wisconsin	8915 W. Connell Ct. P.O. Box 1997 Milwaukee, WI 53226; (414) 266-2420; https://childrenswi.org/medical-care/macc-fund-center/conditions/hematology-and-blood-disorders/blood-disorders/sickle-cell-disease
Wisconsin	Adult Sickle Cell Clinic at Froedtert Hospital	9200 W. Wisconsin Ave. Milwaukee, WI 53226; (414) 805-2220; https://www.froedtert.com/sickle-cell-disease
Wisconsin	Pediatric Sickle Cell Anemia Clinic American Family Children's Hospital	1675 Highland Ave. Madison, WI 53792; (608) 263-6420; https://www.uwhealthkids.org/pediatric-cancer/pediatric-sickle-cell-disease/35373
Wyoming	No Centers	
Washington DC	Georgetown Lombardi Comprehensive Cancer Center	3800 Reservoir Rd. NW Washington D.C. 20057; (202) 444-7599.; https://lombardi.georgetown.edu/pediatric-hematology-oncology/
Washington DC	Howard University Hospital - Center	2041 Georgia Avenue, NW, Washington, DC 20060; (202) 865-8284

	for Sickle Cell Disease	email: sicklecell@howard.edu ; http://huhealthcare.com/healthcare/hospital/specialty-services/sickle-cell-disease-center
Washington DC	Comprehensive Sickle Cell Disease Program at Children's National	111 Michigan Avenue NW, Washington, D.C., 20010; (202) 476-2140; https://childrensnational.org/departments/center-for-cancer-and-blood-disorders/programs-and-services/blood-disorders/programs-and-services/sickle-cell-disease-program

APPENDIX C: DNA STRUCTURE IN SICKLE CELL DISEASE



Appendix Figure 1: Region of point mutation at the Deoxyrebo Nucleic Acid (DNA) in patients with Sickle Cell Disease

BIBLIOGRAPHY

1. Services USD of H& H. What is Sickle Cell Disease? | CDC. National Center on Birth Defects and Developmental Disabilities (NCBDDD). <https://www.cdc.gov/ncbddd/sicklecell/facts.html>. Published 2019. Accessed October 1, 2020.
2. Ashley-Koch A, Yang Q, Olney RS. American Journal of EPIDEMIOLOGY Sickle Hemoglobin (Hb S) Allele and Sickle Cell Disease: A HuGE Review.; 2000. <https://academic.oup.com/aje/article-abstract/151/9/839/50321>. Accessed October 24, 2019.
3. Joseph E Maakaron, MD; Ali T Taher, MD, PhD F. Sickle Cell Anemia: Practice Essentials, Background, Genetics. medscape. <https://emedicine.medscape.com/article/205926-overview#a6>. Published 2020. Accessed October 4, 2020.
4. Services USD of H& H. What is Sickle Cell Trait? | CDC. October 21, 2019. <https://www.cdc.gov/ncbddd/sicklecell/traits.html>. Published 2019. Accessed July 13, 2020.
5. Ware RE, de Montalembert M, Tshilolo L, Abboud MR. Sickle cell disease. Lancet (London, England). 2017;390(10091):311-323. doi:10.1016/S0140-6736(17)30193-9
6. Alexandra S, Anton M, Alexander R, Alida P, Gotlieb V. Hereditary Persistence of Hemoglobin F Is Protecti...: Full Text Finder Results. Vol 12.; 2019. <http://resolver.ebscohost.com/pitt.idm.oclc.org/openurl?sid=Entrez%3APubMed&pmid=29079125&site=ftf-live>. Accessed July 9, 2020.
7. Olaniyi JA, Arinola OG, Odetunde AB. FOETAL HAEMOGLOBIN (HbF) STATUS IN ADULT SICKLE CELL ANAEMIA PATIENTS IN IBADAN, NIGERIA. Ann Ibadan Postgrad Med. 2010;8(1):30-33. doi:10.4314/aipm.v8i1.63955
8. Panawala L. What is the Function of Hemoglobin in the Human Body. Pediaa. 2017;(February):7. https://www.researchgate.net/publication/313841668_What_is_the_Function_of_Hemoglobin_in_the_Human_Body. Accessed October 23, 2019.
9. Ballas SK, Kesen MR, Goldberg MF, et al. Beyond the definitions of the phenotypic complications of sickle cell disease: an update on management. ScientificWorldJournal. 2012;2012:949535. doi:10.1100/2012/949535
10. U.S Department of Health and Human Services NI of H, National Heart L and BI. Evidence-Based Management of Sickle Cell Disease: Expert Panel Report, 2014 | NHLBI,

- NIH. <https://www.nhlbi.nih.gov/health-topics/evidence-based-management-sickle-cell-disease>. Published 2014. Accessed October 28, 2020.
11. Sickle-Cell Anaemia Report by the Secretariat PREVALENCE OF SICKLE-CELL ANAEMIA.; 2006.
 12. Sickle Cell Disease Coalition. <http://www.scdcoalition.org/priorities/global.html>. Accessed October 24, 2019.
 13. Wanjiku CM, Njuguna F, Asirwa FC, et al. Establishing care for sickle cell disease in western Kenya: Achievements and challenges. *Blood Adv.* 2019;3(Suppl 1):8-10. doi:10.1182/BLOODADVANCES.2019GS121620
 14. Motulsky AG. Frequency of Sickling Disorders in U.S. Blacks. *N Engl J Med.* 1973;288(1):31-33. doi:10.1056/NEJM197301042880108
 15. U.S. Department of Health & Human Services. Data & Statistics on Sickle Cell Disease | CDC. 2019. <https://www.cdc.gov/ncbddd/sicklecell/data.html>. Published 2019. Accessed July 13, 2020.
 16. Lanzkron S, Carroll CP, Haywood C. Mortality Rates and Age at Death from Sickle Cell Disease: U.S., 1979–2005. *Public Health Rep.* 2013;128(2):110-116. doi:10.1177/003335491312800206
 17. Sickle Cell Disease | National Heart, Lung, and Blood Institute (NHLBI). <https://www.nhlbi.nih.gov/health-topics/sickle-cell-disease>. Accessed November 10, 2019.
 18. Sickle Cell Disease | American Society of Hematology. 2018. <https://www.hematology.org/Patients/Anemia/Sickle-Cell.aspx>. Accessed October 10, 2019.
 19. Hassell KL. Population Estimates of Sickle Cell Disease in the U.S. *Am J Prev Med.* 2010;38(4):S512-S521. doi:10.1016/j.amepre.2009.12.022
 20. Therrell BL, Hannon WH. NATIONAL EVALUATION OF US NEWBORN SCREENING SYSTEM COMPONENTS. doi:10.1002/mrdd.20124
 21. Piel FB, Patil AP, Howes RE, et al. Global distribution of the sickle cell gene and geographical confirmation of the malaria hypothesis. *Nat Commun.* 2010;1(8):1-7. doi:10.1038/ncomms1104
 22. Kato GJ, Piel FB, Reid CD, et al. Sickle cell disease. *Nat Rev Dis Prim.* 2018;4(1):1-22. doi:10.1038/nrdp.2018.10
 23. Grosse SD, Odame I, Atrash HK, Amendah DD, Piel FB, Williams TN. Sickle cell disease in Africa: A neglected cause of early childhood mortality. *Am J Prev Med.* 2011;41(6 SUPPL.4):S398. doi:10.1016/j.amepre.2011.09.013

24. Piel FB, Howes RE, Patil AP, et al. The distribution of haemoglobin C and its prevalence in newborns in Africa. *Sci Rep.* 2013;3(1):1-8. doi:10.1038/srep01671
25. Trachoo O, Sura T, Sakuntabhai A, et al. Molecular Characterization of Hereditary Persistence of Fetal Hemoglobin in the Karen People of Thailand. Vol 27. Taylor & Francis; 2003. doi:10.1081/HEM-120021542
26. Ibrahim SA, Mustafa D. Sickle-cell Haemoglobin O Disease in a Sudanese Family. *Br Med J.* 1967;3(5567):715-717. doi:10.1136/bmj.3.5567.715
27. Farooq F, Mogayzel PJ, Lanzkron S, Haywood C, Strouse JJ. Comparison of US Federal and Foundation Funding of Research for Sickle Cell Disease and Cystic Fibrosis and Factors Associated With Research Productivity. *JAMA Netw open.* 2020;3(3):e201737. doi:10.1001/jamanetworkopen.2020.1737
28. Bemrich-Stolz CJ, Halanych JH, Howard TH, Hilliard LM, Lebensburger JD. Exploring Adult Care Experiences and Barriers to Transition in Adult Patients with Sickle Cell Disease. *Int J Hematol Ther.* 2015;1(1). doi:10.15436/2381-1404.15.003
29. Stollon NB, Paine CW, Lucas MS, et al. Transitioning adolescents and young adults with sickle cell disease from pediatric to adult health care: Provider perspectives. *J Pediatr Hematol Oncol.* 2015;37(8):577-583. doi:10.1097/MPH.0000000000000427
30. Yanni E, Grosse SD, Yang QH, Olney RS. Trends in Pediatric Sickle Cell Disease-Related Mortality in the United States, 1983-2002. *J Pediatr.* 2009;154(4):541-545. doi:10.1016/j.jpeds.2008.09.052
31. Alexandra Power-Hays, M.D., and Patrick T. McGann MD. PERSPECTIVE 2 Racism and Sickle Cell Disease. *N Engl J Med.* 2020. doi:10.1056/NEJMp2022125
32. Kunal Sanghavi, Margaret Holtz, Kathleen Dempsey, Beth Vogel, Michele Caggana, Joann Bodurtha DC. Use of telemedicine to improve access to clinical services and treatment for children with sickle cell disease | oneSCDvoice. American Society of Pediatric Hematology/Oncology. <https://www.onescdvoice.com/education-and-research/use-telemedicine-improve-access-clinical-services-treatment-children-sickle-cell-disease/>. Published 2016. Accessed October 22, 2020.
33. WOODS K, KUTLAR A, GRIGSBY RK, ADAMS L, STACHURA ME. Primary-Care Delivery for Sickle Cell Patients in Rural Georgia Using Telemedicine. *Telemed J.* 1998;4(4):353-361. doi:10.1089/tmj.1.1998.4.353
34. Telehealth for global partnership. The Importance of Telehealth in Sickle Cell Communities - Global Partnership for TeleHealth. <https://gpth.org/2019/03/08/the-importance-of-telehealth-in-sickle-cell-communities/>. Published 2020. Accessed October 22, 2020.
35. Manley AF. Legislation and Funding for Sickle Cell Services, 1972-1982 - PubMed. *American Journal of Pediatric Hematology/Oncology.*

- <https://pubmed.ncbi.nlm.nih.gov/6711766/>. Published 1984. Accessed June 23, 2020.
36. Jenny Wang JC. Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018 (Public Law 115-327) | SciPol.org. SciPol.org. <https://scipol.org/track/s-2465-sickle-cell-disease-and-other-heritable-blood-disorders-research-surveillance-0>. Published 2020. Accessed October 27, 2020.
 37. Scott T. S.2465 - 115th Congress (2017-2018): Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018. 2018. <https://www.congress.gov/bill/115th-congress/senate-bill/2465>. Accessed September 17, 2020.
 38. World Health Organisation F ninth world HA. Sickle-Cell Anaemia Report by the Secretariat.\n.; 2006. https://apps.who.int/iris/bitstream/handle/10665/20890/A59_9-en.pdf?sequence=1&isAllowed=y. Accessed June 8, 2020.
 39. SERVICES USDOHAH, Service PH, Health NI of, National Heart, Lung and BI. THE MANAGEMENT OF SICKLE CELL DISEASE.; 2002.
 40. DeSimone J, Heller P, Hall L, Zwiers D. 5-Azacytidine stimulates fetal hemoglobin synthesis in anemic baboons. *Proc Natl Acad Sci U S A*. 1982;79(14 I):4428-4431. doi:10.1073/pnas.79.14.4428
 41. Perumbeti A, Malik P. Genetic correction of sickle cell anemia and beta-thalassemia: progress and new perspective. *ScientificWorldJournal*. 2010;10:644-654. doi:10.1100/tsw.2010.67
 42. Bourzac K. GENE THERAPY: Erasing sickle-cell disease. *Nature*. 2017;549(7673):S28-S30. doi:10.1038/549S28a
 43. Benson JM, Therrell BL. History and Current Status of Newborn Screening for Hemoglobinopathies. *Semin Perinatol*. 2010;34(2):134-144. doi:10.1053/j.semperi.2009.12.006
 44. El-Haj N, Hoppe CC. Newborn screening for SCD in the USA and Canada. *Int J Neonatal Screen*. 2018;4(4). doi:10.3390/ijns4040036
 45. Prof. Ishita Mukerji. About Sickle Cells-Informational Links. http://www.sicklecellinfo.net/info_links/sc_centers.htm. Published 2004. Accessed October 7, 2020.
 46. NATIONAL RESOURCE DIRECTORY National Center on Birth Defects and Developmental Disabilities Division of Blood Disorders. <https://stacks.cdc.gov/view/cdc/11903>. Accessed October 7, 2020.
 47. BatchGeo LLC. BatchGeo: Make a map from your data. <https://batchgeo.com/>. Published 2020. Accessed October 7, 2020.

48. Kiriza N. Pediatric Sickle Cell Disease Centers inUSA. Batchgeo.
<https://batchgeo.com/map/f3c67154597e55952bee0ee1a03c7013>. Published October 2020. Accessed December 8, 2020.
49. Kiriza N. Adult Sickle Cell Disease Centers in United States.
<https://batchgeo.com/map/a5dbfb5e737581438b17575d618508c1>. Published October 7, 2020. Accessed December 8, 2020.
50. Kiriza N. Adult & Pediatric SCD Centers.
<https://batchgeo.com/map/329bea4827e2b3c9e95c7ef9a71e20e4>. Published October 7, 2020. Accessed December 8, 2020.
51. U.S. Department of Commerce. U.S. Census Bureau QuickFacts: United States.
<https://www.census.gov/quickfacts/fact/table/US/POP010210>. Accessed October 7, 2020.
52. Arora S, Thornton K, Murata G, et al. Outcomes of Treatment for Hepatitis C Virus Infection by Primary Care Providers. *N Engl J Med*. 2011;364(23):2199-2207.
doi:10.1056/nejmoa1009370