Ohio | Department of Health

SICKLE CELL ANNUAL REPORT 2021

This page has been intentionally left blank.

Ohio Sickle Cell Services Program
2021 Annual Report

This report includes data from State Fiscal Year 2020

SUBMITTED TO

Members of the Ohio General Assembly

SUBMITTED BY

Ohio Department of Health
Sickle Cell Services Program

Message from the Director of Health

Dear Members of the Ohio General Assembly:

On behalf of the families we serve, I am pleased to submit to you the annual report for the Ohio Department of Health (ODH) Sickle Cell Services Program.

In 1972, the Ohio General Assembly passed legislation establishing programs and services for persons with sickle cell disease. Ohio House Bill 1024 (section 3701.131 of the Ohio Revised Code), set forth requirements for the Ohio director of health to:

"Encourage and assist in the development of programs of education and research pertaining to the causes, detection, and treatment of sickle cell disease and provide for rehabilitation and counseling of persons possessing the trait of or afflicted with this disease."

This annual report to the General Assembly serves to outline the receipt and disbursement of funds and the implementation and progress of various programs undertaken pursuant to this section.

For more information on sickle cell disease, the contents of this report, or services provided by ODH Sickle Cell Services Program, contact Lisa Griffin, Director of Government Affairs, Lisa.Griffin@odh.ohio.gov or 614-644-9164.

Sincerely,

Bruce Vanderhoff, MD, MBA
Director of Health

Table of Contents

Lists of Tables and Figures

Tables

Figures

Dedication and Acknowledgments

Dedication

"Individuals and families living with sickle cell disease face many kinds of loss, not only the possibility of death at a young age but also the multiple losses along the way as the person experiences the challenges of the disease."[1]

This report is dedicated to all the individuals who lost their battle with sickle cell disease during 2020. These **sickle cell warriors** will truly be missed by their families, their friends and the professional community who served them.

Acknowledgments

Many individuals at the Ohio Department of Health (ODH) participated in the editorial review of the Sickle Cell Annual Report. These individuals gave generously of their time and expertise, and their cooperation and assistance were greatly appreciated.

We are especially appreciative of the data analysis provided by Ryan Harrison (ODH Bureau of Maternal, Child, and Family Health) and the design services provided by Janet Steadman (ODH Office of Communications) in the development of this report.

A special acknowledgment and thank you is also extended to the project directors and staff at the ODH-funded sickle cell projects around Ohio. This report is made possible by their dedication and hands-on participation in the completion of required program data collection and reporting forms during state fiscal year (SFY) 2020.

Most importantly, we would like to thank the many patients and families at the Ohio pediatric and adult sickle cell treatment centers and the affected family support group members *living with sickle cell disease*, for their continuous contributions to our education.

Executive Summary

In State Fiscal Year (SFY) 2020 (July 1, 2019-June 30, 2020), the Ohio Department of Health (ODH) funded a network of seven sickle cell projects: a Statewide Sickle Cell Project (SWSCP) located in Columbus and six Regional Sickle Cell Projects (RSCPs) located in Cincinnati, Dayton, Toledo, Columbus, Cleveland, and Akron. These regional projects are responsible for collecting data pertaining to the level and scope of hemoglobinopathy* services in their respective regions or statewide for the reporting SFY. The data in this report is compiled from SFY 2020 Minimum Data Set collection forms and other program reporting formats.

Newborn Hemoglobinopathy Screening

- The RSCPs received notification of 3,498 abnormal newborn hemoglobinopathy screening results from the ODH Public Health Laboratory during SFY 2020. This number accounts for 2.6% of all Ohio births (n=133,677) during the reporting period.

    - There were 136 (4% of abnormal screening results, <1% of the total births in SFY 2020) newborns that had a disease hemoglobinopathy screening result and 3,362 (96% of abnormal screening results, 2.5% of the total births in SFY 2020) that had a carrier hemoglobinopathy screening result.

Hemoglobinopathy Testing

- The RSCPs reported confirmatory testing on 2,079 (59%) of newborns identified in SFY 2020 with an abnormal newborn hemoglobinopathy screening result. Documentation of confirmatory testing was not obtained on 1,419 (41%) newborns with an abnormal screening notification due to the parent or guardian being lost to follow up†, the physician of record not reporting to the RSCP, the parent or guardian declining RSCP services or the infant expiring before testing.

Of the 136 newborns with a disease hemoglobinopathy screening result:

    - There were 122 (90%) newborns who received confirmatory testing within two months of life and 14 (10%) received confirmatory testing results after two months.

* A hemoglobinopathy is an inherited blood disorder passed down through families (inherited) in which there is an abnormal form of hemoglobin (variant) or decreased production of hemoglobin (thalassemia). Hemoglobin is the oxygen-carrying protein in the red bold cells. (See Appendix A.)
† "Lost to follow up" refers to the status of a case when all standardized procedures to establish *direct* (e.g., face to face) or indirect (e.g., telephone, letter) contact with a newborn's parents/guardians/physician of record have been exhausted and a final diagnosis is unknown.

- There were 91 (67%) who received treatment within three months of birth, and none received treatment after three months. There were 42 (31%) newborns who did not receive treatment, either due to being confirmed as a carrier or having diseases not requiring treatment. Of the remaining newborns, two (1%) had parents decline treatment and one (<1%) died before being tested.

- There were 1,642 (79%) newborns with confirmatory testing for hemoglobinopathies who identified as Black or African American. There were 50 (2%) newborns with confirmatory testing who identified as Hispanic.

- A total of 1,708 non-newborns[‡] received hemoglobinopathy testing services through an RSCP in SFY 2020, with 601 (35%) identified with a carrier hemoglobinopathy and 22 (1%) identified with a disease hemoglobinopathy. A total of 1,085 (64%) non-newborns were identified with no hemoglobinopathy.

- There were 1,235 (72%) non-newborns receiving hemoglobinopathy testing services who identified as Black or African American. There were 259 (17%) non-newborns receiving testing services who identified as Hispanic.

- Of those who received hemoglobinopathy testing services, 2,079 (55%) were newborns from 53 counties and 1,708 (45%) were non-newborns from 23 counties in Ohio.

Hemoglobinopathy Counseling

- Of the 2,079 newborns born in SFY 2020 who received confirmatory testing, 2,065 (99%) had a parent or guardian who received hemoglobinopathy counseling by the RSCPs.

    - There were 2,125 parents or guardians who received hemoglobinopathy counseling in association with these newborns.
    - For the 13 confirmed newborns whose parents or guardians did not receive counseling, all 13 (100%) were due to the caregivers declining counseling.

- Hemoglobinopathy counseling services were provided to 1,708 non-newborns. Of these, 520 (30%) were parents of non-newborn infants and 1,188 (70%) were other non-newborns directly tested. All non-newborns who received testing were subsequently counseled.

[‡] Non-newborn is defined as an individual born before SFY 2020 (07/01/19 - 06/30/20) who received hemoglobinopathy follow-up services through an RSCP during SFY 2020.

Hemoglobinopathy Outreach Education

- Sickle cell project staff (SWSCP and RSCP) provided 377 education events, totaling 795 hours of direct education to an estimated 11,821 members of the public, health care providers, and community professionals.

    - There were 127 (34%) education events that took places in medical provider offices, 77 (21%) that took place in pediatric hospitals, and 37 (10%) that took place virtually (e.g., webinars). The remaining locations each made up less than 10% of the total.

    - The top two event topics were general hemoglobin disease and trait overview, and newborn screening. There were 332 (25%) hemoglobin overview events and 228 (17%) events about newborn screening.

    - Most education events were small group instructions, at 169 (45%) of all education events.

    - Education events were held in 34 Ohio counties and awareness events were held in 78 Ohio counties. Both included the five counties in Ohio with the highest proportion of African American[§] residents (Cuyahoga, Hamilton, Franklin, Montgomery, and Lucas counties).

- In addition, project staff conducted 274 awareness activities, with an estimated 12,097,575[**] contacts made to raise awareness of sickle cell disease and other hemoglobinopathies.

    - The top three modes of awareness activities were 104 community and professional outreach (38%), 88 material distribution (32%), and 60 traditional media activities (22%).

[§] The term "African American" comes directly from the database in which the information was gathered. This differs from "Black or African American", which is the wording from the minimal data sheet used by ODH to collect sickle cell information.

[**] This number includes all people potentially reached by awareness activities, included social media, radio and television ads, and newsletters.

INTRODUCTION

Program Background

Ohio Revised Code section 3701.131 sets forth requirements for the director of health to:

"(A) Encourage and assist in the development of programs of education and research pertaining to the causes, detection, and treatment of sickle cell disease and provide for rehabilitation and counseling of persons possessing the trait of or afflicted with this disease;

"(B) Advise, consult, cooperate with, and assist, by contract or otherwise, agencies of this state and the federal government, agencies of the governments of other states, agencies of political subdivisions of the state, and private organizations, corporations, and associations in the development and promotion of programs pertaining to the causes, detection, and treatment of sickle cell disease and rehabilitation and counseling of persons possessing the trait of or afflicted with this disease;

"(C) Accept and administer grants from the federal government or other sources, public or private, for carrying out any of the functions enumerated in divisions (A) and (B) of this section."

In addition, section 3701.501 requires that:

"Except as provided in division (A)(2) of this section, all newborn children shall be screened for the presence of the genetic, endocrine, and metabolic disorders specified in rules adopted pursuant to this section."

To carry out these requirements, ODH funded two grant initiatives in SFY 2020 under the Sickle Cell Services Program related to sickle cell disease (SCD), sickle cell trait (SCT), and other hemoglobinopathies:

The **Sickle Cell Initiative** is composed of a regional network of six sickle cell projects based in four pediatric hospitals and two community-based agencies located in Cincinnati, Dayton, Toledo, Columbus, Cleveland, and Akron. (See Appendix C through H.) These projects are funded to ensure the provision of comprehensive sickle cell services for newborns, children, and adults, including:

- Newborn screening coordination and follow-up of abnormal hemoglobin disease and hemoglobin trait results.
- Hemoglobinopathy counseling and education for patients and their families.

- Public and professional outreach/education/awareness activities and resource materials.
- Referral services to specialized medical teams for hemoglobin disease management.

The **Statewide Family Support Initiative** project, located in Columbus (see Appendix I), is funded to support the provision of statewide training, education, and empowerment resources to individuals (adults/young adults) and families at risk for or affected by SCD, SCT and other hemoglobinopathies, and to the professionals who serve them. These services include:

- Statewide public awareness and media campaigns.
- Professional training and outreach.
- Consumer support/empowerment resources.
- Advisory organization for the Ohio Sickle Cell Affected Family Association.
- Linkage with the Sickle Cell Disease Association of America Inc. (SCDAA).

Receipt and Disbursement of Funds

In accordance with rule 3701-55-20 of the Ohio Administrative Code:

"In addition to the laboratory fee authorized by rule 3701-49-01.1 of the Administrative Code, the director of health shall charge and collect a fee of twenty-six dollars and thirty-one cents for performing genetic, endocrine, and metabolic disorder screenings required by section 3701.501 of the Revised Code and this chapter. The fee shall be disbursed as follows:

"Six dollars and five cents shall be deposited into the state treasury to the credit of the sickle cell fund. Money credited to the sickle cell fund shall be used to defray costs of programs authorized under section 3701.131 of the Revised Code."

For SFY 2020, fees generated from the sale of newborn screening kits to Ohio hospitals and birthing facilities enabled ODH to award grant subsidies in the amount of $800,000 (See Table 1.)

- The six Regional Sickle Cell Projects located in Cincinnati, Dayton, Toledo, Columbus, Cleveland, and Akron were awarded a total of $710,000 to provide services/activities (see Program Background) under the Sickle Cell Initiative.

- The Sickle Cell Project located in Columbus was awarded $90,000 to provide services/activities (see Program Background) under the Statewide Family Support Initiative.

Funding to the Regional Sickle Cell Projects for SFY 2020 under both the Sickle Cell Initiative and the Statewide Family Support Initiative were continuation grant awards distributed through an established ODH grant application process.

Table 1. Grant Award Allocations

Region	Agency Name	City/County	SFY 2020 Award
Sickle Cell Initiative			
I	Cincinnati Children's Hospital Medical Center	Cincinnati/Hamilton	$125,957
II	Dayton Children's Hospital	Dayton/Montgomery	$72,932
III	Neighborhood Health Association of Toledo, Inc.	Toledo/Lucas	$54,743
IV	Nationwide Children's Hospital	Columbus/Franklin	$171,595
V	American Sickle Cell Anemia Association	Cleveland/Cuyahoga	$188,164
VI	Children's Hospital Medical Center-Akron	Akron/Summit	$96,609
Statewide Family Support Initiative			
	Ohio Sickle Cell and Health Association	Columbus/Statewide	$90,000

PROGRAM IMPLEMENTATION

Newborn Hemoglobinopathy Screening

Since March 1990, all infants born in Ohio are screened at birth for sickle cell disease, sickle cell trait, and other hemoglobinopathies, as part of the newborn bloodspot screenings mandated by Ohio Administrative Code. The primary purpose of hemoglobinopathy screening is to identify infants with sickle cell disease and initiate penicillin prophylaxis, which has been shown to substantially reduce the incidence of pneumococcal sepsis in infancy.[2] Early identification, when linked to timely diagnostic testing, parental education, and comprehensive care, can markedly reduce morbidity and mortality for sickle cell disease in infancy and early childhood.

At present all 50 states, the District of Columbia, and the U.S. territories require every newborn be tested for sickle cell disease as part of a newborn screening program.[3]

Newborn hemoglobinopathy screening also identifies infants with other hemoglobinopathies, such as carriers of hemoglobin variants. While not clinically significant, detection of a carrier state (e.g., sickle cell trait), provides a genetic window into the family that can result in the identification of couples at risk for having children with sickle cell disease in subsequent pregnancies. It may also identify other family members at risk or affected by sickle cell disease, sickle cell trait, or a related hemoglobinopathy. Thus, the value of trait identification is threefold: (1) educate families; (2) test other family members, especially those who are at reproductive age and who may not have been screened at birth; and (3) provide hemoglobinopathy counseling.

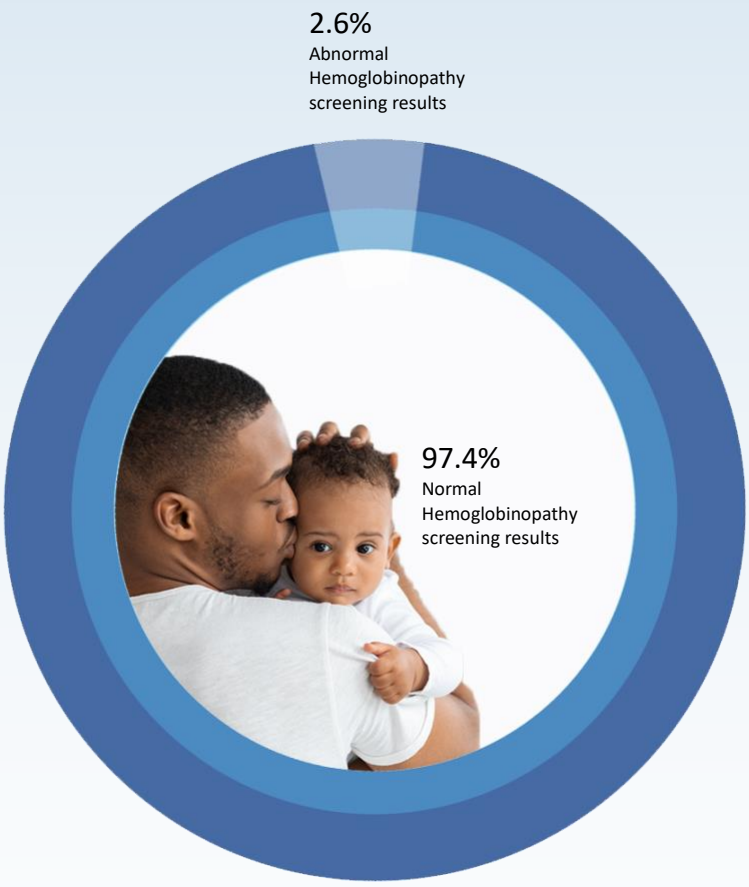
All bloodspot screenings performed in Ohio are analyzed by the ODH Public Health Laboratory under the Newborn Screening (NBS) Program. The Regional Sickle Cell Projects, under the Sickle Cell Initiative, are an integral part of this program. They are directly responsible for case-by-case follow-up of all presumptive positive abnormal hemoglobin results (hemoglobin disease and hemoglobin trait) reported by the Newborn Screening Program to the newborns' physician of record. Follow-up of abnormal newborn hemoglobin screening results is in accordance with rule 3701-55-08 of the Ohio Administrative Code:

"A child with abnormal results on diagnostic tests for sickle cell and other hemoglobinopathies shall be referred to a state funded Ohio regional sickle cell project for hemoglobin counseling and follow-up."

This follow-up includes assisting with and/or providing a point of referral for confirmation, consultation, education, counseling, reporting and medical management (*if required*) of those newborns identified with an abnormal newborn hemoglobinopathy screening result.

During SFY 2020, the Regional Sickle Cell Projects received notification of 3,498 abnormal newborn hemoglobinopathy screening results (from the ODH Public Health Laboratory). This figure accounts for 2.6% of all Ohio births (n=133,677) during this reporting period. The remaining 97.4% received normal hemoglobinopathy screening results. (See Figure 1.)

Figure 1. Newborns with an Abnormal Hemoglobinopathy Screening Notification



Sources: Ohio Public Information Warehouse, Birth Occurrence (Birth Comprehensive 2019 and 2020 (Preliminary); Minimum Dataset SFY 2020 Table 1.

Hemoglobinopathy Testing

Confirmation of a presumptive positive hemoglobinopathy screening result is an integral part of the newborn screening follow-up process. In addition to confirmation of newborns with an abnormal hemoglobin result, the Regional Sickle Cell Projects may also provide diagnostic testing services to individuals at risk[††] for hemoglobinopathies. These individuals, referred to as non-newborns, include:

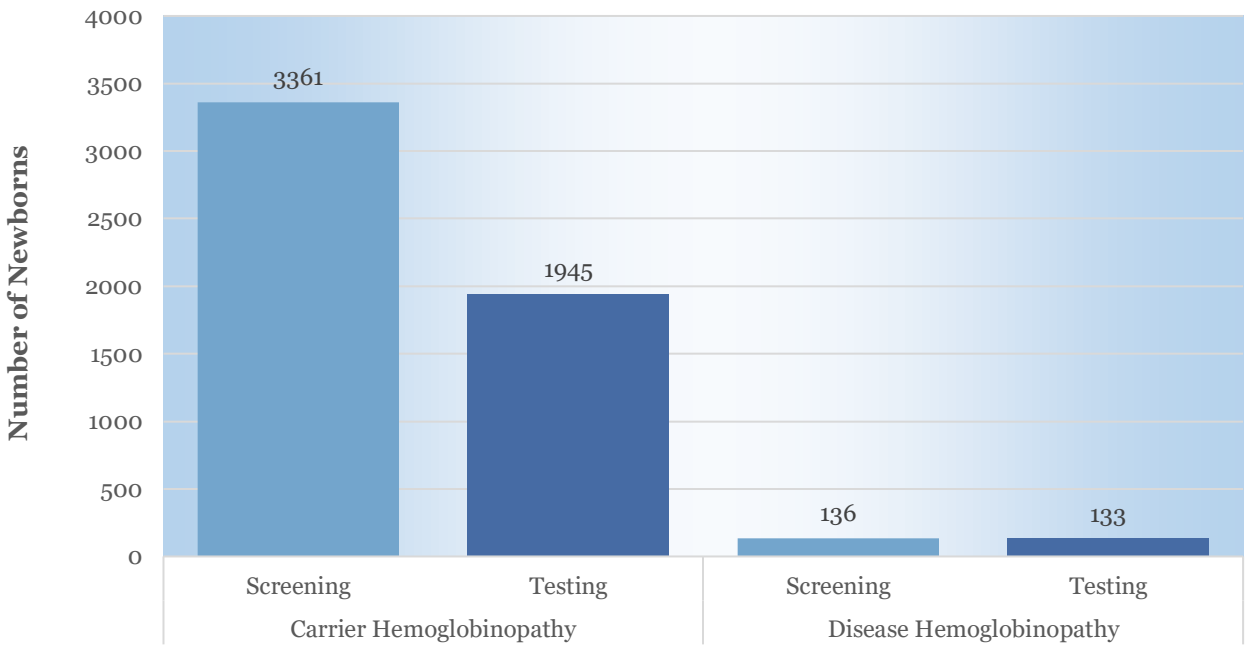
- Parents and family members of infants identified with abnormal newborn hemoglobin screening results.
- Adults (not associated with an abnormal newborn screening result) unaware of their hemoglobin status.
- Individuals of childbearing age (representing various racial and ethnic populations) considered to be at increased risk for hemoglobinopathies.
- Children whose parents do not know if they are trait positive.
- Student-athletes participating in collegiate sports (mandatory requirement of the National Collegiate Athletic Association).

[††] At risk segments of the community include individuals with heritage from sub-Saharan Africa; Spanish speaking regions in the Western Hemisphere (South America, the Caribbean, and Central America); Saudi Arabia; India; and Mediterranean countries such as Turkey, Greece, and Italy.

Newborn Hemoglobinopathy Testing

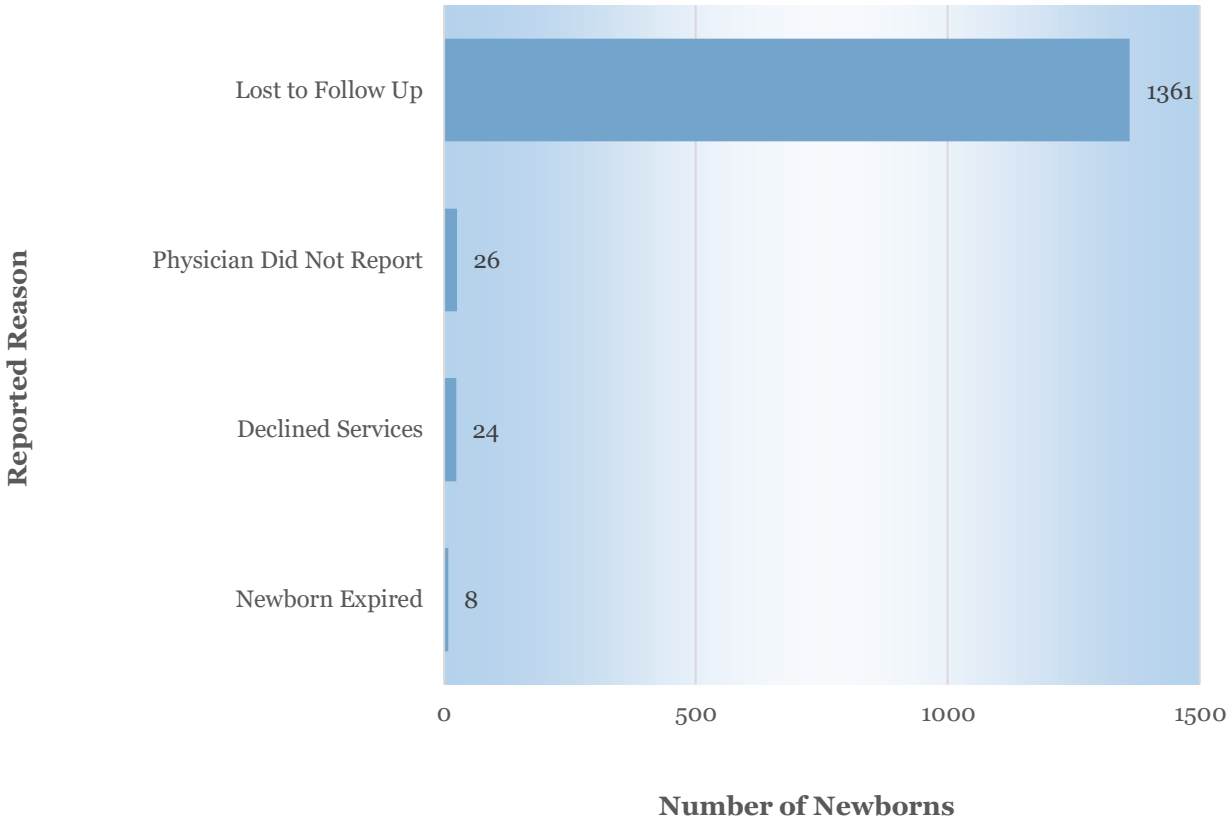
The Regional Sickle Cell Projects received notification of 3,498 abnormal hemoglobinopathy screening results for newborns in SFY 2020. Of these newborns, the Regional Sickle Cell Projects reported that 2,079 (59%) received confirmatory testing. One newborn with a test result of FA (normal) is not shown below. (See Figure 2.) The reasons newborns were not documented as having confirmatory testing is described in Figure 3.

Figure 2. Newborns: Abnormal Screening Notification and Confirmatory Testing



Source: Minimum Dataset SFY 2020 Tables 1, 2a.

Figure 3. Reasons Newborns Were Not Documented as Having Confirmatory Testing (n=1,419)



Source: Minimum Dataset SFY 2020 Table 2b.

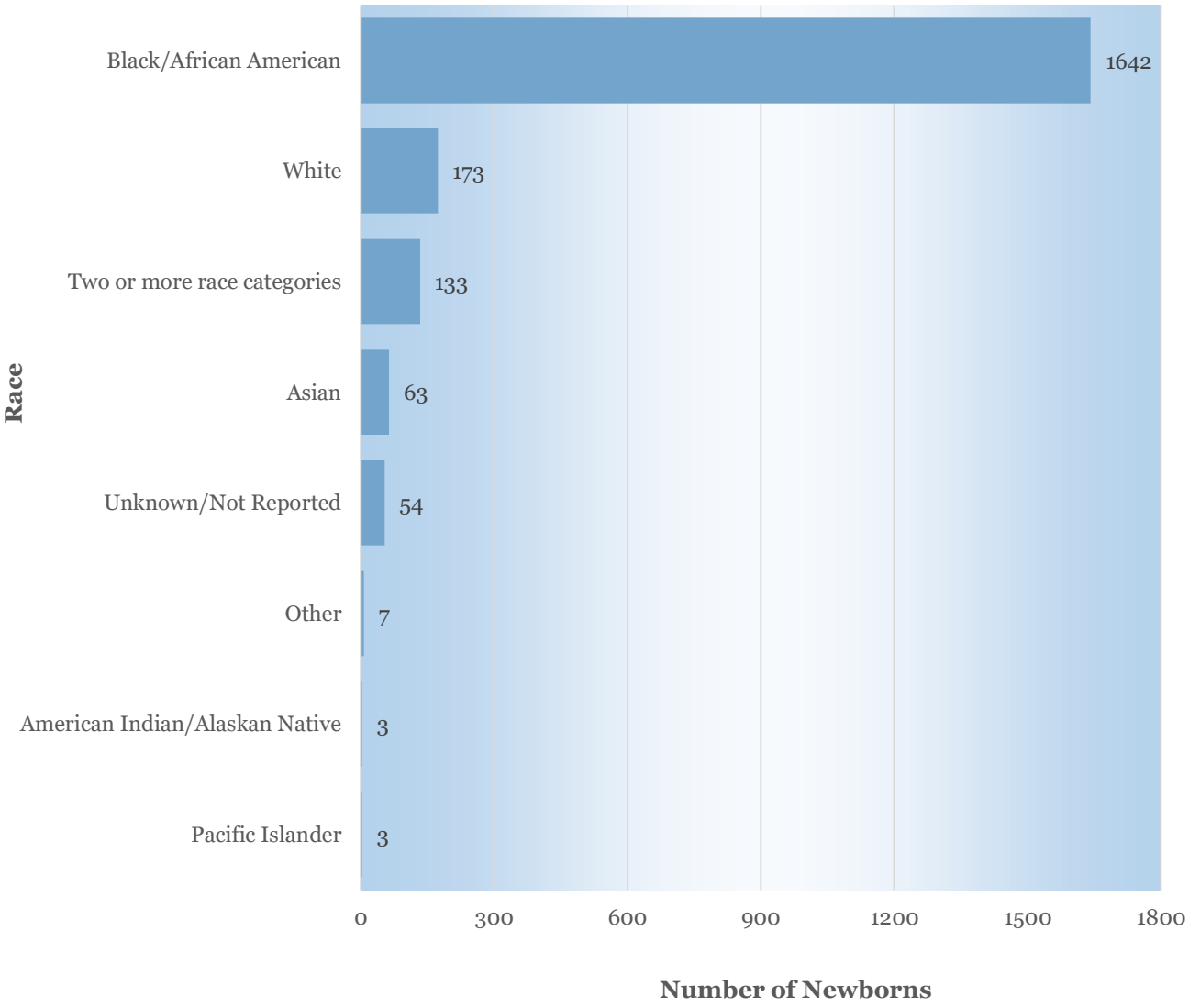
Time from Birth to Diagnosis and Treatment

During SFY 2020, the Regional Sickle Cell Projects received notification of 136 abnormal newborn screening results indicating a disease hemoglobinopathy. Of these, 122 (90%) received confirmatory testing within the first two months of life and 14 (10%) received confirmatory testing after two months.

Newborns with treatable hemoglobinopathies should begin treatment (initiation of penicillin prophylaxis for sickle cell disease is a standard of care) within the first three months of life. Of the 136 newborns with a disease hemoglobinopathy screening result, Regional Sickle Cell Projects reported 91 (67%) newborns receiving treatment within three months of birth and none receiving treatment after three months. There were 42 (31%) newborns who did not receive treatment, either due to being confirmed as carriers or having diseases not requiring treatment. There were two (1%) newborns whose parents declined treatment and one (<1%) who had an unknown treatment status.

Of the newborns tested, 1,642 (79%) identified as Black or African American, 173 (8%) identified as white, and 133 (6%) identified as two or more races. (See Figure 4.)

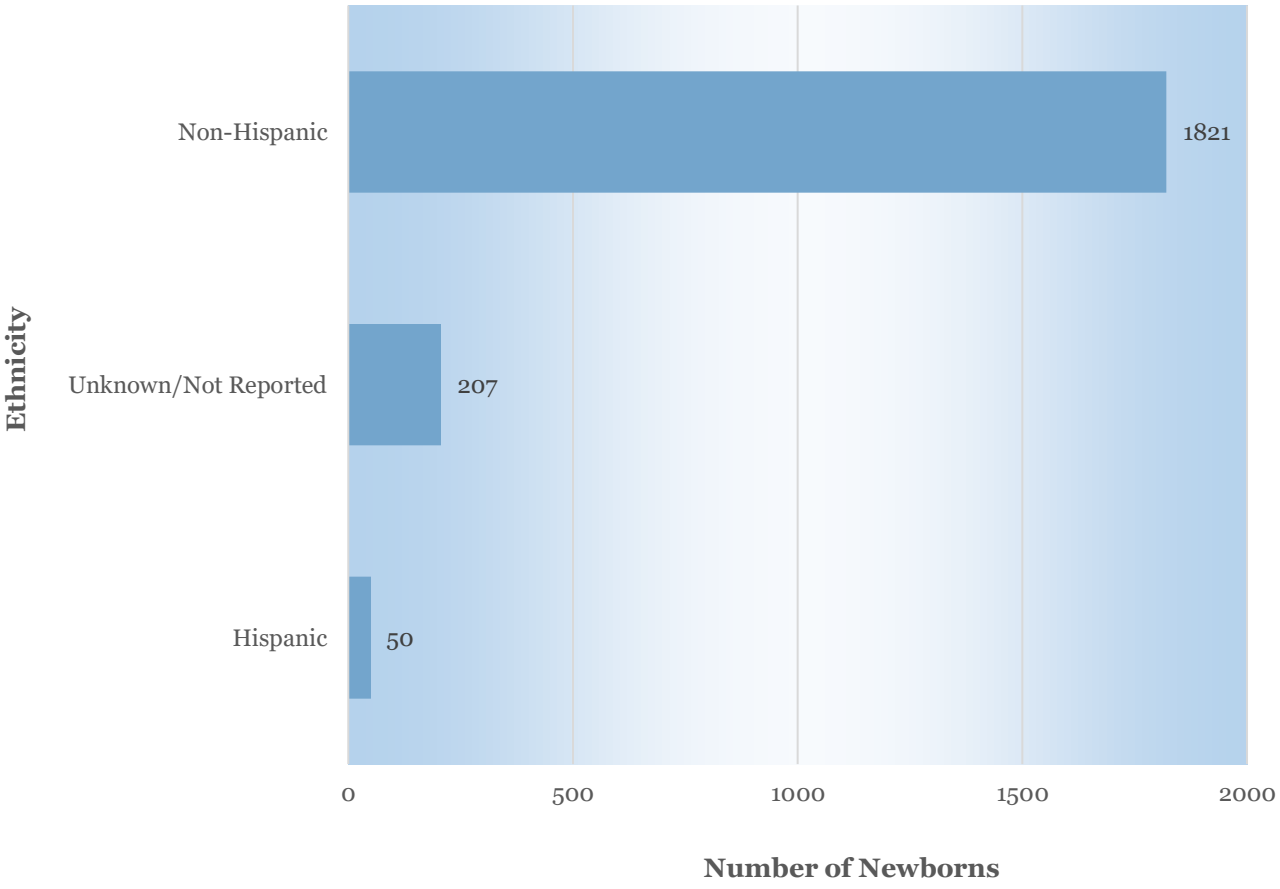
Figure 4. Newborns with Documented Confirmatory Testing by Race (n=2,078)



Source: Minimum Dataset SFY 2020 Table 7.

Of the newborns tested, 1,821 (88%) identified as non-Hispanic, 50 (2%) identified as Hispanic, and 207 (10%) were of unknown ethnicity. This was the first-year ethnicity was reported, and the percentage of newborns with unknown ethnicity status is expected to be lower in future years. (See Figure 5.)

Figure 5. Newborns with Documented Confirmatory Testing by Ethnicity (n=2,078)

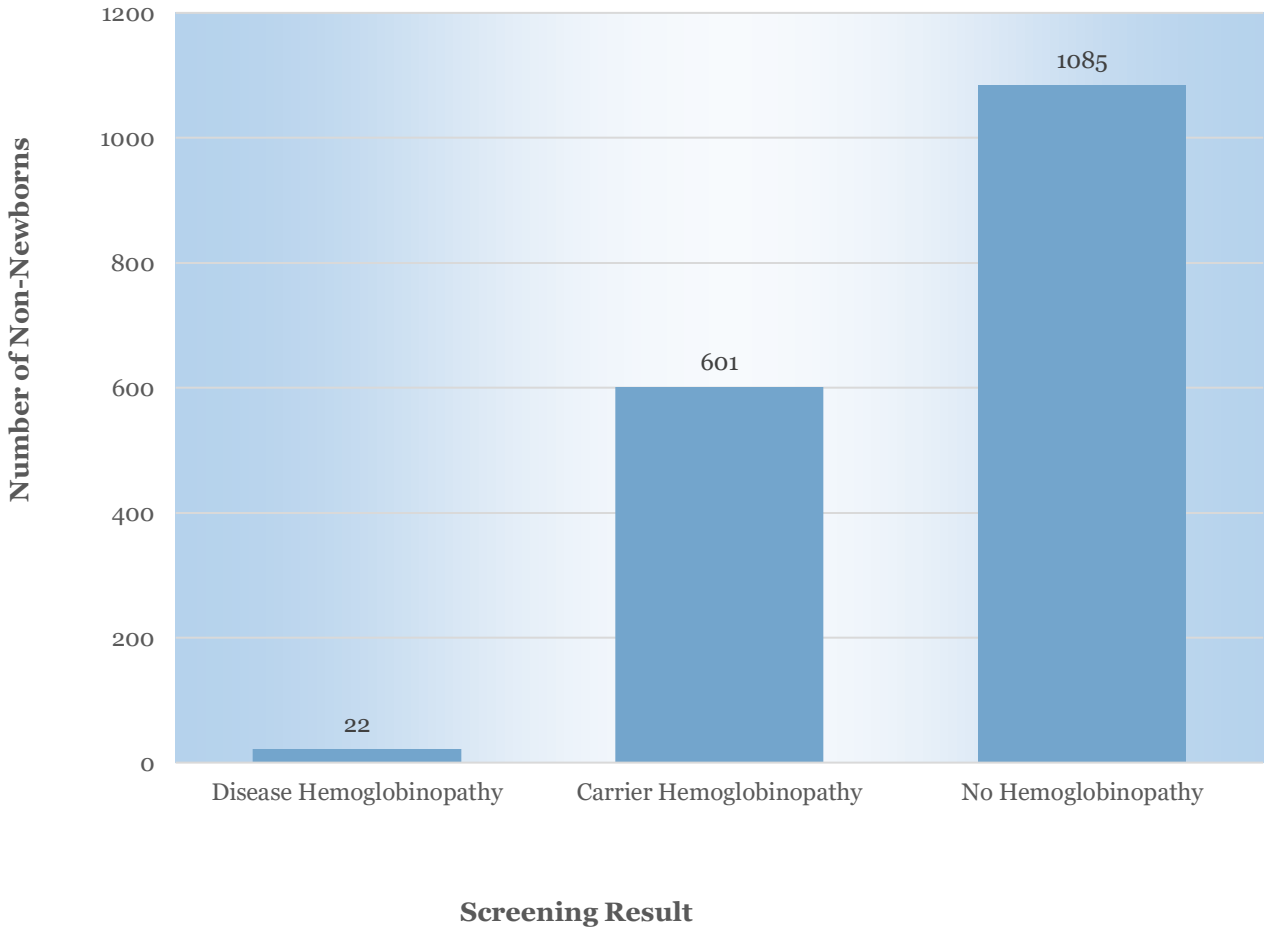


Source: Minimum Dataset SFY 2020 Table 6.

Non-Newborn Hemoglobinopathy Testing

In SFY 2020, 1,708 non-newborns received hemoglobinopathy testing services through a Regional Sickle Cell Project, with 22 (1%) identified with a disease hemoglobinopathy and 601 (35%) identified with a carrier hemoglobinopathy. A total of 1,085 (64%) non-newborns were identified with no hemoglobinopathy. (See Figure 6.)

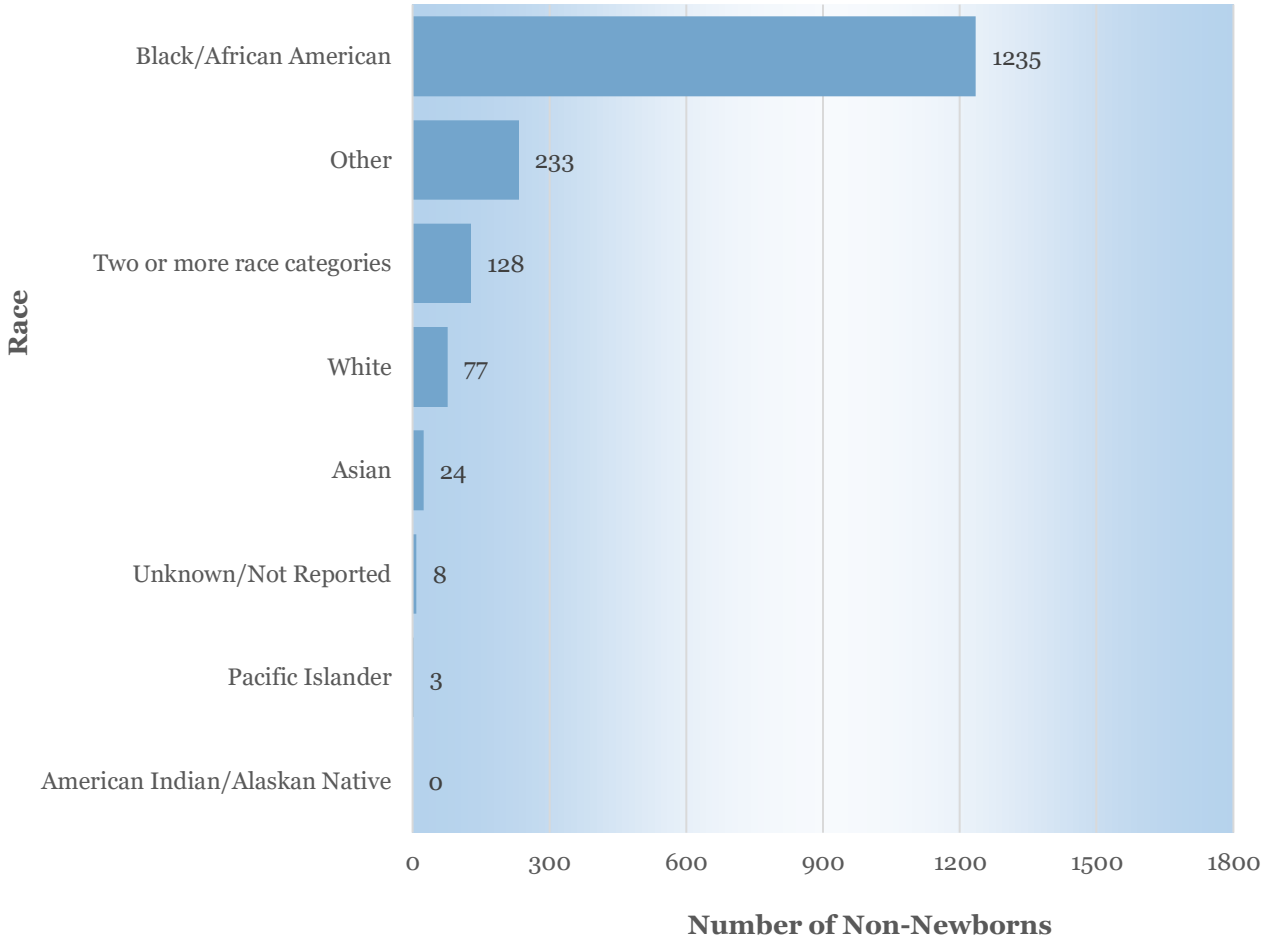
Figure 6. Non-Newborns with Hemoglobinopathy Testing (n=1,708)



Source: Minimum Dataset SFY 2020 Table 9.

Of the non-newborns receiving hemoglobinopathy testing, 1,235 (72%) identified as Black or African American, 128 (7%) were listed as two or more race categories, and 77 (5%) identified as white. (See Figure 7.)

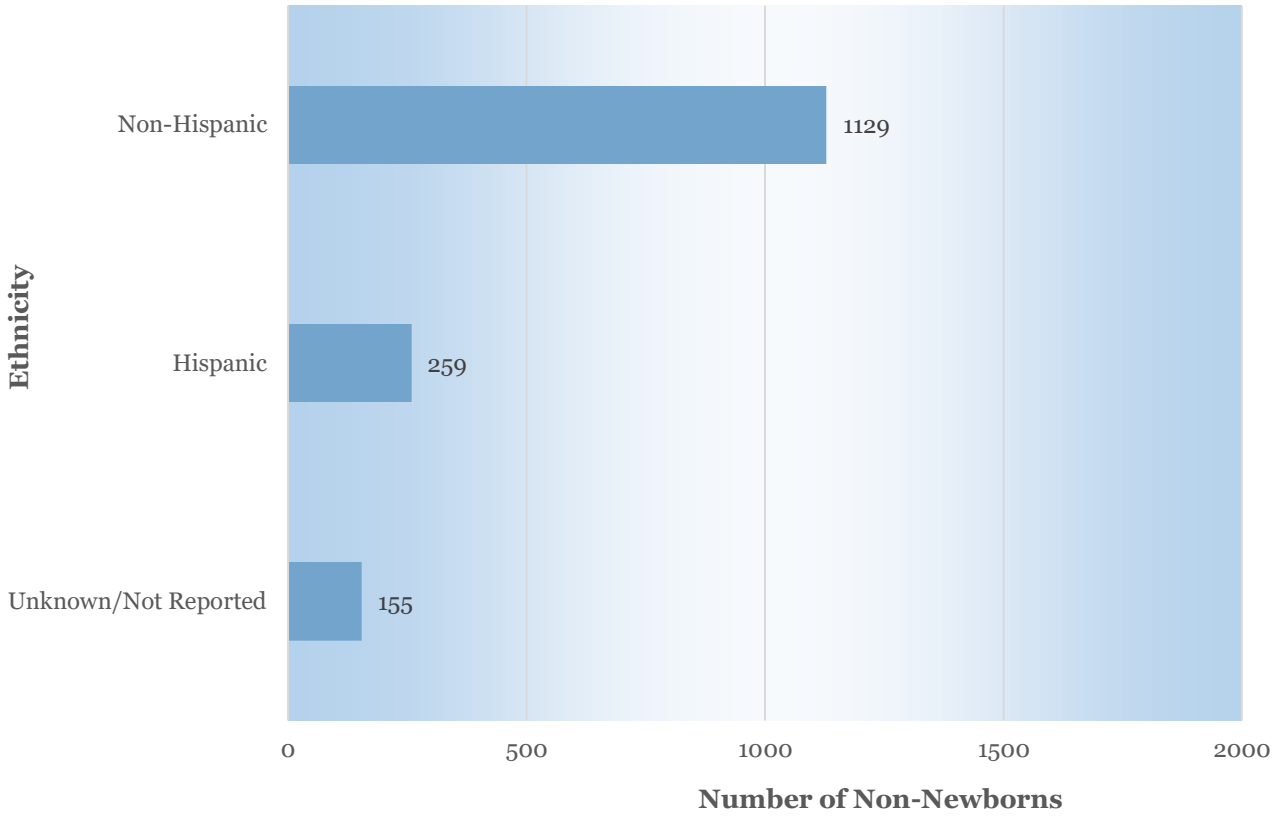
Figure 7. Non-Newborns with Hemoglobinopathy Testing by Race (n=1,708)



Source: Minimum Dataset SFY 2020 Table 13.

Of the non-newborns receiving hemoglobinopathy testing, 1129 (88%) identified as non-Hispanic, 50 (2%) identified as Hispanic, and 207 (10%) were of unknown ethnicity. (See Figure 8.)

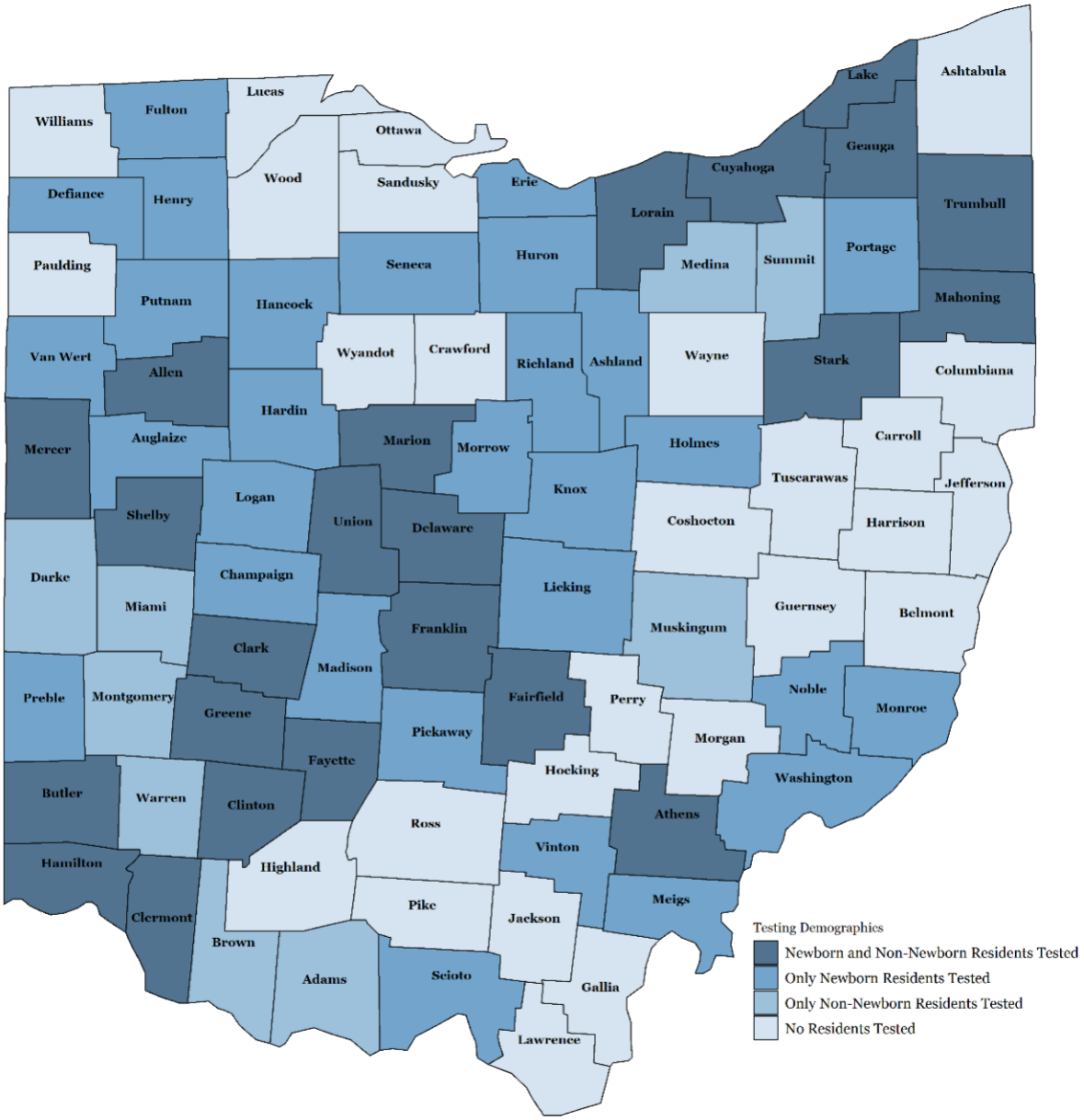
Figure 8. Non-Newborns with Hemoglobinopathy Testing by Ethnicity (n=1,543)



Source: Minimum Dataset SFY 2020 Table 12.

Of those who received hemoglobinopathy testing services, 2,079 (55%) were newborns from 53 counties and 1,708 (45%) were non-newborns from 23 counties. (See Figure 9.) Two tested newborns were listed as out-of-state.

Figure 9. Newborns and Non-Newborns with Hemoglobinopathy Testing by County (n=3,786)



Source: Minimum Dataset SFY 2020 Table 8 and Table 14.

Hemoglobinopathy Counseling

Counseling related to the diagnosis of a hemoglobinopathy is a vital link to the successful implementation of comprehensive, specialized clinical healthcare services. Hemoglobinopathy counseling services[‡‡] provided by the Regional Sickle Cell Projects are offered to the parents and/or family members of all infants identified and confirmed with an abnormal newborn hemoglobinopathy screening result. Counseling is also offered to non-newborns who are self-identified or identified through various referral sources, including physicians and other healthcare providers, community providers, and ODH partner programs.

Children with a diagnosis of sickle cell disease, sickle cell trait, or other hemoglobinopathy confirmed outside of the newborn period are also offered hemoglobinopathy counseling services upon referral and/or request.

In addition, other providers external to the Regional Sickle Cell Projects may choose to counsel parents of newborns with a confirmed abnormal hemoglobin result themselves, and not refer to the Regional Sickle Cell Project.

Newborns

Of the 2,079 newborns born in SFY 2020 who received confirmatory testing, 2,065 (99%) had parents or guardians receive hemoglobinopathy counseling. In association with these newborns, Regional Sickle Cell Projects documented 2,125 parents or guardians who received hemoglobinopathy counseling. There were 13 (1%) confirmed newborns who did not receive counseling due to their parents or guardians declining counseling.

Non-Newborns

Hemoglobinopathy counseling services were provided to 1,708 non-newborns. Of these, 520 (30%) were parents/guardians/family members of non-newborn infants and 434 (25%) were other non-newborns directly tested. All parents and guardians of non-newborns who received testing were subsequently counseled.

[‡‡] In Ohio, Regional Sickle Cell Project staff providing hemoglobinopathy counseling services are required to receive training through an approved Hemoglobinopathy Counselor Training Course.

Hemoglobinopathy Outreach Education

As one of its primary goals, the ODH Sickle Cell Services Program, in partnership with the network of state-funded Regional Sickle Cell Projects and the Statewide Sickle Cell Project, promotes and disseminates information about hemoglobinopathies and related services to healthcare and community professionals, the general public, and at-risk populations.

The implementation and delivery of education services at the local level is of primary importance because of 1) its direct impact on the quality and accessibility of healthcare services for individuals at risk or affected by hemoglobinopathies; and 2) the competency of practitioners involved in these services. Educational services are an integral part of each Regional Sickle Cell Project's objective to reach these targeted audiences.

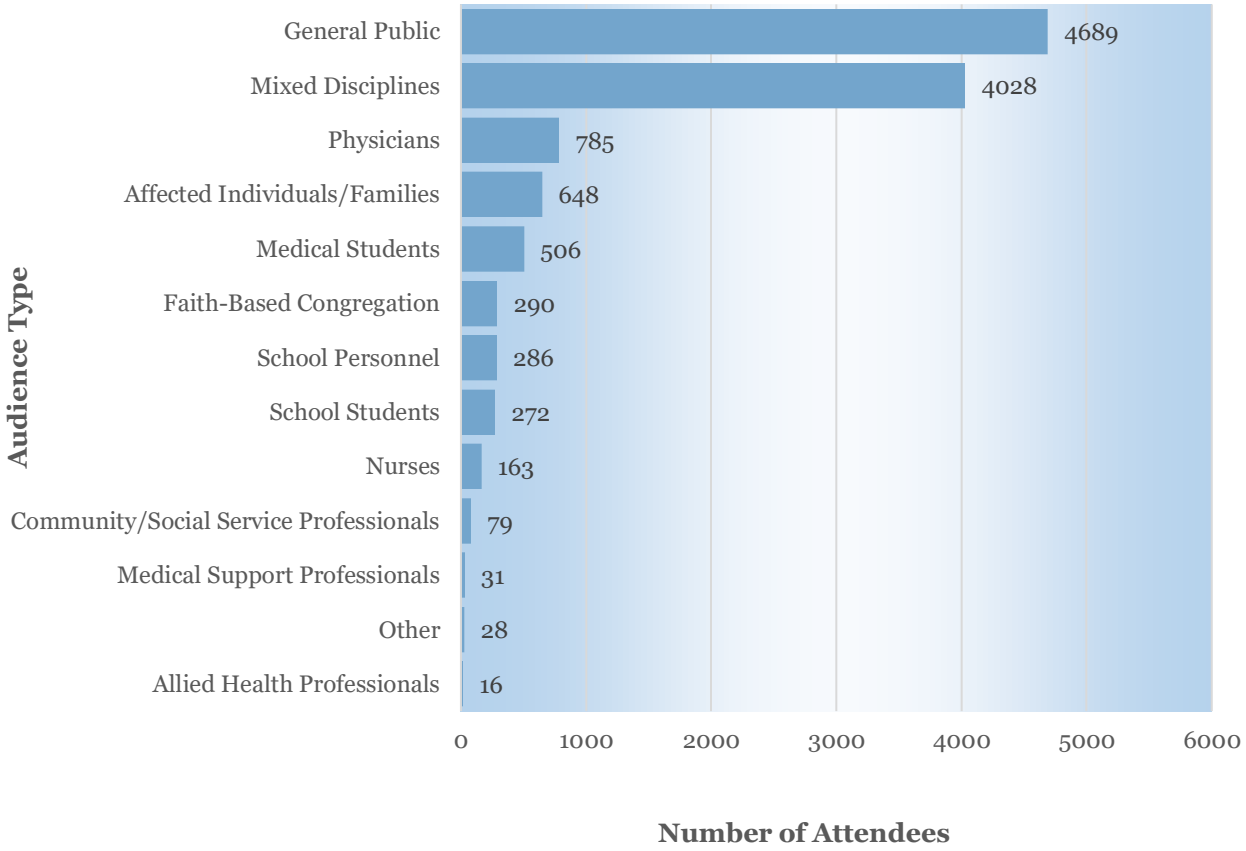
Sickle cell awareness campaigns are another important aspect of professional, patient, and public education designed to reduce the risk and consequence of sickle cell disease and other related hemoglobinopathies. During National Sickle Cell Awareness Month (September) and other select national health observance months (e.g., April/National Minority Health Month; May/Stroke Awareness Month; November/American Diabetes Month), the Regional Sickle Cell Projects and the Statewide Sickle Cell Project carry out awareness activities to:

- Inform the public about sickle cell disease and increase visibility of sickle cell-related services and resources.
- Highlight hemoglobinopathies and their association/link with other health concerns.

Throughout the year, Regional Sickle Cell Projects also engage organizations and stakeholders interested in sickle cell disease to further promote awareness of the disease and educate the public by disseminating current, up-to-date information and key messages, to increase healthy outcomes and reduce sickle cell disease health disparities among various racial, ethnic, and age groups.

During SFY 2020, funded projects conducted a total of 377 education events, which provided education to an estimated 11,821 individuals. (See Figure 10.) The most common attendees of these events were the general public (4,689 people, 40%) followed by 4,028 mixed discipline professionals (34%). The remaining categories each made up less than 10% of the attendees. Audience types listed as other are displayed in Table 2. In total, the projects reported over 795 hours of direct education.

Figure 10. Education Event Attendees by Audience Type (n=11,821)



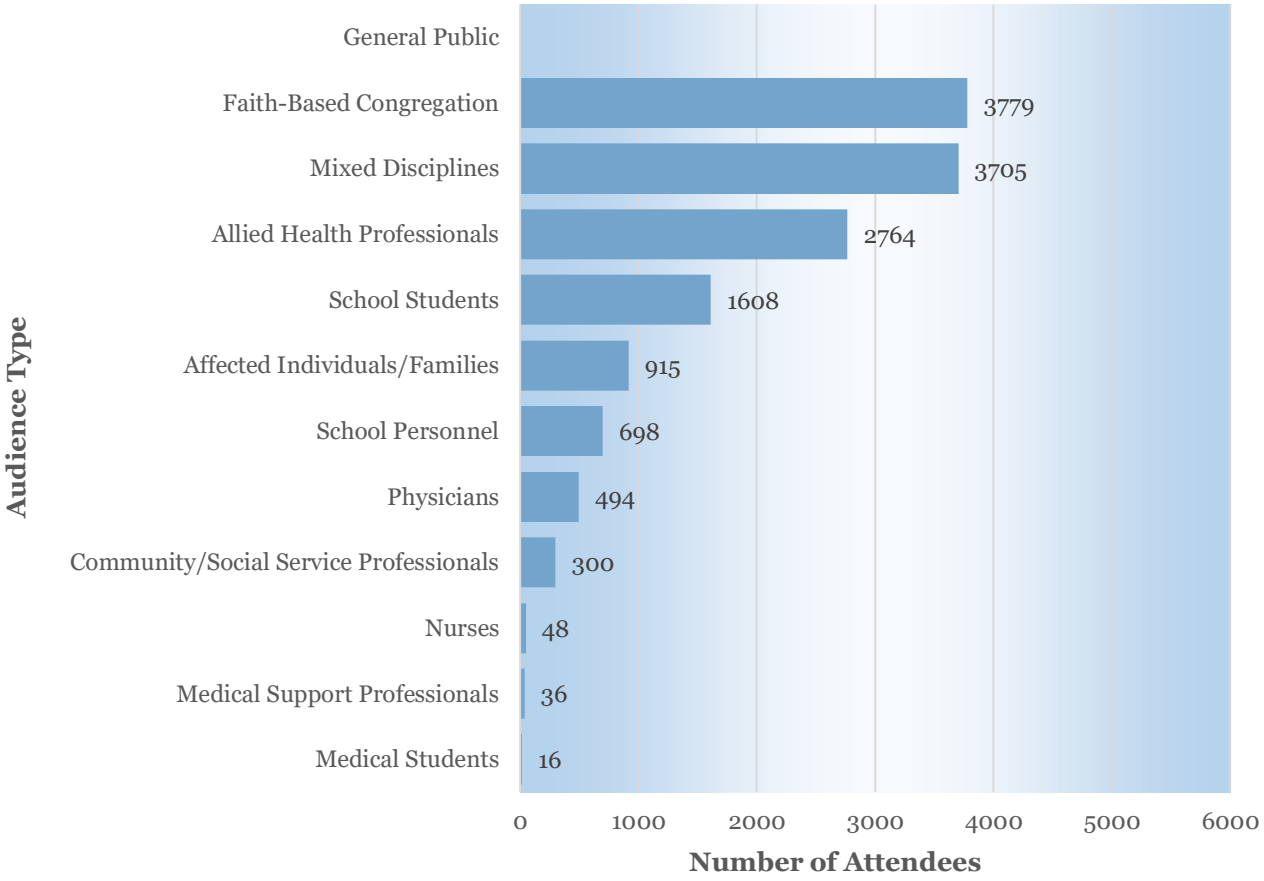
Source: Sickle Cell Projects—Combined Education Event Reporting SFY 2020.

Table 2. Other Education Event Attendees

Other Audience Type	Count
EMTs and Firefighters	25
Public Relations Staff	3

During SFY 2020, funded projects conducted a total of 314 awareness events, which had an estimated reach of 12,097,575** individuals. (See Figure 11.) The general public§§ made up more than 99% (12,085,792) of these individuals. The general public bar was removed from the below graph to better show the relationships between the remaining categories. In total, funded projects reported over 2,011 hours of awareness.

Figure 11. Awareness Events Attendees by Audience Type (n=12,097,575)



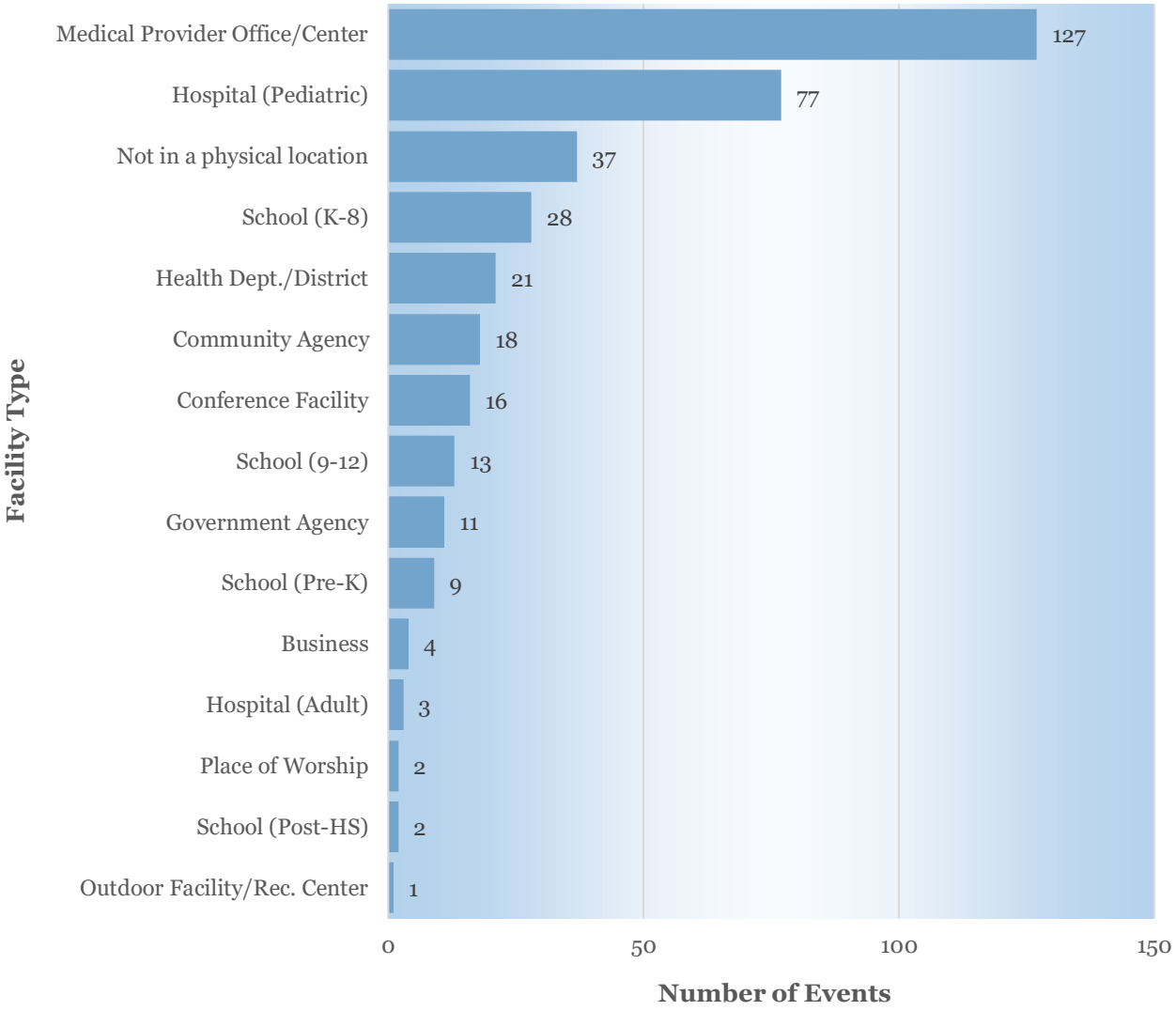
Source: Sickle Cell Projects—Combined Education Event Reporting SFY 2020.

** This number includes all people potentially reached by awareness activities, included social media, radio and television ads, and newsletters.

§§ The general public category is omitted from the figure above to better show the relationship between the remaining reported categories.

Education events took place in a variety of settings. Figure 12 shows the primary facilities for which education events were reported. Medical provider offices held 127 events (34%), pediatric hospitals held 77 events (21%), and 37 events were held online or in other non-physical locations (10%). The remaining facility types each make up less than 10% of the total.

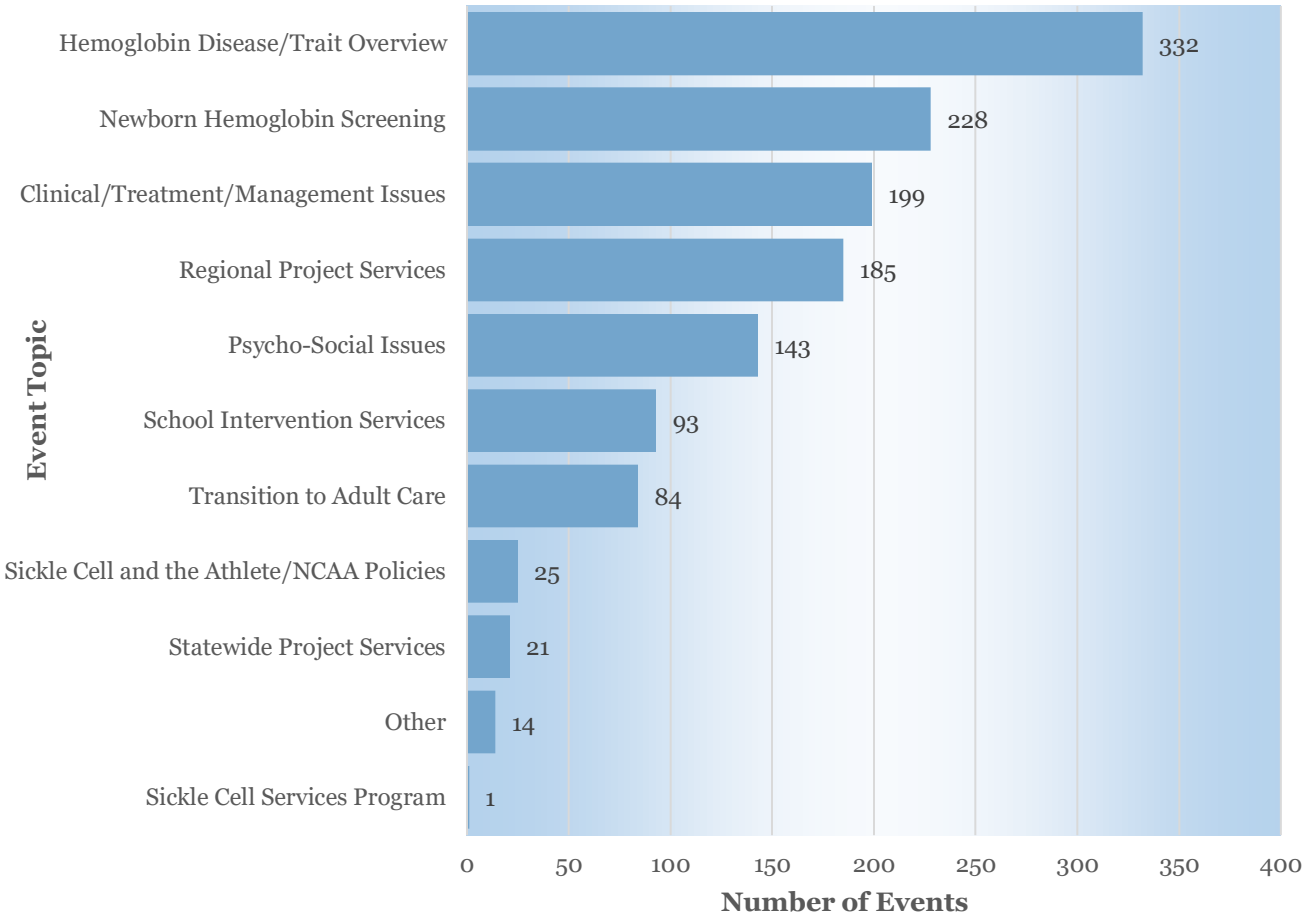
Figure 12. Education Events by Facility Type (n=369)



Source: Sickle Cell Projects—Combined Education Event Reporting SFY 2020.

Education events focused on multiple topics, ranging from information about hemoglobin disease and hemoglobin trait, to treatment and management. Figure 13 shows the primary categories for which education events were reported. General overviews of hemoglobin disease and hemoglobin trait made up 332 events (25%) and newborn screening was covered in 228 events (17%). Table 3 shows the topics specified by those who selected other.

Figure 13. Education Events by Topic (n=1,325)



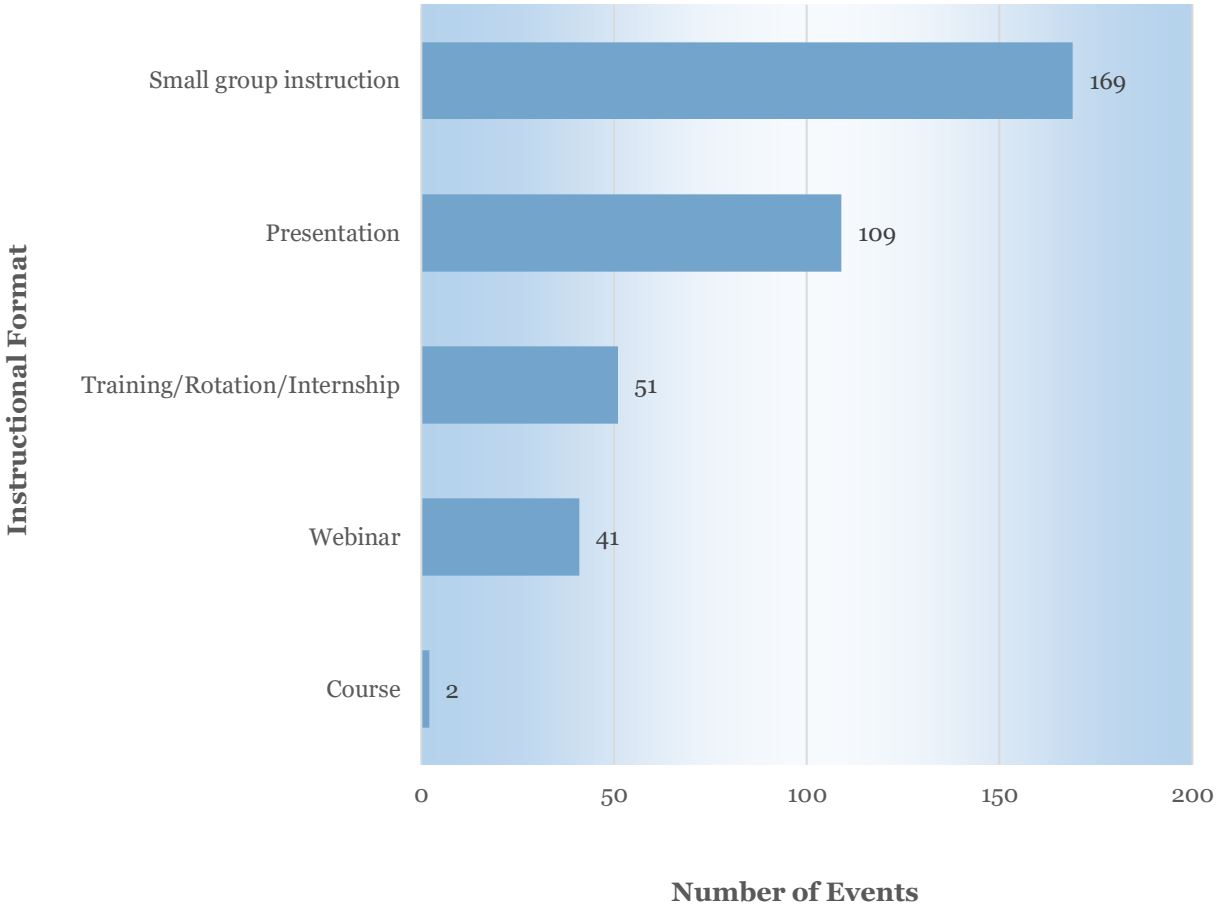
Source: Sickle Cell Projects—Combined Education Event Reporting SFY 2020.

Table 3. Other Education Event Topics

Other Audience Type	Count
Minority Blood Donation and Services	7
COVID-19 and Sickle Cell	5
Health Equity and Sickle Cell	2

Figure 14 shows the instructional format of education events. There were 169 (45%) education events classified as small group instructional sessions, 109 (29%) were classified as presentations, 51 (14%) events were classified as trainings, rotations, or internships, 41 (11%) were classified as webinars, and two (1%) events were classified as courses. All formats were conducted in person, with the sole exception of the webinars.

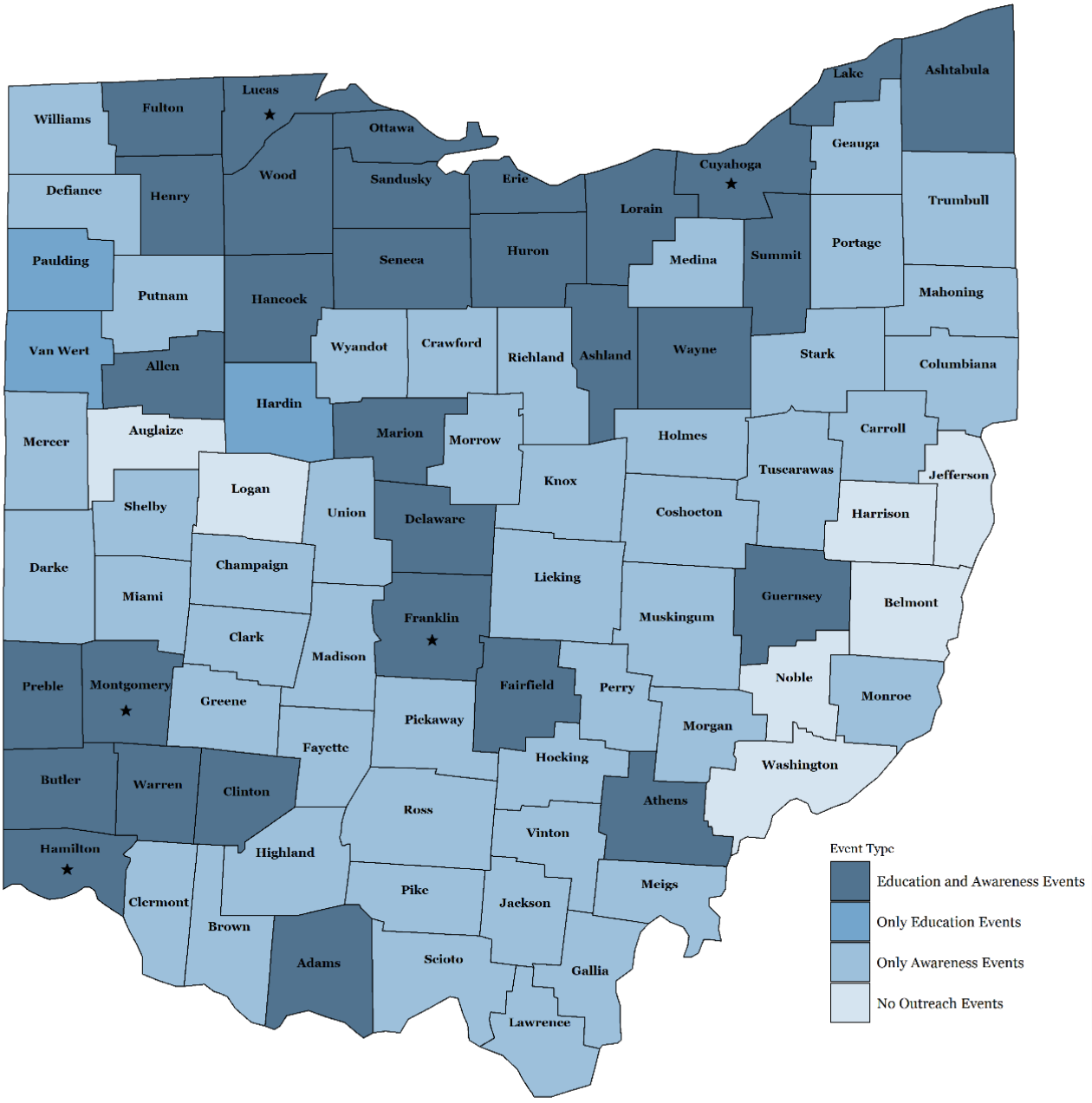
Figure 14. Education Events by Instructional Format (n=372)



Source: Sickle Cell Projects—Combined Education Event Reporting SFY 2020.

Education events took place in 34 Ohio counties and awareness events took place in 78 Ohio counties. (See Figure 15.) This included the five counties with the highest proportion of African American residents (Cuyahoga, Hamilton, Franklin, Montgomery, and Lucas counties).[4] Forty-one education events were web-based and may have affected more than their target county. Awareness events often reached people in several counties (e.g., radio) and the events held impacted 81 counties.

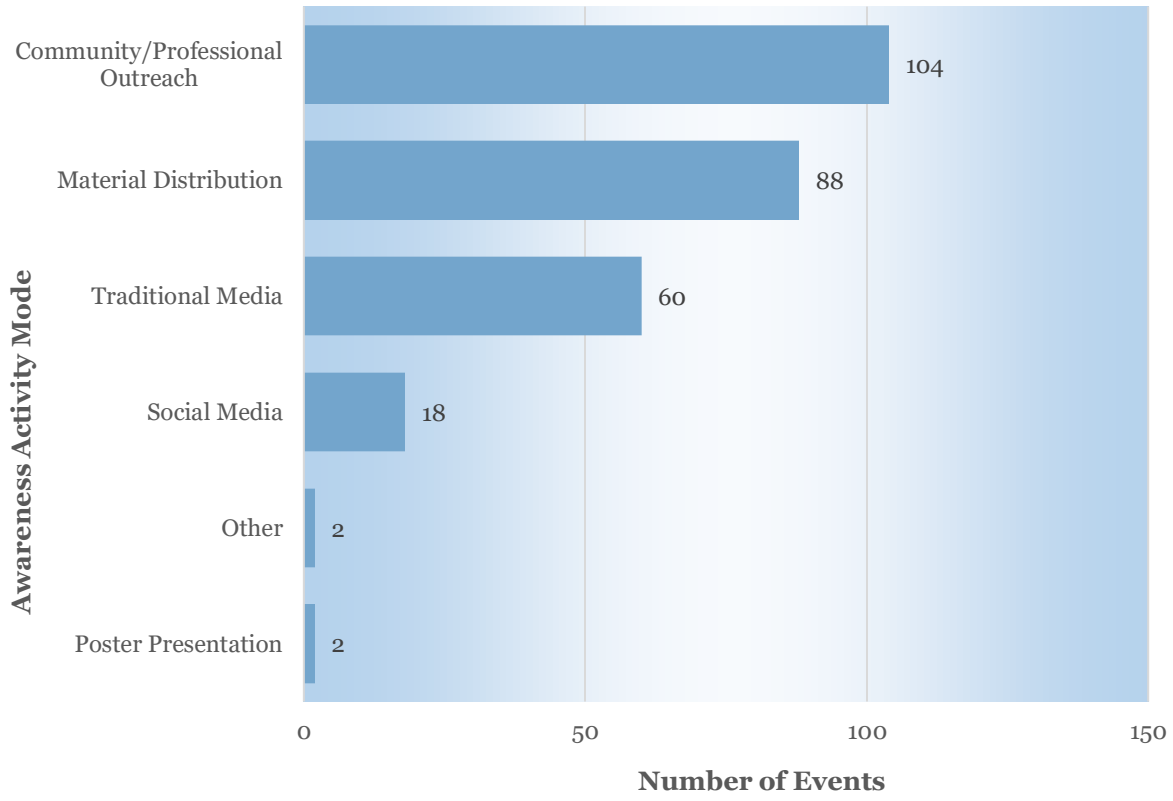
Figure 15. Education and Awareness Events by County (n=1,082)



Source: Sickle Cell Projects Combined Education Event Report SFY 2020.

The Regional Sickle Cell Projects conducted 274 awareness activities during SFY 2020. These activities were estimated to have made 12,097,575 [***]contacts through a variety of modes. In Figure 16, the 104 (38%) community or professional outreach events included community walks, health fairs, exhibits, and blood and bone marrow drives. There were 88 (32%) material distribution events. Traditional media engagement (60 activities, 22%) included newspaper, television, radio, and electronic newsletter activities. Social media engagement (18 events, 7%) included Facebook, Twitter, and Instagram. Table 4 includes a breakdown of the events that were included in the other category.

Figure 16. Awareness Activity by Mode (n=274)



Source: Sickle Cell Projects—Combined Education Event Reporting SFY 2020.

Table 4. Other Awareness Event Modes

Other Awareness Mode	Count
Education Event for Patients and Family Members	2

[***] This number includes all people potentially reached by awareness activities, included social media, radio and television ads, and newsletters.

References

Dedication

1. Wilkie, D.J., Johnson, B., Mack, A.K., Labotka, R., & Molokie, R.E. (2010). Sickle cell disease: an opportunity for palliative care across the life span. *The Nursing Clinics of North America, 45*(3), 375–397. https://pubmed.ncbi.nlm.nih.gov/20804884/

Newborn Hemoglobinopathy Screening

2. Kladny, B., Gettig, E.A., & Krishnamurti, L. (2005). Systematic follow-up and case management of the abnormal newborn screen can improve acceptance of genetic counseling for sickle cell and other hemoglobinopathy trait. *Genetics in Medicine*, *7*(2), 139–142. https://doi.org/10.1097/01.GIM.0000153662.88425.68

3. National Heart, Lung, and Blood Institute. (2020 July). *Sickle cell disease*. NHLBI. https://www.nhlbi.nih.gov/health-topics/sickle-cell-disease

Hemoglobinopathy Outreach Education

4. US-Places. (n.d.). *Ohio population by county—percentage of Black residents*. US-Places. https://us-places.com/Ohio/black-percentage-population-comparison.htm

Sickle Cell Facts

5. Center for Disease Control and Prevention. (2019). *What is Sickle Cell Trait?* CDC. https://www.cdc.gov/ncbddd/sicklecell/traits.html.

6. Centers for Disease Control and Prevention. (2019). *Data & statistics on sickle cell disease*. CDC. https://www.cdc.gov/ncbddd/sicklecell/data.html

7. American Society of Hematology. (2016). *State of sickle cell disease: 2016 report*, p. 4. http://www.scdcoalition.org/pdfs/ASH%20State%20of%20Sickle%20Cell%20Disease%202016%20Report.pdf

8. Ibid, p. 2.

APPENDICES

Appendix A: Sickle Cell Facts

Sickle cell disease is a term used to describe a group of inherited disorders characterized by the predominance of hemoglobin-S in the red blood cell. These inherited disorders include:

- Sickle cell anemia (HbSS)
  People who have this form of SCD inherit a gene for sickle hemoglobin (HbS) from each parent. HbSS is the most common type of SCD and is usually the most severe form of the disease.

- Hemoglobin sickle C disease (HbSC)
  People who have this form of SCD inherit a gene for HbS from one parent and from the other parent, a gene for an abnormal hemoglobin called "C". Hemoglobin is a protein that allows red blood cells to carry oxygen to all parts of the body. HbSC is usually a milder form of SCD.

- Hemoglobin sickle beta (β) thalassemia syndromes (HbSβ$^+$and HbSβ$^\circ$-thalassemia)
  People who have this form of SCD inherit one gene for HbS from one parent and one gene for β thalassemia, another type of anemia, from the other parent. There are two types of β thalassemia: HbSβ$^+$-thalassemia and HbSβ$^\circ$-thalassemia. Those with HbSβ$^\circ$-thalassemia usually have a clinical course similar to HbSS. People with HbSβ$^+$-thalassemia tend to have a milder form of SCD.

- Hemoglobin SD, hemoglobin SE, and hemoglobin SO (HbSD, HbSE and HbSO)
  People who have these rare forms of SCD inherit one gene for HbS and one gene from an abnormal type of hemoglobin ("D," "E," or "O"). The severity of these rarer types of SCD varies.

Sickle Cell Trait is the carrier state in which a person inherits one gene for HbS from one parent and one normal gene ("A") from the other parent. Most people with SCT usually do not have any of the symptoms of SCD[†††] but can pass the trait on to their children.

According to the Centers for Disease Control and Prevention, the exact number of people living with SCD is unknown. In the United States, it is estimated that:

- SCD affects approximately 100,00 Americans.
- SCD occurs among about 1 out of 365 Black or African American births.

[†††] While most people with SCT do not have any symptoms of SCD—in rare cases—people with SCT might experience complications of SCD, such as pain crises and, in extreme circumstances, sudden death. In their extreme form, and in rare cases, the following conditions could be harmful for people with SCT: increased pressure in the atmosphere, low oxygen levels in the air, dehydration, and high altitudes.[5]

- SCD occurs among about 1 out of every 16,300 Hispanic American births.
- About 1 in 13 Black or African American babies are born with SCT.[6]

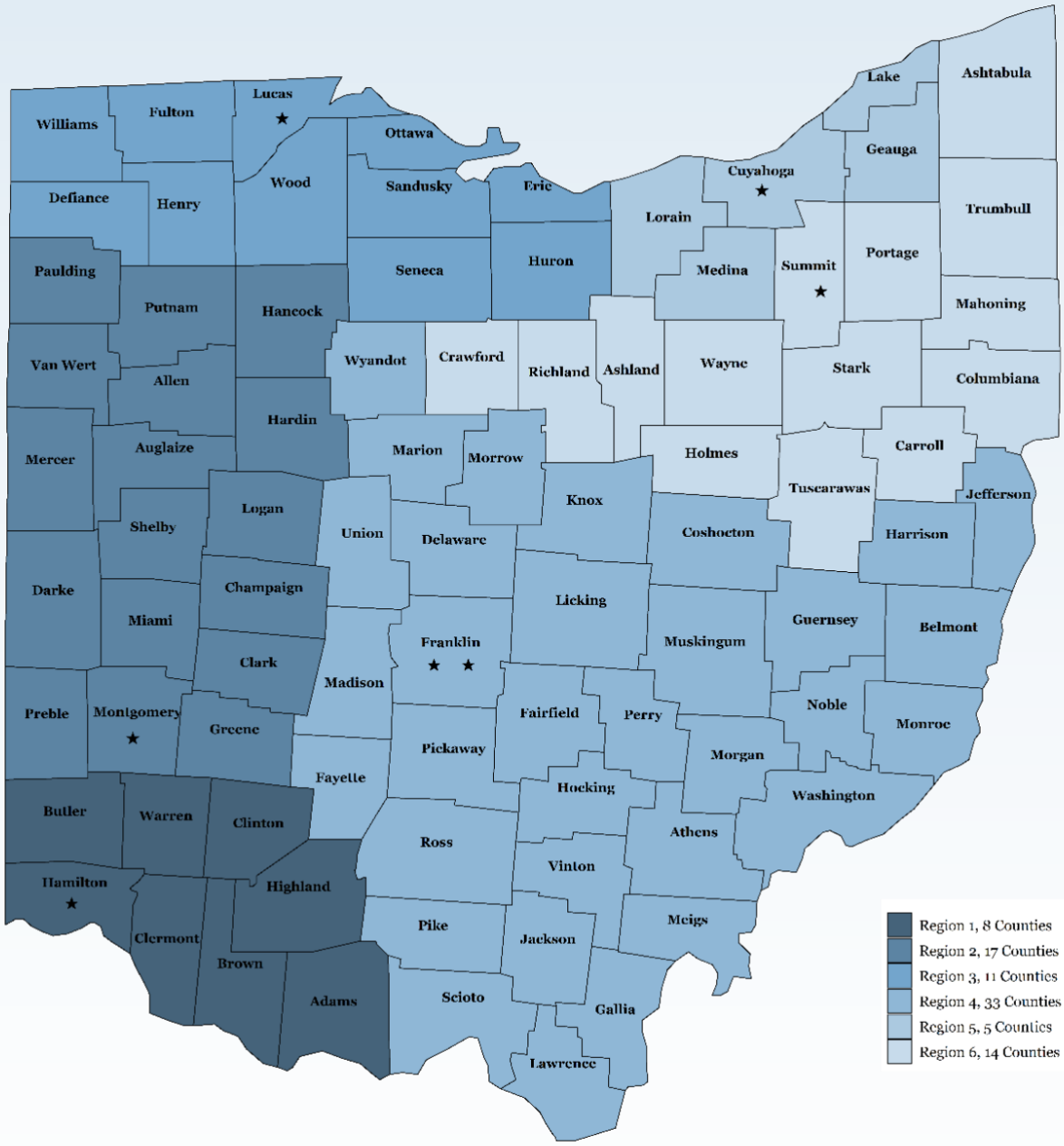
Sickle cell disease is one of the most commonly inherited diseases worldwide. While most predominant among Blacks or African Americans in the U.S., individuals with heritage from sub-Saharan Africa; Spanish-speaking regions in the Western Hemisphere (South America, the Caribbean, and Central America); Saudi Arabia; India and Mediterranean countries such as Turkey, Greece and Italy may also be affected. Globally, it is estimated that:

- SCD occurs in approximately 300,000 births annually.
- SCD is most prevalent in malaria endemic parts of the world, primarily Africa, the Middle East, and South Asia.
- In many African countries 10% to 40% of the population carries the sickle-cell gene, resulting in an estimated SCD prevalence of at least 2%.[7]

Sickle cell disease, which causes a wide range of severe and even life-threatening consequences, is caused by a mutation in the DNA instructions for hemoglobin, a protein vital for carrying oxygen in the red blood. As a result of this mutation, individuals with SCD experience life-long complications including anemia, infections, stroke, tissue damage, organ, intense painful episodes, and premature death. These debilitating symptoms and the complex treatment needs of individuals living with SCD often limit their education, career opportunities, and quality of life.[8]

Currently, there is no universal cure for sickle cell disease.

Appendix B: Sickle Cell Project Map‡‡‡



‡‡‡ The stars on the map represent the locations of the state-funded sickle cell projects. The two stars in Franklin County represent the location of both the Region IV Sickle Cell Project and the Statewide Family Support Project.

Appendix C: Sickle Cell Project Profile - Region I

Cincinnati Comprehensive Sickle Cell Center
Cincinnati Children's Hospital Medical Center
3333 Burnet Ave., MLC 7015
Cincinnati, OH 45229
513-636-7541
https://www.cincinnatichildrens.org/service/s/sickle-cell

Region I Counties:
Adams, Brown, Butler, Clermont, Clinton, Hamilton, Highland, Warren

ODH SFY 2020 Funding Allocation: $125,957

Standard Services:

- Newborn screening coordination, counseling, and education.
- Outreach education and training for healthcare professionals and the public.
- Care coordination for pediatric patients diagnosed with sickle cell disease.
- Regional center for hemoglobinopathy educational materials.
- Sickle Cell Sabbath/Sunday and Sickle Cell Month (September) educational activities.

Expanded Services and Programs:

- Annual newsletter for regional healthcare providers.

Non-Grant Supported Services and Programs (provided through the Comprehensive Sickle Cell Center at Cincinnati Children's Hospital Medical Center):

- Comprehensive sickle cell clinic for pediatric patients, including social work and school intervention program.
- Tailored educational and support programs for individuals/families with sickle cell disease.
- Extensive clinical research studies for individuals/families with sickle cell disease.
- Transition to adult care program with University of Cincinnati Adult Sickle Cell Clinic.
- Quality improvement outcomes projects for sickle cell disease, including a regional eight-state, ten-site learning network (Sickle Treatment Outcomes Research in the Midwest – STORM).
- Healthcare provider education programs, including the annual National Hemoglobinopathy Counselor Training Course and STORM's monthly Project ECHO and Health Equity ECHO.
- Training/rotation in hemoglobin disorders.

Project Director: Lisa Shook, DHPE, MCHES
Medical Director: Charles Quinn, MD

Appendix D: Sickle Cell Project Profile - Region II

West Central Ohio Comprehensive Sickle Cell Center
Dayton Children's Hospital
One Children's Plaza
Dayton, OH 45404
937-641-3111or 1-800-228-4055, ext. 5014
https://www.childrensdayton.org/patients-visitors/services/hematology-oncology/sickle-cell-disease

Region II Counties:
Allen, Auglaize, Champaign, Clark, Darke, Greene, Hancock, Hardin, Logan, Mercer, Miami, Montgomery, Paulding, Preble, Putnam, Shelby, Van Wert

ODH SFY 2020 Funding Allocation: $72,932

Standard Services:

- Newborn screening coordination and follow-up.
- Hemoglobinopathy counseling and education.
- Care coordination and specialty resource referrals.
- Community education and outreach.
- Regional resource clearinghouse of educational materials.
- Sickle Cell Sabbath/Sunday and Sickle Cell Month (September) activities.

Expanded Services and Programs:

- Patient and family disease education.
- School intervention program (inpatient tutoring).
- Patient assistance program (help with utilities, medications, rent, etc.).
- Special family events/activities (e.g., Family Day, Flying Horse Farms Summer Camp).
- Sickle Cell Advisory Committee (external committee).
- Satellite clinics at Specialty Care Center – Lima (St. Rita Eastside Urgent Care Center, 967 Bellefontaine Ave., Lima) and South Campus – Springboro (3333 W. Tech Road, Miamisburg).

Non-Grant Supported Services and Programs (provided through the Hematology/Oncology Department at Dayton Children's Hospital):

- Diagnostic evaluation, treatment, and management services for patients' birth to 22 years of age.
- Consultation, collaboration, and transition to adult healthcare systems and providers.
- Professional training/rotation/internship in hemoglobin disorders.
- Specialty Services: Social Work, Psychology, Nutrition, Child Life, Genetic Counseling, Hematology/Oncology Clinical Pharmacist.
- Free hemoglobin testing for adults of child-bearing age (available upon funding).

Project Director: Cynthia L. Moon, MSEd
Medical Director: Mukund Dole, MD

Appendix E: Sickle Cell Project Profile - Region III

Sickle Cell Project of Northwest Ohio
Neighborhood Health Association of Toledo, Inc.
313 Jefferson Ave. (mailing address)
Toledo, OH 43604

Nexus Health Care
1415 Jefferson Ave. (location address)
Toledo, OH 43604
419-214-5700, ext. 5028
http://nhainc.org/sickle-cell-project-nwo

Region III Counties:
Defiance, Erie, Fulton, Henry, Huron, Lucas, Ottawa, Sandusky, Seneca, Williams, Wood

ODH SFY 2020 Funding Allocation: $54,743

Standard Services:
- Newborn screening coordination and follow-up services.
- Hemoglobinopathy counseling (off-site locations at Toledo Children's Hospital and Mercy Children's Hospital).
- Education, outreach, and awareness activities for professional/public/community audiences.
- Regional resource center for hemoglobinopathy educational materials.
- Sickle Cell Sabbath/Sunday and Sickle Cell Month (September) activities.

Expanded Services and Programs:
- Patient Services/Programs: Patient/family disease education, school outreach and interventions, genetic counseling (in collaboration/referral to the University of Toledo Division of Genetics).
- Sickle Cell Awareness of Toledo Support Group.
- External Advisory Committees (Brightside Policy Council and Health Advisory Committee, Toledo-Lucas Minority Health Committee, Mental Health Diversity Inclusion Advisory Committee, National Association for the Advancement of Colored People (NAACP), Getting to 1 Coalition).

Non-Grant Supported Services and Programs (provided through Nexus and External Partners):
- On-site services: primary and pediatric medical care for uninsured and underinsured populations, social work services, pharmacy, laboratory, WIC, and dental services.
- Neighborhood Health Association Facebook Page: https://www.facebook.com/NHAToledo/.
- Research study (in collaboration with Toledo Children's Hospital and Mercy Children's Hospital Hematology/Oncology departments).
- Certified Community Health Worker (CHW) Program (in affiliation with SCDAA).
- Community engagement activities (in collaboration with OSCHA).

Project Director: La'Shardae Scott, MSW, CHW, CHES
Medical Advisors: Crawford Strunk, MD (Toledo Children's Hospital) and Melisa Mullins, MD (Mercy Children's Hospital)

Appendix F: Sickle Cell Project Profile - Region IV

Comprehensive Sickle Cell and Thalassemia Program
Nationwide Children's Hospital
700 Children's Drive
Columbus, OH 43205
614-722-5948
http://www.nationwidechildrens.org/sickle-cell-and-thalassemia-program

Region IV Counties:
Athens, Belmont, Coshocton, Delaware, Fairfield, Fayette, Franklin, Gallia, Guernsey, Harrison, Hocking, Jackson, Jefferson, Knox, Lawrence, Licking, Madison, Marion, Meigs, Monroe, Morgan, Morrow, Muskingum, Noble, Perry, Pickaway, Pike, Ross, Scioto, Union, Vinton, Washington, Wyandot

ODH SFY 2020 Funding Allocation: $171,595

Standard Services:
- Newborn screening coordination and follow-up services.
- Hemoglobinopathy counseling.
- Hemoglobinopathy education, outreach, and awareness activities.
- Sickle Cell Sabbath/Sunday and Sickle Cell Month (September) activities.

Expanded Services and Programs:
- School/daycare intervention program.
- Patient/family disease education.
- Blood/bone marrow donor education and registry drives.
- Nursing education.
- Transition to adult care.
- Satellite clinic at Nationwide Children's – Close to Home with Urgent Care Center (6435 E. Broad St., Columbus).

Non-Gant Supported Services and Programs (provided through the Hematology/Oncology/BMT Division at Nationwide Children's):
- Infusion services.
- Confirmatory testing for abnormal newborn screening hemoglobin results.
- Comprehensive medical management and follow-up for hemoglobin disease.
- Specialty Services: Genetic counseling, extended family testing, case management, dental evaluations, psychological testing, evaluations, and clinical research trials.
- Apheresis Program.
- Student training.

Project Director: Tanica Jeffries, MS, LPC, LSW
Medical Director: Anthony Villella, MD

Appendix G: Sickle Cell Project Profile - Region V

American Sickle Cell Anemia Association
10900 Carnegie Ave.
DD Building, Suite DD1-201
Cleveland, OH 44106
216-229-8600
https://www.ascaa.org

Region V Counties:
Cuyahoga, Geauga, Lake, Lorain, Medina

ODH SFY 2020 Funding Allocation: $188,164

Standard Services:

- Newborn screening follow-up and diagnostic testing.
- Hemoglobinopathy counseling and education (additional on-site counseling locations at the Cleveland Clinic, Metro Health Hospital, McCafferty Health Center, J. Glenn Health Center, Miles/Broadway Health Center, Lorain City Health Center, Lake County Health Department, Medina County Health Department, MetroHealth Center Ohio City, Elyria Health Department and Geauga Health Department).
- Resource Center for hemoglobinopathy education materials.
- Collaborative relationships with Region V hospitals.
- Hispanic community direct services and outreach.
- Sickle Cell Sabbath/Sunday and Sickle Cell Month (September) activities.

Expanded Services and Programs:

- Social Media: Website, Facebook, Twitter, YouTube, and Instagram.
- School/home intervention program.
- Supportive services/crisis intervention/community referrals.
- Global/international education and referral initiative.

Non-Grant Supported Services and Programs (provided through the American Sickle Cell Anemia Association):

- On-site diagnostic hemoglobin testing (in association with the Cleveland Clinic).
- Community Service and Internship Programs: National Black Caucus Senior Community Service Program, Cleveland Clinic Summer Internship Program for High School Students, and Bryant & Stratton Pre-Graduate Internship Program.
- Cleveland Clinic resident physician rotation program.
- Special Events: Annual Culinary Sickle Cell Event, Firefighters Bucket Drive for "Sickle Cell" and Sickle Cell Christmas Holiday Event.

Project Director: Ira Bragg-Grant, LSW
Medical Advisor: Grace Onimoe, MD (MetroHealth Hospital)

Appendix H: Sickle Cell Project Profile - Region VI

Ohio Region VI Sickle Cell Program
Akron Children's Hospital
One Perkins Square
Akron, OH 44306
330-543-8580 or 800-262-0333, ext. 8730
https://www.akronchildrens.org/departments/Sickle-Cell-Program.html

Region VI Counties:
Ashland, Ashtabula, Carroll, Columbiana, Crawford, Holmes, Portage, Mahoning, Richland, Stark, Summit, Trumbull, Tuscarawas, Wayne

ODH SFY 2020 Funding Allocation: $96,609

Standard Services and Programs:

- Newborn screening coordination and follow-up.
- Patient and family advocacy.
- Hemoglobinopathy counseling and patient/family education.
- Resource Center for audiovisual and print materials regarding hemoglobinopathies.
- Physician communication on newborn screening and follow-up standards and practices.
- Hemoglobinopathy education, outreach, and awareness activities for health care professionals/providers, consumers, and the public.
- Sickle Cell Sabbath/Sunday and Sickle Cell Awareness Month (September) activities.

Expanded Services and Programs:

- Patient Services/Programs: School intervention services, patient and family disease education, monthly parent/patient support group meetings, adolescent transition program.
- Holiday events for patients and their families.
- Annual sickle cell awareness walk.
- Annual weekend summer camp (Camp Ed Bear for patients age 6-16 and Counselor in Training Program for patients age 16-21).

Non-Grant Supported Services and Programs (provided through the Showers Family Center for Childhood Cancer and Blood Disorders at Akron Children's Hospital):

- Monthly comprehensive clinics for sickle cell disease patients (with incorporated genetic, psychosocial counseling, nutrition, physical therapy, and radiology services).
- Confirmatory testing for abnormal newborn screening hemoglobin results.
- Individual testing hematological consultation and diagnostic testing.
- Hematology/Oncology Quarterly Newsletter.

Project Director: LaTonya Lewis
Medical Director: Prasad Bodas, MD

Appendix I: Sickle Cell Project Profile - Statewide

Ohio Sickle Cell and Health Association, Inc (OSCHA)
341 South Third St.
Suite 200
Columbus, OH 43215
614-228-0157
http://www.ohiosicklecell.org

Counties:
Statewide-88 Ohio Counties

ODH SFY 2020 Funding Allocation: $90,000

Standard Services and Programs:

- Consumer education, empowerment, support, and outreach resources.
- Professional education and training.
- Statewide public awareness and media campaigns.
- Sickle Cell Month (September) and Sickle Cell Sabbath/Sunday activities.

Expanded Services and Programs:

- Administrator of the Empowerment Scholarship Fund for educational events.
- Advisory organization to the Ohio Sickle Cell Affected Families Association and Ohio certified sickle cell foundations/organizations.
- Blood and bone marrow drives.
- Consumer case management and physician referral; empowerment events for young adults/adults living with sickle cell disease and advocacy with health/insurance systems.
- Information and referral services for extended family testing.
- Statewide coordination of Sickle Cell Runs, Walks and Jogs in Ohio.
- Social media engagement and marketing of statewide and regional sickle cell activities and events.
- Ohio Chapter of the Sickle Cell Disease Association of America, Inc. (SCDAA).

Non-Grant Supported Services and Programs (provided through the Ohio Sickle Cell and Health Association and Sickle Cell Disease Association of America**):**

- Community Based Organization (CBO) training and development.
- Community Health Worker Training (in collaboration with SCDAA).
- Consumer legislative advocacy for issues related to sickle cell disease, clinical trials, pharmaceutical research, and development.
- Consumer emergency support and medication adherence assistance.
- "Get-Connected" SCDAA database collection.
- Statewide collaboration and coordination of adult (including young adult) transition services.
- National social marketing campaigns for individuals/families with sickle cell disease.

Project Director: Annie J. Ross-Womack
Medical Advisor: Mamle Anim, MD (Five Rivers Medical Surgical Health Center – Dayton, OH)

This page had been intentionally left blank.

Ohio | Department of Health

Mike DeWine, Governor
Jon Husted, Lt.Governor

Bruce Vanderhoff, MD, MBA, Director

An Equal Opportunity Employer/Provider
2021