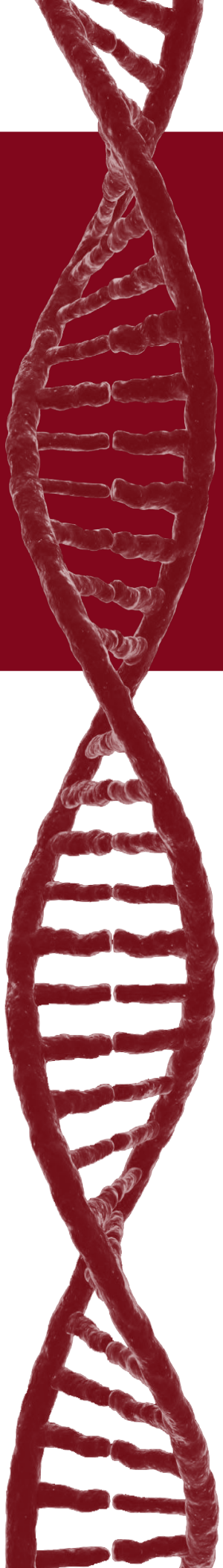

SICKLE CELL DISEASE IN MARYLAND

May 2023

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INTRODUCTION

The Sickle Cell Disease in Maryland report was commissioned and authored by the Statewide Steering Committee on Sickle Cell Disease, as required by HB 1188, Chapter 279 of the General Assembly Acts of 2022. The purpose of this report is to make recommendations on how to enhance access services for people with sickle cell disease, whether to establish a sickle cell disease registry, how to enhance the coordination of health services for individuals with sickle cell disease who are transitioning from pediatric to adult care, and how to engage with community-based events to outreach to individuals with sickle cell disease. The basis of the report came from a meeting in October 2022 of Committee members which includes adult and pediatric hematologists, community-based organizations, people living with sickle cell disease, and caregivers to people living with sickle cell disease.

OVERVIEW OF THE DISEASE

Sickle cell disease (SCD) is a group of inherited red blood cell disorders that affect hemoglobin, the protein that carries oxygen through the body. The condition affects more than 100,000 people in the United States and twenty million people worldwide[1]. SCD is a lifelong illness, and there are few effective treatments that can reduce symptoms and prolong a patient's life.

Sickle cell disease is inheritable, and people who inherit two sickle cell alleles (one from each parent) will have SCD. Someone who inherits one sickle cell allele, and one unaffected allele will have the sickle cell trait (SCT). People with the trait do not have symptoms of SCD, but they can pass the trait on to their children, or even pass on SCD to their children if their partner has the trait.

SCD is most prevalent among those whose ancestors lived in sub-Saharan Africa; Spanish-speaking regions in the Western Hemisphere (South America, the Caribbean, and Central America). It is also prevalent among those whose ancestors lived in Saudi Arabia, India, and Mediterranean countries such as Turkey, Greece, and Italy[2].

The disease, with limited research funding, and lack of availability of treatment options reveals many of the racial inequities in our healthcare system. In addition, structural racism has severely impacted the ability of many people living with SCD to receive appropriate care. The State's interest in bringing equity to the healthcare system for all Marylanders makes addressing the needs of people living with SCD a necessity.

PREVALENCE AND IMPACT OF THE DISEASE

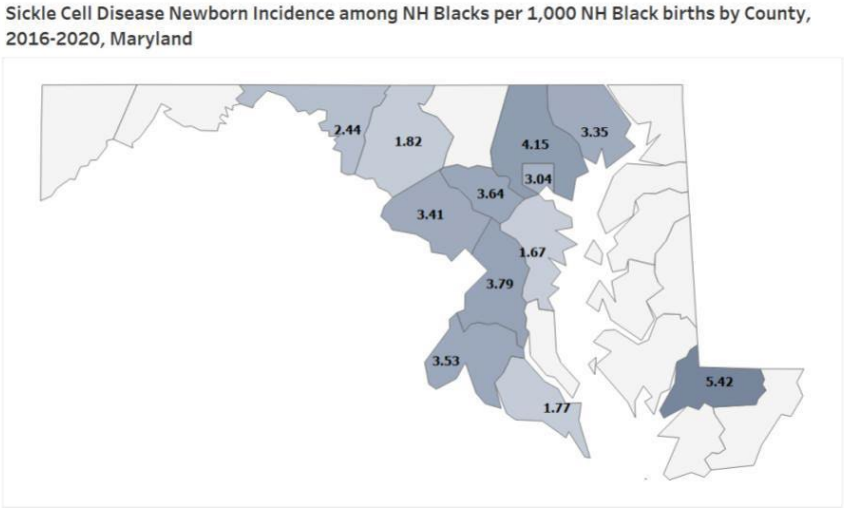
The U.S. Centers for Disease Control and Prevention (CDC) estimates that about 100,000 Americans have SCD. About one in every 365 Black or African American babies, and about one in every 16,300 Hispanic babies are born with SCD. About one in every 13 Black or African American babies are born with Sickle Cell Trait (SCT). SCD and SCT is also seen among immigrants and newborns from the higher

[1] NIH National Heart, Lung and Blood Institute https://www.nhlbi.nih.gov/health/sickle-cell-disease#:~:text=The%20condition%20affects%20more%20than,or%20%E2%80%9Csickle%E2%80%9D%2Dshaped.

[2] Mohsen A. F. El-Hazmi, Ali M. Al-Hazmi and Arjumand S. Warsy "Sickle cell disease in Middle East Arab countries." Indian J Med Res 134, November 2011, pp 597-610

risk geographic regions mentioned above[3]. Further details about sickle cell population estimates can be found in the article by Dr. Hassell (4).

The following map indicates the rates of new cases of SCD in Non-Hispanic Blacks identified in newborn screening by jurisdiction in Maryland.



There are many disparities that are systemic in institutions across the healthcare system that have led to persistent poor outcomes for people living with SCD[4]. Although SCD is more common than hemophilia or cystic fibrosis (100,000 people with SCD vs. 15,000 and 35,000 people, respectively) people living with hemophilia or cystic fibrosis benefit from more than 130 comprehensive treatment centers. These centers offer multidisciplinary teams that improve outcomes that lead to decreased costs and improve access to high-quality care. In contrast, specialized SCD health care providers with comprehensive expertise are scarce, particularly in low-income and rural communities. At this time, without an accurate count of people with SCD and where they live, it is unclear where additional funding and resources should be provided in the state to meet the needs for those living with SCD.

It is critical to identify where people with SCD live and receive care in Maryland. This is the first step in building the necessary infrastructure to overcome the lack of access to high quality care for this historically underserved population in MD and to improve outcomes.

It is now recognized that the only way to improve care for people with SCD is to follow the lead of colleagues who care for people with cystic fibrosis and hemophilia and that is to ensure that all people living with SCD receive care from a sickle cell disease expert in a comprehensive sickle cell program. The required elements needed to provide comprehensive care for both children and adults with SCD have recently been described and these elements have been used by the National Alliance for Sickle Cell Centers (NASCC) to recognize over seventy centers across the country. In Maryland, the Johns Hopkins Sickle Cell Center for Adults is a NASCC recognized center. Prior to establishing additional centers, knowing where patients live and receive care is essential.

Due to the wide-ranging and diverse populations affected, and the diversity of the state, all the communities likely to have a high prevalence are not easy to identify. Identification of areas with high

[3] https://www.cdc.gov/ncbddd/sicklecell/data.html
[4] https://pubmed.ncbi.nlm.nih.gov/33411430/

prevalence of the disease and trait is necessary to enable the State to target available resources effectively.

Living with Sickle Cell Disease

A person with SCD can live a long and high-quality life[5]. Management of SCD is focused on preventing and treating organ damage, pain episodes, and other complications. Prevention strategies include medical screening and interventions to prevent SCD complications[6]. Access to a sickle cell expert at a comprehensive sickle cell program is necessary to enable patients to receive the care needed.

Although recent improvements in care have resulted in most children with SCD surviving into adulthood, access to adult sickle cell care is poor in many parts of the United States. Increased acute care utilization, disjointed care delivery, and early mortality for patients are a few consequences of the lack of specialized care. A dearth of classical hematologists, the lack of a national SCD registry, and the absence of a centralized infrastructure to facilitate comparative quality assessment compounds these issues.[7]

Optimal management of people with SCD requires that they understand their disease and have access to the specialized medical services listed above. The public health approach to sickle cell disease is to provide education, assure an adequate specialized provider workforce, and to assure the linkage of persons with SCD to that specialized provider resource.

CURRENT RESOURCES

ORGANIZATIONS AND ASSOCIATIONS

The Statewide Steering Committee on Sickle Cell Disease

The Statewide Steering Committee on Services for Adults with Sickle Cell Disease was originally created by legislation in 2007, and included a group of persons living with SCD, health care providers, medical insurers, and community representatives, appointed by the Secretary of the Maryland Department of Health (MDH) charged with educating Marylanders about SCD and identifying resources and services that could be used to improve the lives of affected residents. The legislation expired in 2009, but the Committee was reinstated in 2019 as the Statewide Steering Committee on Sickle Cell Disease.

The Committee is charged with educating residents with sickle cell disease, health care providers, and the public. For that purpose, the Committee establishes partnerships with institutions and communities, as well as a statewide network of service providers for adults with sickle cell disease.

The William E. Proudford Sickle Cell Fund

The Fund supports comprehensive, multi-disciplinary state-of-the-art treatment and research at leading institutions in the Mid-Atlantic area. They offer the artSPEAKS Program, which encourages children with SCD and their families to create works of art that express the pain, struggles, triumphs, and hopes

[5] https://www.cdc.gov/ncbddd/sicklecell/documents/SickleCell_infographic_5_Facts.pdf

[6] https://www.cdc.gov/ncbddd/sicklecell/facts.html

[7] Blood Adv. 2020 Aug 25;4(16):3804-3813

of living with sickle cell disease and trait. The fund fosters collaboration through SiNERGe, a program that builds connections among community-based organizations in the Northeast region. They also raise awareness about sickle cell disease and trait, advocate for expanded access to high-quality care, and encourage participation in clinical studies.

The Association for the Prevention of Sickle Cell Disease in Harford and Cecil County and the Eastern Shore

The mission of the Association for the Prevention of Sickle Cell Anemia of Harford/Cecil Counties and Eastern Shore is to provide education and medical and financial assistance to individuals and their families living with SCD. In addition, the Association focuses on broadening public awareness and raising funds to assist in medical research and education.

The Sickle Cell Disease Association of the National Capital Area (SCANCA)

The Sickle Cell Association of the National Capital Area, Inc. (SCANCA, Inc.) focuses on educating individuals about the management of SCD. SCANA serves the Maryland counties of Montgomery and Prince Georges, as well as the District of Columbia and Northern Virginia.

SCANCA provides workshops, health fairs, client support groups and publications that inform the community, including health and social professionals about sickle cell disease. It offers programs including counseling, referrals, and advocacy for individuals with sickle cell disease and its families, and it partners with community organizations to provide medical and social resources and assist in research about sickle cell disease.

The Armstead-Barnhill Sickle Cell Foundation

Armstead- Barnhill works to find a cure for SCD by through activities that include annual fund-raising events, public awareness campaigns, facilitating meetings with sickle cell researchers for updates on current sickle cell treatment and research projects; and maintaining a sickle cell hotline that provided resources to sickle sufferers and their families regarding medical providers, current treatments and social services.

Sally's Sunshine Foundation

Sally's Sunshine Foundation was started in memory of Sally Jallow. The Foundation advocates for better healthcare for minorities suffering from sickle cell disease, promote the importance of blood donations from the minority community. The foundation seeks to bridge the gap between those with sickle cell disease and the community through sponsored social events. It also supports early detection sickle cell trait screenings.

Eastern Shore of Maryland Sickle Disease Association

The purpose of the Eastern Shore of Maryland Sickle Cell Disease Association is to identify needs and the gaps in services, advocate for individuals and families affected by SCD, and educate communities for the advancement toward a cure.

Maryland Sickle Cell Disease Association

The Maryland Sickle Cell Disease Association (MSCDA) was formed by concerned parents and interested individuals seeking to improve the lives of persons affected by Sickle Cell Disease in Maryland. MSCDA works with patients, families, healthcare providers, federal and state agencies, and community-based organizations to promote advocacy, education, research, and healthcare delivery.

MSCDA seeks to work with patients, families, healthcare providers, federal and state agencies and other community-based organizations to promote advocacy, education, research and excellent healthcare delivery.

MSCDA offers Public School Nurses Training Programs, which provide a Clinical Pediatric Nurse to hold in-services for Howard County Public School Nurses and helps educate Nursing Assistants on identifying the symptoms of sickle cell disease. MSCDA offers Public School Administrators and Educators Training Programs, and holds monthly support discussion groups for sickle cell disease patients and caregivers.

MSCDA also works with SCD providers to identify individuals and families affected by SCD who need emergency financial assistance. The organization also provides educational materials, such as pamphlets and literature, and they produce Voices of MSCDA Videos, a video collection which highlights vlogs created by a Sickle Cell Warrior, Pam Moore[8]. Lastly, the organization offers a directory of doctors and sickle cell centers in the Maryland/Washington DC area.

Project SPIRIT Sickle Cell (PSSC), Inc.

Project **SPIRIT*** Sickle Cell, (PSSC), Inc., (****SPIRIT*** = ***S****ickle cell* ***P****astoral* ***I****ntervention* ***R****eaching* ***I****ndividuals in* ***T****ransition*), provides spiritually integrated, non-denominational, inter-faith support for individuals living with SCD and post-transplant, providing space within an inclusive community for personal transformation, exploration of life transitions and new awakenings. Services are provided throughout Maryland at no financial cost to participants. A vital part of PSSC's overall mission is promoting awareness and education about SCD for and with the greater community.

Sickle Cell Coalition of Maryland

The Sickle Cell Coalition of Maryland (SCCM) emerged with the purpose of enhancing the well-being of individuals impacted by sickle cell disease and their caregivers, with a particular focus on the southern Maryland region encompassing Prince George's, St. Mary's, and Charles counties. SCCM aims to provide assistance and valuable resources to all sickle cell patients, who are often referred to as sickle cell warriors, throughout the entire state of Maryland. SCCM's vision is to ensure every sickle cell warrior in Maryland has access to the tools they need to THRIVE in all aspects of life.

CLINICAL PROVIDERS

The Sickle Cell Center at Johns Hopkins

The Sickle Cell Center for Adults at Johns Hopkins: The mission of the Johns Hopkins Sickle Cell Center for Adults is to provide comprehensive and state-of-the-art care to patients with sickle cell disease and other hemoglobin disorders. Established in 2000, the Center is staffed by a team of world-renowned

[8] See Sickle Cell Coalition

physicians, nurses, advanced practice providers, and staff who are devoted to clinical care and research in sickle cell disease.

The services provided to patients at the Johns Hopkins Sickle Cell Center for Adults include treatment and management of patients with SCD, as well as pain management, wound care, social services, case management, genetic counseling, patient education, and psychiatric services.

University of Maryland Capital Region and Children's National Clinic in Lanham

The Maryland Community Health Resources Commission is a commission formed by the Maryland legislature to fund projects that will have a significant impact on the health of Marylanders. In 2022, CHRC awarded Johns Hopkins $2 million to begin work on improving access to high quality sickle cell care in Prince George's county. Funds are being used to support sickle cell care at the University of Maryland Capital Region and Children's National Clinic in Lanham's c. Prince George's County was identified as the county with the greatest number of SCD patients and lacking the availability of comprehensive SCD care.

University of Maryland Medical Center – Baltimore

The University of Maryland Medical Center in Baltimore provides a multidisciplinary approach to care for patients with SCD. Their emergency department provides specialized care for patients presenting with sickle cell pain crisis (vaso-occlusive pain crisis).

Howard University Sickle Cell Center

The Howard University Center for Sickle Cell Disease is committed to a six-fold goal that includes comprehensive medical care, research, testing, education, counseling, and community outreach. Although located in the District of Columbia, they provide services to residents of Maryland.

MedStar Hospital Center

MedStar Hospital Center offers health services for children, adolescents and young adults with cancer and blood disorders, including SCD. Although located in the District of Columbia, they provide services to residents of Maryland.

PEDIATRICS

The following organizations offer pediatric services to children with SCD.

- Pediatric Hematology at Johns Hopkins
- University of Maryland Medical Center – Baltimore
- LifeBridge Sinai Hospital
- Children's National is in Washington DC and provides services to Maryland residents through a satellite location in Prince George's County.
- Howard University (located in DC and provides services to Maryland residents.)
- Georgetown University (located in DC and provides services to Maryland residents.)

GOVERNMENTAL ENTITIES

Maryland Department of Health Sickle Cell Disease Follow-Up Program

The Maryland Department of Health's Sickle Cell Disease Follow-Up Program ensures that babies identified with SCD through newborn screening are connected to a pediatric hematologist and follows newborns, children, and young adults up to age 18, providing them and their families information about SCD and other hemoglobin disorders. The program informs families on what to expect from providers and specialists, offers guides to living with SCD, and provides a range of information pertaining to daycare, school, sports, transitioning to an adult provider, web resources and organizations of interest to persons with SCD. The program also seeks to ensure that children up until the age of six receive penicillin prophylaxis and recommended vaccinations. They have been recognized as one of the best newborn screening programs in the country.

The available resources are not sufficient to meet the needs of Maryland residents with SCD. Geographically, the state has many areas that lack easy access to many of the sites discussed above. To target populations with the greatest needs for services, a disease surveillance program or registry is needed.

Some limitations on the implementation of a registry include that although newborn screening is mandated in all 50 states, the District of Columbia, Puerto Rico, Guam, and the U.S. Virgin Islands, it is ineffective in capturing individuals living with sickle cell disease (SCD) who were born prior to universal screening or outside of the United States and its territories. Even for those born in the U.S. and identified with SCD through newborn screening, there is only data available on where they were born. There is no universal way to track individuals as they move between states. Furthermore, the disease course of SCD is not identical for all those individuals living with the disease. It is important to understand the varying range of complications and impact, and to identify any trends that could lead to better or worsening outcomes. Additionally, data about individuals with SCD must be governed by strict adherence to HIPAA requirements, ensure respect for patient privacy and confidentiality, and ensure that data are not used to discriminate against patients.

BENEFITS AND CHALLENGES OF IMPROVED SURVEILLANCE

Despite the available resources in the state, it is still not known if Marylanders living with SCD are receiving high-quality evidence-based care. It is known that primary care providers often lack information specific to SCD and there are a limited number of hematologists who specialize in SCD care[9]. If Maryland was able to better identify individuals living with SCD, understand where they live and the current resources available to them, the state would be better able to improve access to the existing healthcare system, improve the system of care where most underserved patients live, and facilitate access to national clinical trials, new treatments, and other resources as they become available.

Additionally, ensuring that everyone living with SCD has access to a sickle cell expert and educating primary care providers to refer patients to a sickle cell expert is important to improving the lives of Maryland residents living with SCD.

[9] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7486208/

The CDC's Sickle Cell Data Collection (SCDC) program[10] was developed by the CDC in 2015 with a goal of collecting health information about people with sickle cell disease (SCD) to study long-term trends in diagnosis, treatment, and healthcare access for people with SCD in the United States. The SCDC program began operating in California and Georgia in 2015, and these long-term participants are seeing documented benefits for their SCD patients, families, and health providers.

In California, because the sickle community has been able to leverage the information collected through the surveillance program, there are now appropriations in the state's budget to provide financial resources to create comprehensive networks of care to provide better access for adults with SCD. SCDC data were used to help advocates identify the state's areas of highest need for these SCD specialty care centers, including parts of the state that were previously unknown to have a high prevalence of SCD. The Sickle Cell Disease Foundation of California uses SCDC data to identify and engage with primary care providers, connect them with patients, and provide resources to address the treatment of SCD.

In Georgia, SCDC data have been used to identify locations with high prevalence of SCD and few providers with SCD expertise. These locations have been targeted for satellite clinics staffed by faculty from established comprehensive SCD clinical centers both in person and through telemedicine.

The SCDC program, operated by CDC, currently includes the states of Alabama, California, Colorado, Georgia, Indiana, Michigan, Minnesota, North Carolina, Tennessee, and Wisconsin. These eleven states benefit from participating in the program by, among other benefits, developing maps that show where people with SCD live, overlayed with the location of healthcare providers and facilities. These maps help participating states identify areas with high need for services. SCDC information also helps states understand changes in where and when individuals are likely to shift from pediatric care to adult care to target transition services and resources where it is most needed.

Trust in the medical system and government has to be considered when developing a surveillance system for SCD. In a meeting of the Statewide Steering committee this issue was raised by stakeholders. The consensus was that if the benefits of having this system were explained and there was transparency the community would be more accepting of the program.

People with SCD are living longer, making it more important to use surveillance information to study common health problems that patients experience as they age. Understanding the intersections of aging and SCD is an opportunity to better understand the needs of a variety of patients, SCD patients as well as those with related disorders, as they age.

SCDC data support policy decisions at the state and federal level, inform and educate those living with the disease, their families and communities, and health care providers on the disease, treatment options and best practices. The Maryland Department of Health, in partnership with the Johns Hopkins School of Medicine, applied for the 2023 Request for Applications for the SCDC program.

[10] https://www.cdc.gov/ncbddd/hemoglobinopathies/scdc.html

CONCLUSIONS AND RECOMMENDATIONS

ESTABLISH A REGISTRY

Increasing surveillance leads to enhanced identification and improvements in response capacity. It is necessary to understand how many people have the disease, and where they live to position needed services, evaluate the need for mobile or telehealth services in rural areas and provide better access.

The SCDC program has demonstrated the benefits of surveillance and persons affected by SCD in Maryland should have the same opportunity to benefit as current participants.

ENHANCE COORDINATION OF SERVICES

Ensuring that every Maryland resident who lives with SCD is identified, seen by a knowledgeable primary healthcare provider as well as an SCD specialist to guide their care is essential. Ensuring that providers implement existing standard-of-care guidelines and best practices, developing resources to help physicians identify SCD and provide treatment based on the latest research and best practices while minimizing the impact of racial bias is also central to the quality of care offered. Community health workers and social workers are needed to address the full range of supports needed for residents with SCD, although it is important to note that they do not eliminate the need for trained specialists and treatment facilities.

Transitions for those aging out of pediatric care into adult care settings is important to ensuring the quality of care is consistent and requires coordination through enhanced training and retention efforts for providers who treat SCD, targeted to those areas most in need of specialized providers and services. With Maryland CBOs obtaining grants in this area there is an opportunity for providers to work with the CBOs to enhance the transition experience for adolescents and young adults.

INCENTIVIZED TRAINING FOR PHYSICIANS AND HEALTH PROVIDERS

A surveillance program for SCD would help the State to develop an actionable plan to provide resources and ensure access to expert care for people living with SCD throughout the state. In addition, programs to inform providers and best practices in pain management and reversible conditions known to precipitate pain crises, such as dehydration and infection, would directly benefit patients with SCD and their families. In addition, education for physicians managing sickle cell pain and believing patients' self-reported pain and symptoms is key. Incentivizing physicians and other providers to participate in trainings can broaden the reach of the training.

COMMUNITY ENGAGEMENT

Community engagement includes both the community of individuals directly affected by SCD (those living with the disease, family members, friends, caregivers, teachers, clinical providers, pharmaceutical manufacturers, etc.) and the broader community of Marylanders who are not directly impacted by SCD in their daily lives. Strategies to reach both groups are important. Many who are directly impacted with SCD may not be aware of available resources and treatments and can benefit from knowing others who are similarly situated in terms of the health condition that impacts them. Outreach to the broader community is critical to raising awareness about SCD. Increased awareness can lead to increased interest leading to increased allocation of resources to improve the lives of those affected by SCD.

There should be increased community engagement around sickle cell trait education. 1 in 13 people of African descent carry the sickle cell trait (SCT). Maryland has no education programs for those affected with the trait or their families. Likewise, schools, caregivers, and health care providers lack the resources and information needed to assist those with the disease.

SCD is inherited from parents carrying the SCT. Therefore, it is essential for carriers of SCT to know their status and have access to non-directive genetic counseling to make informed reproductive decisions.

Health fairs and other community events can be a valuable resource to help educate the public and enhance access to care. Additionally, health fairs often provide health screenings and assessments. Additionally, these venues can be used to engage the community in the issues facing SCD patients, expanding public understanding of the need for a surveillance program, and educating the public on how a registry or surveillance program would protect patient privacy.

SUMMARY

Any course of action to improve identification and treatment of SCD will be contingent on an understanding of where the disease is most prevalent. The CDC's SCDC program offers its participants information to identify where people with SCD live. A similar system in MD would help the State target patient programs, physician education and specialized services to geographic areas of high prevalence, reduce emergency hospital visits through preventative actions, and ensure appropriate specialists are available, using telehealth as necessary, where they are needed most.

APPENDIX

Sickle Cell Report Addendum Components

(1) how to enhance access to services for individuals with sickle cell disease with a **focus on areas of the State where there is a statistically high number of individuals with sickle cell disease and areas where there is a lack of providers with expertise in treating sickle cell disease.**

Prince George's County: High rate and high count of SDC

Current status and ideas for evolution:

- Two -year pathways grant currently funds one advanced practice provider, and one social worker.
- Can apply for five additional years (competitive, no guarantee)
- Infusion services available through grant at UMCR
- Need for LCSW services for SCD patients.

Desirable data/info to compile:

1. Would like information on where people are getting care in PG county - MD has data on hospitalizations where preliminary checks have been done

2. Compile infusion data (HSCRC and CRISP should have necessary data) and develop a report on acute care utilization, as well as request that CRISP provide ongoing data about acute care utilization

Eastern Shore: High rate but low count of SCD (due to small population)

Current status and ideas for evolution:

- Tidal Health had very limited services
- Children's National Hospital has a clinic on the shore, could assign an advanced practice provider to see adults there?
- Local hematologists may not have much interest in focusing on sickle cell care
- Travel and distance are significant barriers. Use of telemedicine may be preferable to periodic clinics as a solution to this problem.
- CHWs could be funded in CBOs for care coordination and navigation services.

Desirable data/info to compile:

1. describe and compile list of current available resources on Eastern Shore

2. Gather info on patient population – including infant screening data (a lot of this is stored as paper files with MD gov), report on inpatient/outpatient data to see where adults are (using ICD-10 coding so it'll be de-identified but will give idea of utilization and location), children numbers, and whether patients are moving into the state

Western Maryland: Modest rate, low count (low population), but fewest services

Current status and ideas for evolution:

- Few services, many go to Frederick, PA, or WV
- Need telemedicine and transportation services
- Could use a part-time CHW for navigation and care coordination

Baltimore City Region: High rate and high count of SCD

Current status and ideas for evolution:

- Currently no CHWs and 1 Social Worker at JHU, inadequate services available at all SCD centers in the city (Sinai, UMMS, JHU)
- Transportation resources exist through Medicaid, but not for emergent needs (lead time issues)
- Limited food and financial support service available through CBO's but patients may be unaware

Desirable data/info to compile:

1. Compile 911 data for how often SCD patients call for transport/care, make available for a cost-benefit analysis of setting up transportation infrastructure

2. Need data from community hospitals admissions and outcomes at sites with less sickle expertise – develop a metric as quality measure e.g. no current info on repeat visit frequency, need a proxy for complications of disease (modified Charleson for SCD) – with goal of getting people transferred from ED to sites with expertise faster

Statewide:

Current status and ideas for evolution:

- Expand Prince George's County Pathways model to other parts of the State.
- Implement a Statewide Trans-Cranial Doppler (TCD) testing program,

Desirable data/info to compile:

Action items: 1. Compile data on who does and doesn't get TCD testing – could use CPT coding for TCDs (data is deidentified)

2. Lots of data on benefit of TCDs and stroke prevention, compile some measurable statistics to demonstrate benefit

(2) **whether to establish a sickle cell disease registry, and if recommended**, **the process and guidelines for establishing a registry, obtaining information, connecting with the State designated exchange, and protecting data privacy.**

Questions that a registry could help answer:

- Who has SCD?
- Where do SCD patients get their care?
- How much time does it take to get specialized SC care?
- Is transportation readily available to get to care?
- Which patients are not connected to the necessary care?

- Which geographic areas have insufficient resources for care?
- Are our programs and interventions having an impact?
    - Are we reducing the following?
        - SCD ED visit rates
        - SCD hospital admission rates
        - SCD readmission rates
        - Reducing travel time to get to specialized services
    - Are we improving the following:
        - Hydroxyurea use rates
        - TCD screening rates

This would require a registry of incidence, prevalence, and treatment.

By comparison, the MD cancer registry is only an incidence registry, not a treatment registry.

Still, the MD cancer registry experience provides some model for data privacy management.

Outreach to patients identified with needs will require community buy-in. A public awareness campaign for this purpose will be needed.

Sickle cell surveillance has been done in other states, CA and GA for example, and so this could be replicated.

(3) **how to enhance the coordination of health care services for individuals with sickle cell disease who are transitioning from pediatric to adult health care in the State including the identification of available resources for individuals who are transitioning.**

Current status and ideas for evolution:

- Maryland has four strong pediatric programs
- Transition to adult care programs exist in the centers at JHU and UMB
- Two available transition programs: Got Transition and ASH
- Mismatch: more adult than pediatric SCD patients, but more pediatric than adult hematologists

Ideas for evolution:

- Scale up some components of the PG County Pathways model. Develop a hub and spoke model in the Eastern Shore and other places with limited access to sickle cell specialist.
- Nurse navigator models have been studied to see if they enhance successful transition. Needs of the transition population is high and they are most likely group to have high levels of acute care utilization and early mortality. Combination of CHW's and transition navigators can be deployed to help ensure patients are going consistently to appointments and adhere to therapies in the years before and after transition to adult care.
- Use of CBOs to provide transition services

(4**) how to engage with community–based health fairs and other community–sponsored events** in **areas with a statistically high number of individuals with sickle cell disease** to **provide outreach and education on living with sickle cell disease and how to access health care services.**

If funded, CBOs can provide the following outreach services:

- Health fairs (SDC part of a larger context, unlikely SDC specific health fairs)
- School education programs for SCD and SCT
- Monthly support groups
    - Grief management/spiritual support for life transitions and crises
    - Clinical trial enrollment
    - Available therapies
    - Life insurance issues
    - Care for the caregiver
    - Addressing workplace (HR) challenges and concerns for those living with sickle cell disease
    - SC Curative discussions (stem, bone marrow transplants, gene therapy), pro, cons, and other considerations
- Social media outreach, including via influencers

CBO role in SCT screen test program