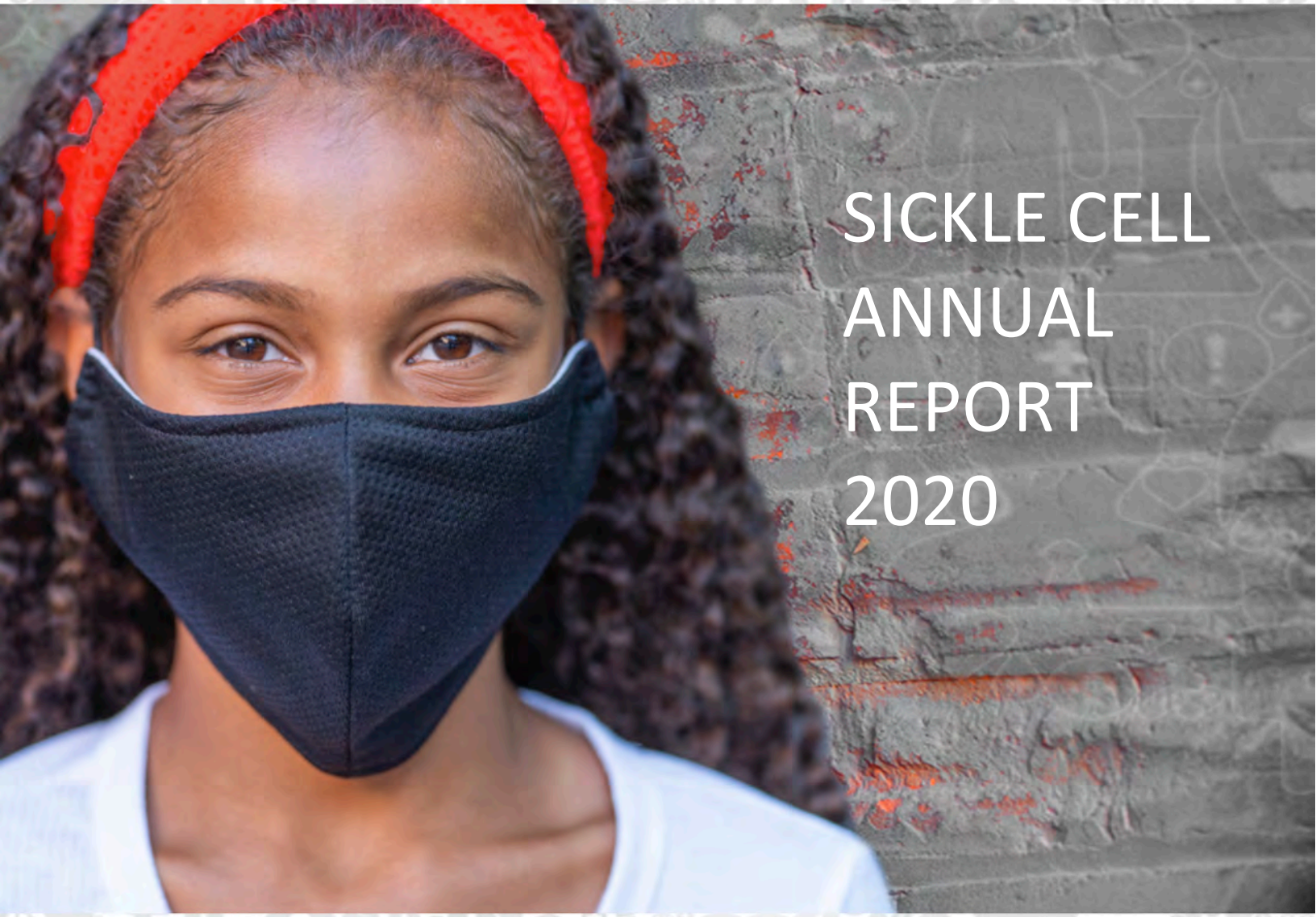
SICKLE CELL ANNUAL REPORT 2020

Ohio Department of Health

Page Intentionally left blank.

This report includes data from state fiscal year 2019.



SICKLE CELL ANNUAL REPORT 2020

SUBMITTED TO
Members of the General Assembly

SUBMITTED BY
Ohio Department of Health
Sickle Cell Services Program

From the Director

Dear Members of the General Assembly:

On behalf of the patients and 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 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.

Anyone requesting additional information on sickle cell disease, the contents of this report, or services provided by ODH Sickle Cell Services Program should direct inquires to Lisa Griffin, Director of Government Affairs, Lisa.Griffin@odh.ohio.gov or 614-644-9164.

Sincerely,

Stephanie McCloud, Director

Stephanie McCloud
Director of Health

Table of Contents

Table of Contents 1

List of Tables and Figures 2

Acknowledgments 3

Executive Summary 4

Introduction

Program Background 8

Receipt and Disbursement of Funds 10

Program Implementation

Newborn Hemoglobinopathy Screening 12

Hemoglobinopathy Testing 14

Hemoglobinopathy Counseling 20

Hemoglobinopathy Outreach Education 21

References 29

Appendices

Appendix A: Sickle Cell Facts 31

Appendix B: Sickle Cell Project Profile – Region I 33

Appendix C: Sickle Cell Project Profile – Region II 34

Appendix D: Sickle Cell Project Profile – Region III 35

Appendix E: Sickle Cell Project Profile – Region IV 36

Appendix F: Sickle Cell Project Profile – Region V 37

Appendix G: Sickle Cell Project Profile – Region VI 38

Appendix H: Sickle Cell Project Profile – Statewide 39

Lists of Tables and Figures

Tables

Table 1. Grant Award Allocations 10
Table 2. Other Education Event Attendees 22
Table 3. Other Awareness Event Attendees 23
Table 4. Other Education Event Facilities 24
Table 5. Other Education Event Topics 25
Table 6. Other Awareness Event Modes 28

Figures

Figure 1. Newborns With an Abnormal Hemoglobinopathy Screening Notification 13
Figure 2. Abnormal Newborn Screening Notification and Confirmatory Testing 14
Figure 3. Reasons Newborns Were not Documented as Having Confirmatory Testing 15
Figure 4. Newborns With Documented Confirmatory Testing by Race 16
Figure 5. Non-Newborns With Hemoglobinopathy Testing 17
Figure 6. Non-Newborns With Hemoglobinopathy Testing by Race 18
Figure 7. Newborns and Non-Newborns With Hemoglobinopathy Testing by County . 19
Figure 8. Education Events by Audience Type 22
Figure 9. Awareness Events by Audience Type 23
Figure 10. Education Events by Facility Type 24
Figure 11. Education Events by Topic 25
Figure 12. Education Events by Instructional Format 26
Figure 13. Education and Awareness Events by County 27
Figure 14. Awareness Activity by Mode 28

Acknowledgements

Many individuals at ODH participated in the editorial review of the Sickle Cell Annual Report to the General Assembly. These individuals gave generously of their time and expertise, and their cooperation and assistance are 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 Public Affairs and Communications) in the development of this report.

A special acknowledgement and thank you is also extended to the project directors and staff at ODH-funded sickle cell projects. This report was made possible by their dedication and hands-on participation in the completion of required program data collection and reporting forms during the state fiscal year (SFY) 2019.

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 for their continuous contributions to our education.

Finally, this report is dedicated to all the individuals who lost their fight with sickle cell disease during 2019. These **sickle cell warriors** will be truly missed by their families, their friends, and the professional community who served them.

Executive Summary

In SFY 2019 (July 1, 2018-June 30, 2019), 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. The 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 2019 Minimum Data Set collection forms and other program reporting formats.

Newborn Hemoglobinopathy Screening

- The RSCPs received notification of 3,625 abnormal newborn hemoglobinopathy screening results from ODH Public Health Laboratory during SFY 2019. This number accounts for 2.69% of all Ohio births (n=134,562) during the reporting period.

    - There were 181 newborns who had a disease hemoglobinopathy screening result, accounting for 5% of abnormal screening results and <1% of total births.
    - There were 3,444 newborns who had a carrier hemoglobinopathy screening result, accounting for 95% of abnormal screening results, nearly 3% of total births.

Hemoglobinopathy Testing

- The RSCPs reported confirmatory testing on 2,412 (67%) of newborns identified in SFY 2019 with an abnormal newborn hemoglobinopathy screening result. Documentation of confirmatory testing was not obtained on 1,213 (33%) 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 dying before testing.

Of the 181 newborns with a disease hemoglobinopathy screening result:

- There were 165 (91%) newborns who received confirmatory testing within two months of life and 16 (9%) who received confirmatory testing results after two months.

---

* A hemoglobinopathy is an inherited (passed down through families) blood disorder in which there is an abnormal form of hemoglobin (variant) or decreased production of a hemoglobin (thalassemia).

- There were 94 (52%) infants who received treatment within three months of birth and none who received treatment after three months. There were 83 (46%) newborns who did not receive treatment, either due to being confirmed as carrier or having diseases not requiring treatment. Of the remaining newborns, three (2%) had parents decline treatment and one (<1%) died before being tested.

- There were 1,939 (80%) newborns with confirmatory testing for hemoglobinopathies who were identified as Black or African American.

- A total of 1,980 non-newborns[†] received hemoglobinopathy testing services through an RSCP in SFY 2019, with 868 (44%) identified with a carrier hemoglobinopathy and 85 (4%) identified with a disease hemoglobinopathy. A total of 1,027 (52%) non-newborns were identified with no hemoglobinopathy.

- There were 1,499 (76%) non-newborns receiving hemoglobinopathy testing services who identified as Black or African American.

- Of those who received hemoglobinopathy testing services, 2,412 (55%) were newborns from 50 counties and 1,980 (45%) were non-newborns from 23 counties in Ohio.

Hemoglobinopathy Counseling

- Of the 2,412 newborns born in SFY 2019 who received confirmatory testing, 2,298 (95%) had a parent or guardian receive hemoglobinopathy counseling by the RSCPs.

    - There were 3,188 parents or guardians who received hemoglobinopathy counseling in association with these newborns.
    - For the 114 confirmed newborns whose parents or guardians did not receive counseling, 108 (95%) were due to the physicians of record not responding and 6 (5%) were due to the caregivers declining counseling.

- Hemoglobinopathy counseling services were provided to 1,989 non-newborns. Of these, 796 (36%) were parents/guardians/family members of non-newborn infants and 1,193 (55%) were other non-newborns directly tested.

[†] Non-newborn is defined as an individual (infant, child, or adult) born before SFY 2019 (July 1, 2018–June 30, 2019) who received hemoglobinopathy follow-up services through an RSCP during SFY 2019.

Hemoglobinopathy Outreach Education

- Sickle cell project staff (SWSCP and RSCP) provided 746 education events, totaling 1,528 hours of direct education to an estimated 14,205 members of the public, healthcare providers, and community professionals.

    - There were 345 (46%) education events that took place in pediatric hospitals, 187 (25%) that took place in medical provider offices, and 63 (8%) that took place in K-8 schools. Other locations each made up less than 5% of the total.
    - The top two event topics were general hemoglobin disease and trait overview, and newborn screening. There were 715 (24%) hemoglobin overview events and 563 (19%) events about newborn screening.
    - Most education events were in the format of trainings, rotations, and internships, which combined made up 328 (44%) of all education events.
    - Education events were held in 20 Ohio counties. This included the five counties in Ohio with the highest proportion of African American[‡] residents (Cuyahoga, Hamilton, Franklin, Montgomery, and Lucas).

- In addition, project staff conducted 314 awareness activities, with an estimated 4,392,856 contacts made to raise awareness of sickle cell disease and other hemoglobinopathies.

    - The top three modes of awareness activities were community and professional outreach, with 146 events (47%); material distribution, with 72 events (23%); and traditional media, with 38 events (12%).
    - There were 17 churches that held Sickle Cell Sabbath events.

[‡] The term “African American” here 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.

INTRODUCTION

Program Background

The Ohio Revised Code, under 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 of the Ohio Revised Code requires that:

"… 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 2019 under the Sickle Cell Services Program related to sickle cell disease (SCD), sickle cell trait (SCT), and other hemoglobinopathies:

The **Sickle Cell Initiative** is comprised 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 B through G.) 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 of 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 H), 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 section 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 2019, fees generated from the sale of newborn screening kits to Ohio hospital and birthing facilities were utilized by ODH to award grant subsidies in the amount of $800,000. (See Table 1.)

- The six 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 sickle cell projects for SFY 2019 under both the Sickle Cell Initiative and the Statewide Family Support Initiative were continuation grant awards distributed through an established ODH grant application.

Table 1. Grant Award Allocations

Region	Agency Name	City/County	SFY 2019 Award
Sickle Cell Initiative			
I	Cincinnati Children's Hospital Medical Center	Cincinnati/Hamilton	$125,957
II	Children's Medical Center-Dayton	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

"Newborn screening programmes are comprehensive systems which provide an essential public health service. Their mission is to eliminate or reduce the mortality, morbidity and disability that result from congenital disease by ensuring that all affected infants receive early diagnosis and long-term treatment in an attempt to achieve optimal health, growth and development."[1]

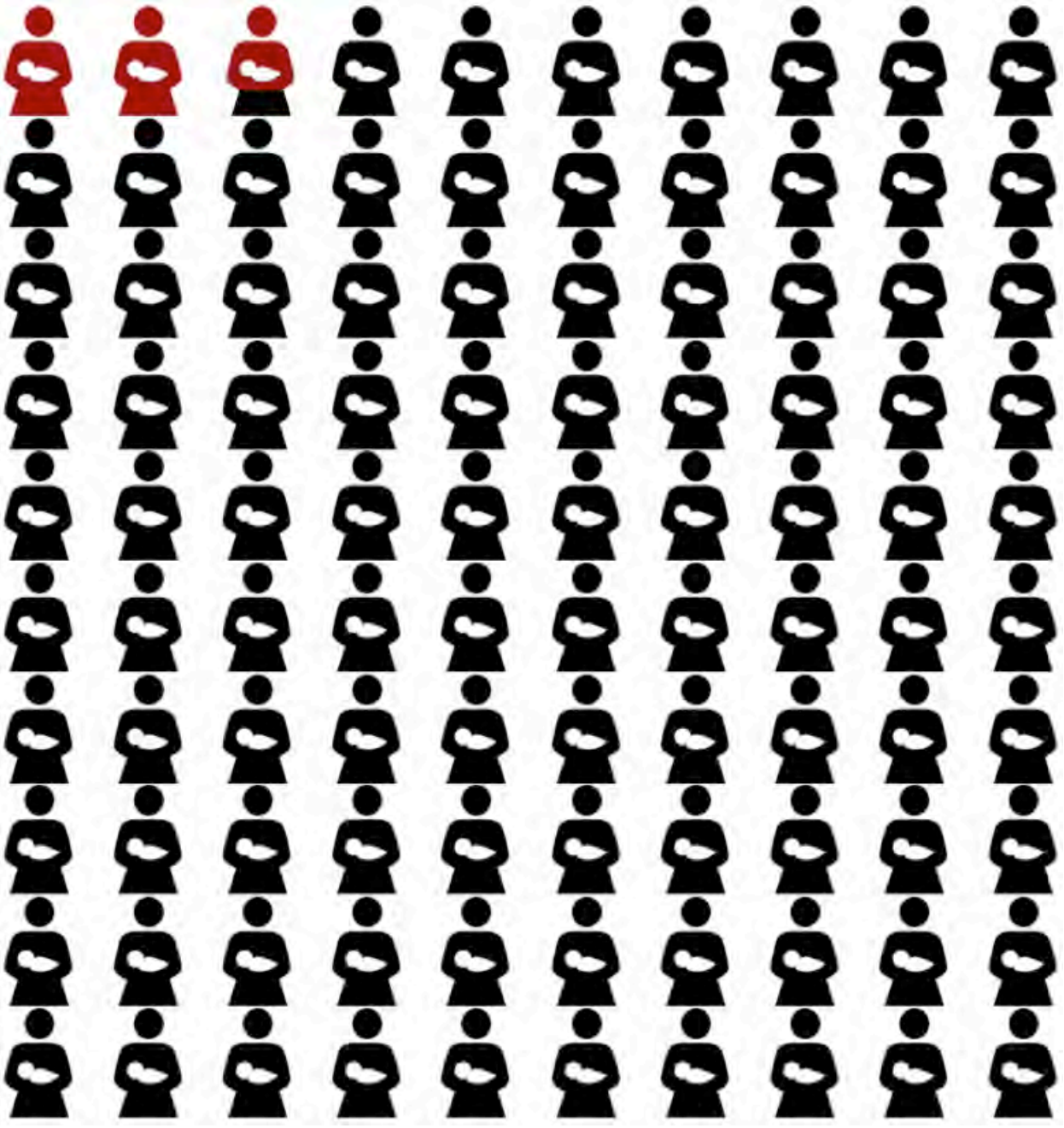
Since March 1990, all infants born in the state of Ohio are screened at birth for SCD, SCT and other hemoglobinopathies as part of the newborn blood spot screenings mandated by Ohio Administrative Code. The primary purpose of hemoglobinopathy screening is to identify infants with a SCD and initiate penicillin 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 SCD in infancy and early childhood. At present, all 50 states, the District of Columbia, and the U.S. territories require that 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., SCT) provides a genetic window into the family and can result in the identification of couples at risk for having children with SCD in subsequent pregnancies. It may also identify other family members at risk or affected by SCD, SCT, 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 blood spot screenings performed in Ohio are analyzed by ODH Public Health Laboratory under the Newborn Screening Program. The RSCPs, 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 (NBS) Program to the newborns' physician of record. Follow-up of abnormal newborn hemoglobin screening results is in accordance with section 3701-55-08 of the Ohio Administrative Code governing Genetic, Endocrine or Metabolic Screening of Newborn Infants. 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 hemoglobin disease result.

During SFY 2019, the RSCPs received notification of 3,625 abnormal newborn hemoglobinopathy screening results (from ODH Public Health Laboratory). This figure accounts for nearly 3% of all Ohio births (n=134,562) during this reporting period. (See Figure 1.)

Figure 1. Newborns With an Abnormal Hemoglobinopathy Screening Notification



Sources: Ohio Public Information Warehouse, Birth Occurrence (Birth Comprehensive 2018 and 2019, preliminary); Minimum Dataset SFY 2019 Table 1.

Hemoglobinopathy Testing

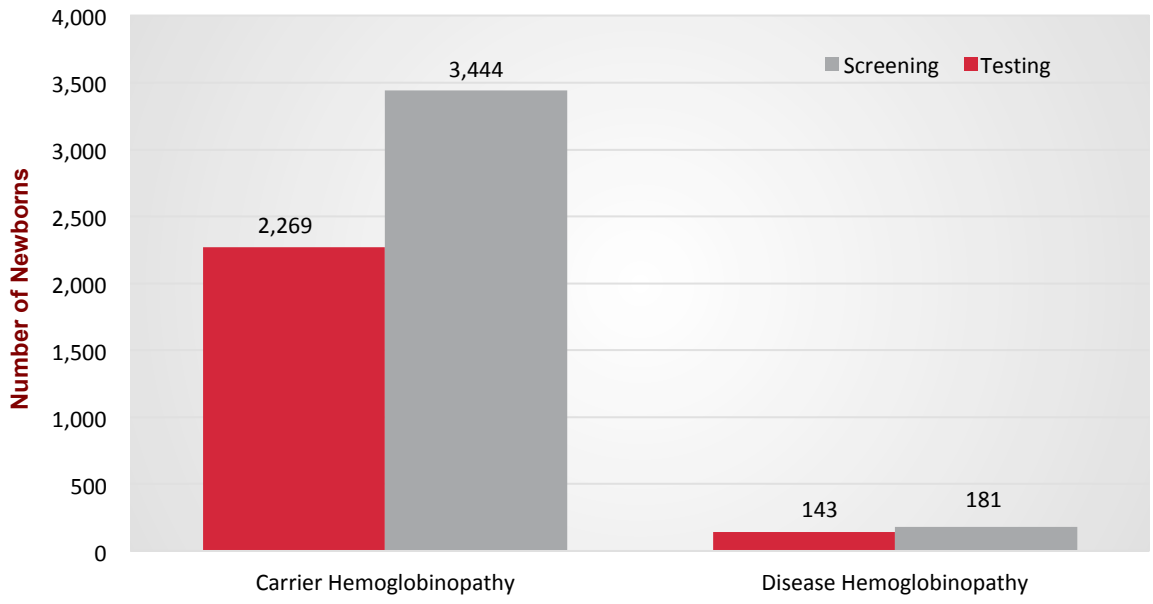
Confirmation of a presumptive positive hemoglobinopathy screening result is an integral part of the NBS follow-up process. In addition to confirmation of newborns with an abnormal hemoglobin result, the RSCPs may also provide diagnostic testing services to individuals at risk for hemoglobinopathies. 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 NBS 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).

Newborn Hemoglobinopathy Testing

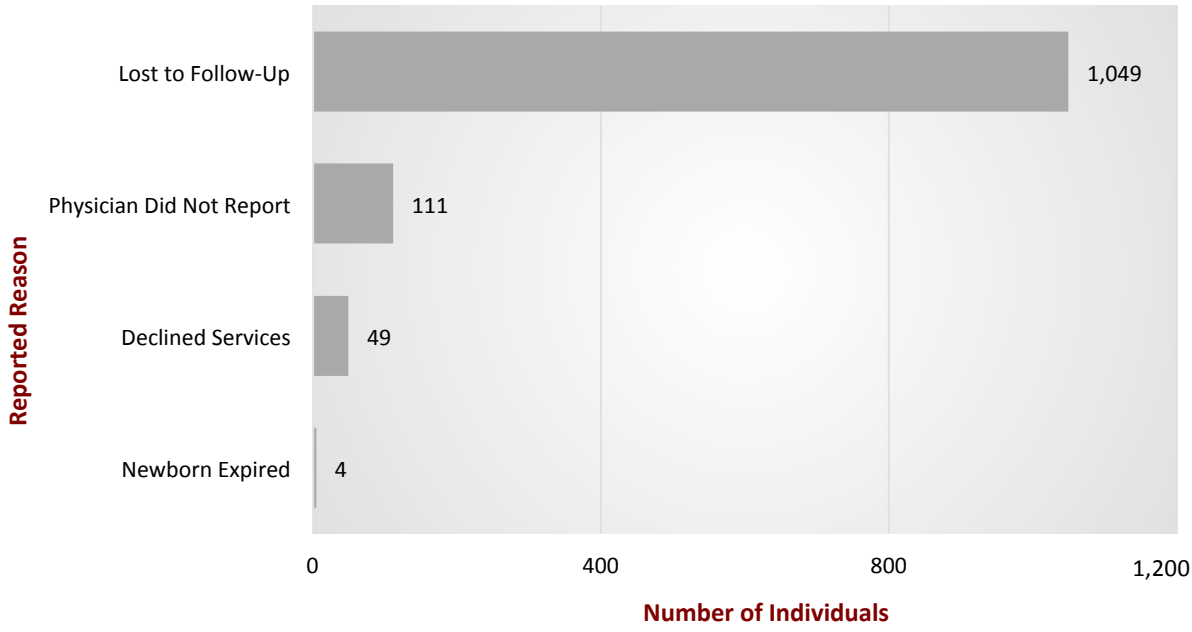
The RSCPs received notification of 3,625 abnormal hemoglobinopathy screening results for newborns in SFY 2019. Of these newborns, the RSCPs reported 2,412 (67%) received confirmatory testing. (See Figure 2.) The reasons newborns were not documented as having confirmatory testing is described in Figure 3.

Figure 2. Abnormal Newborn Screening Notification and Confirmatory Testing



Source: Minimum Dataset SFY 2019 Tables, 1, 2a.

Figure 3. Reasons Newborns Were Not Documented as Having Confirmatory Testing (n=1,168)



Source: Minimum Dataset SFY 2019 Table 2b.

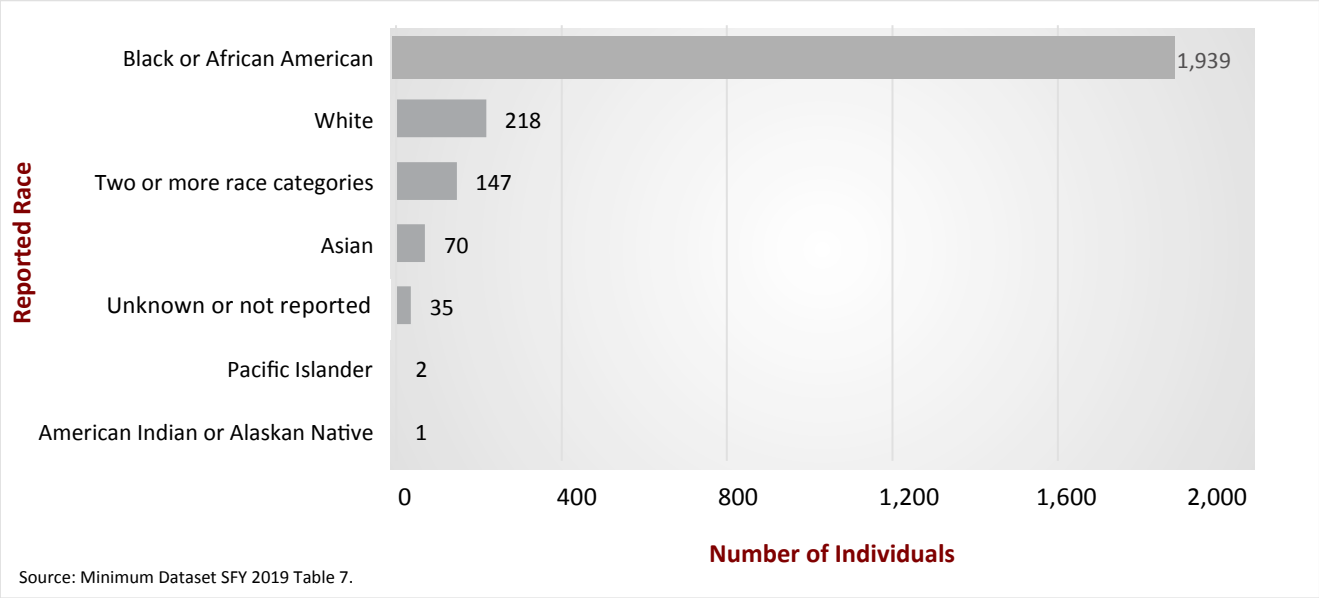
Time from Birth to Diagnosis and Treatment

During SFY 2019, the RSCPs received notification of 181 abnormal newborn screening results indicating a disease hemoglobinopathy. Of these, 165 (91%) received confirmatory testing within the first two months of life and 16 (9%) received confirmatory testing after two months.

Newborns with treatable hemoglobinopathies should begin treatment (initiation of penicillin prophylaxis for SCD is a standard of care) within the first three months of life. Of the 181 newborns with a disease hemoglobinopathy screening result, RSCPs reported 94 (52%) newborns receiving treatment within three months of birth and none receiving treatment after three months. There were 83 (46%) newborns who did not receive treatment, either due to being confirmed as carriers or having diseases not requiring treatment. There were three (2%) newborns whose parents declined treatment, and one (<1%) had an unknown treatment status.

Of the newborns tested, 1,939 (80%) identified as Black or African American, 218 (9%) identified as white, and 147 (6%) identified as two or more races.

Figure 4. Newborns With Documented Confirmatory Testing by Race (n=2,412)

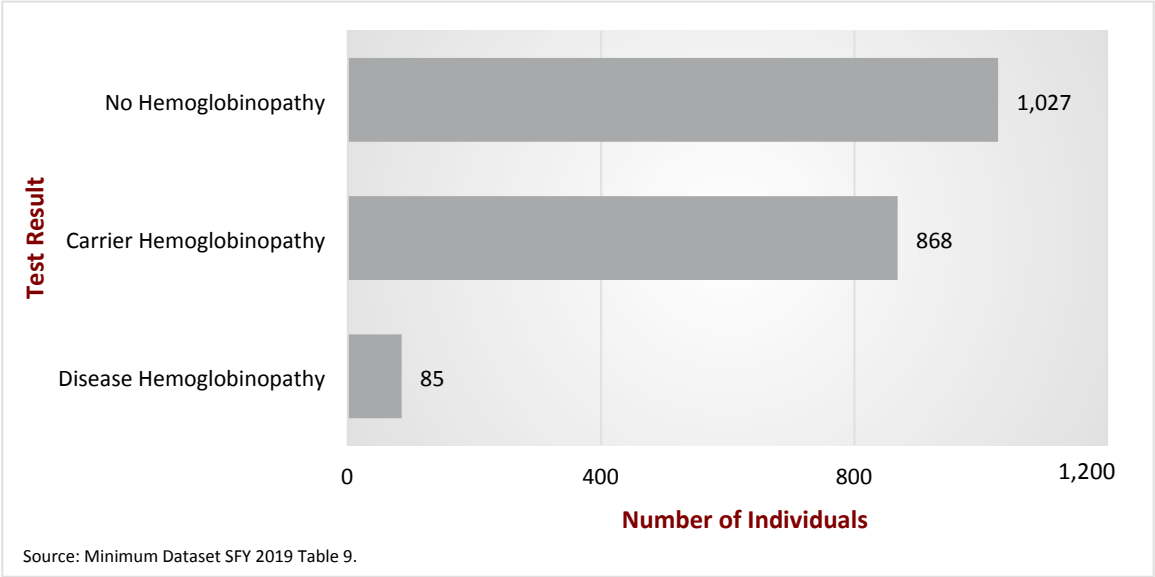


Source: Minimum Dataset SFY 2019 Table 7.

Non-Newborn Hemoglobinopathy Testing

In SFY 2019, 1,980 non-newborns received hemoglobinopathy testing services through an RSCP, with 85 (4%) identified with a disease hemoglobinopathy and 868 (44%) identified with a carrier hemoglobinopathy. A total of 1,027 (52%) non-newborns were identified with no hemoglobinopathy.

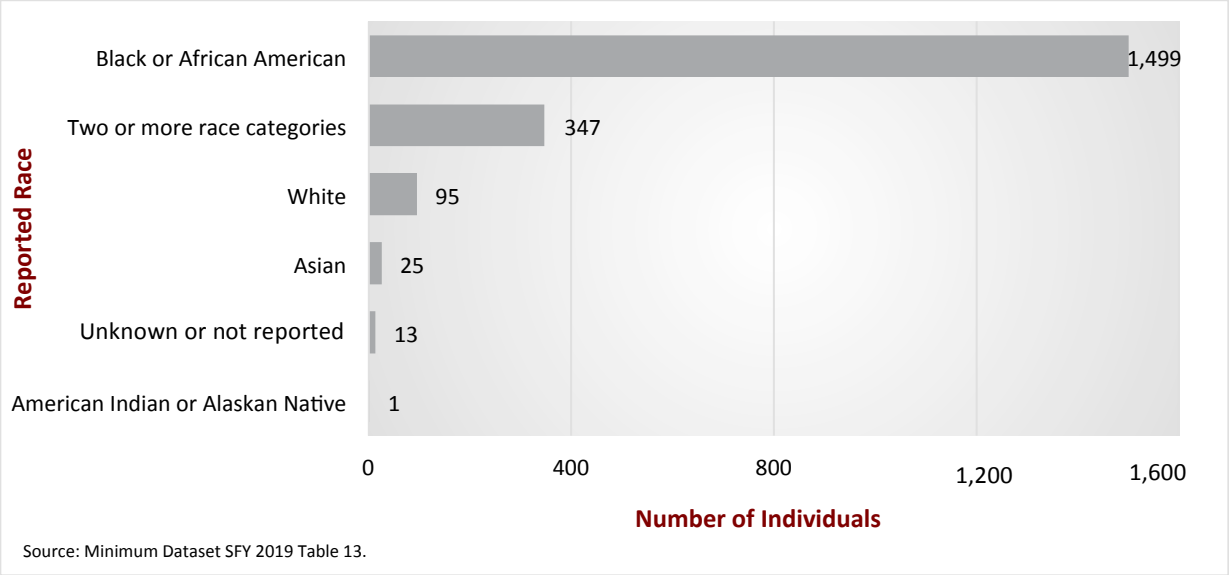
Figure 5. Non-Newborns With Hemoglobinopathy Testing (n=1,980)



Source: Minimum Dataset SFY 2019 Table 9.

Of the non-newborns receiving hemoglobinopathy testing, 1,499 (76%) identified as Black or African American, 347 (17%) were listed as two or more race categories, and 95 (5%) identified as white. (See Figure 6.)

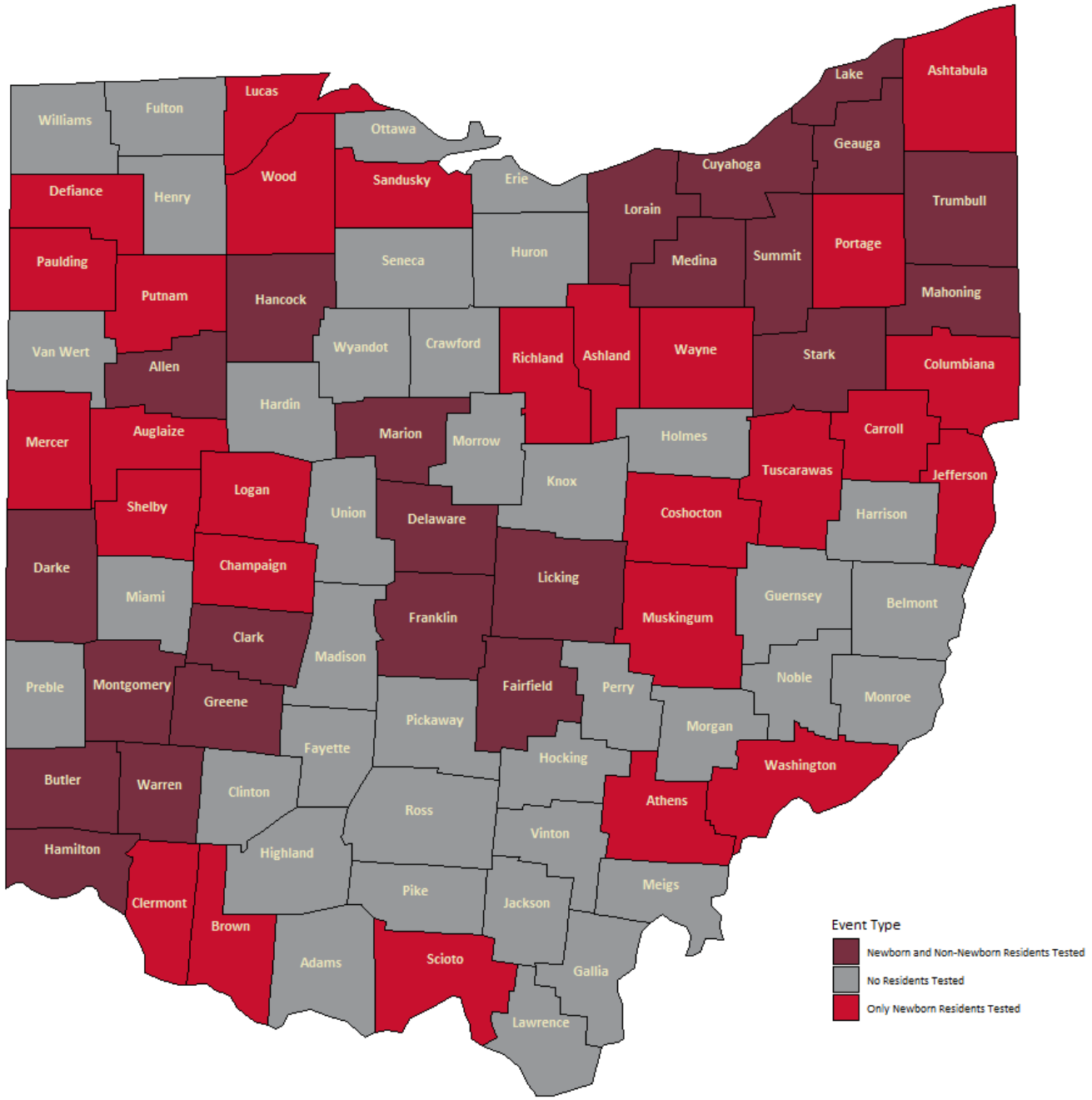
Figure 6. Non-Newborns With Hemoglobinopathy Testing by Race (n=1,980)



Source: Minimum Dataset SFY 2019 Table 13.

Of those who received hemoglobinopathy testing services, 2,412 (55%) were newborns from 50 counties and 1,980 (45%) were non-newborns from 23 counties. (See Figure 7.) Four tested newborns were listed as out-of-state.

Figure 7. Newborns and Non-Newborns With Hemoglobinopathy Testing by County (n=4,392)



Source: Minimum Dataset SFY 2019 Table 8 and Table 14.

Hemoglobinopathy Counseling

Counseling related to the diagnosis of a hemoglobinopathy is a vital link to the successful utilization of comprehensive, specialized clinical healthcare services. Hemoglobinopathy counseling services[§] provided by the RSCPs 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 physician and other healthcare providers, community providers, and ODH partner programs.

Children with a diagnosis of SCD, SCT, or other hemoglobinopathy, identifed outside of the newborn period, are also offered hemoglobinopathy counseling services upon referral and/or request.

In addition, non-RSCP providers (those external to the RSCP) may choose to counsel parents of newborns with a confirmed abnormal hemoglobin result at their primary location and not refer to the RSCP.

Newborns

Of the 2,412 newborns in SFY 2019 who received confirmatory testing, 2,298 (95%) had a parent or guardian receive hemoglobinopathy counseling. In association with these newborns, RSCPs documented 3,188 parents or guardians who received hemoglobinopathy counseling. For 114 confirmed newborns (109 confirmed with SCD and three confirmed with SCT) whose parents or guardians did not receive counseling, 108 (95%) were due to the physician of record not responding and six (5%) were due to the caregivers declining counseling.

Non-Newborns

Hemoglobinopathy counseling services were provided to 1,989 non-newborns. Of these, 796 (36%) were parents/guardians/family members of non-newborns infants and 1,193 (55%) were other non-newborns directly tested.

[§] In Ohio, RSCP staff providing hemoglobinopathy counseling services are required (by the Ohio Sickle Cell Program Standards and Criteria) to receive training through an approved hemoglobinopathy counselor training course.

Hemoglobinopathy Outreach Education

"It is estimated that approximately 100,000 Americans live with sickle cell disease (SCD). One out of every 365 African American children are born with SCD each year, making it the most common inherited blood disorder in the United States."[A]

As one of its primary goals, the ODH Sickle Cell Services Program, in partnership with the network of state-funded sickle cell projects (RSCPs and SWSCP), promotes and disseminates information about hemoglobinopathies and related services to healthcare and community professionals, the general public and at-risk segments of the community.

The implementation and delivery of education services at the project level is of primary importance because of 1) its direct impact on the quality and accessibility of healthcare services for the 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 project's objective to reach these targeted audiences.

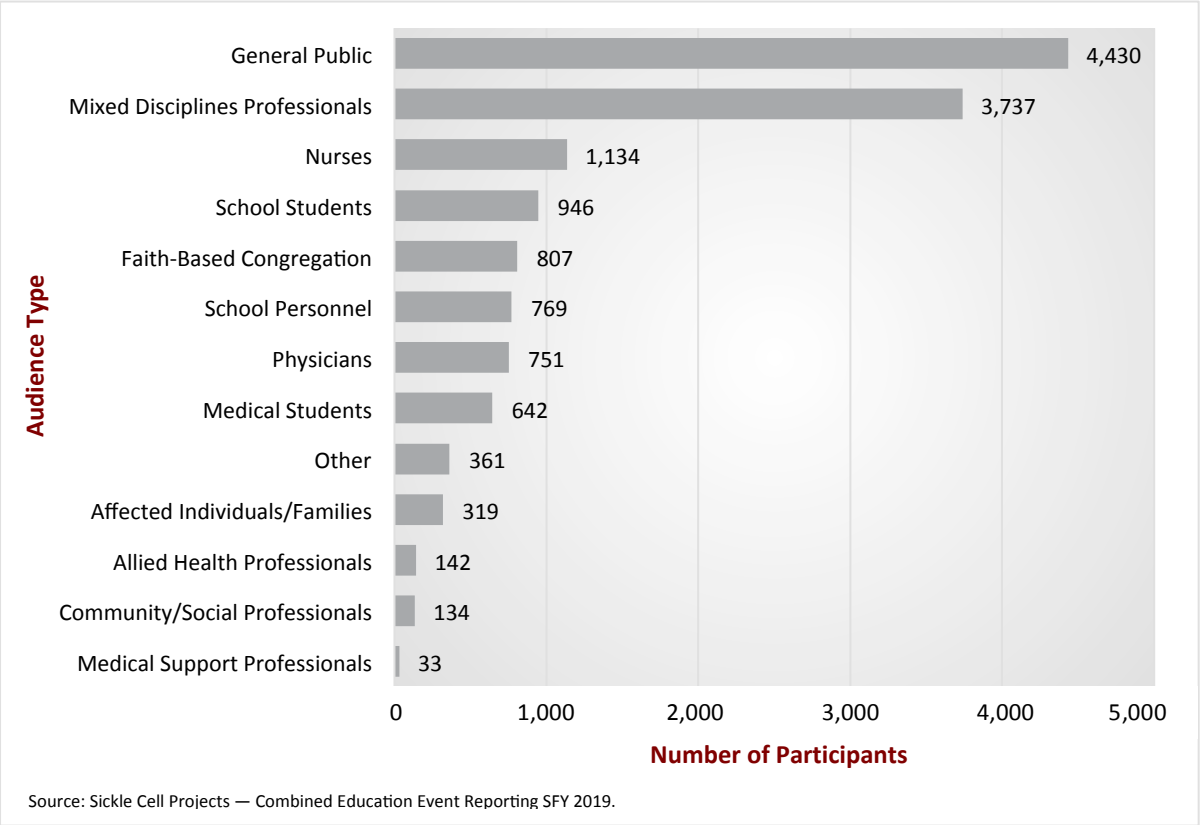
Sickle cell awareness campaigns are another aspect of a larger program of professional, patient, and public education, designed to reduce the risk and consequence of SCD and other related hemoglobinopathies. During the National Sickle Cell Awareness Month (September) and other select National Health Observance Months (e.g., April/National Minority Health Month; May/Stroke Awareness Month; November/American Diabetes Month), the RSCPs and SWSCP carry out awareness activities to:

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

Throughout the year, the projects also engage SCD-interested organizations and stakeholders to further promote awareness of SCD and educate the public by disseminating current, up-to-date information and key messages to increase healthy outcomes among various racial, ethnic, and age groups related to hemoglobinopathies.

During SFY 2019, funded projects conducted a total of 746 education events, which provided education to an estimated 14,205 individuals. (See Figure 8.) The most common attendees of these events were the general public (4,430 people, 31%) followed by 3,737 mixed discipline professionals (26%). 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 more than 1,528 hours of direct education.

Figure 8. Education Events by Audience Type (n=14,205)



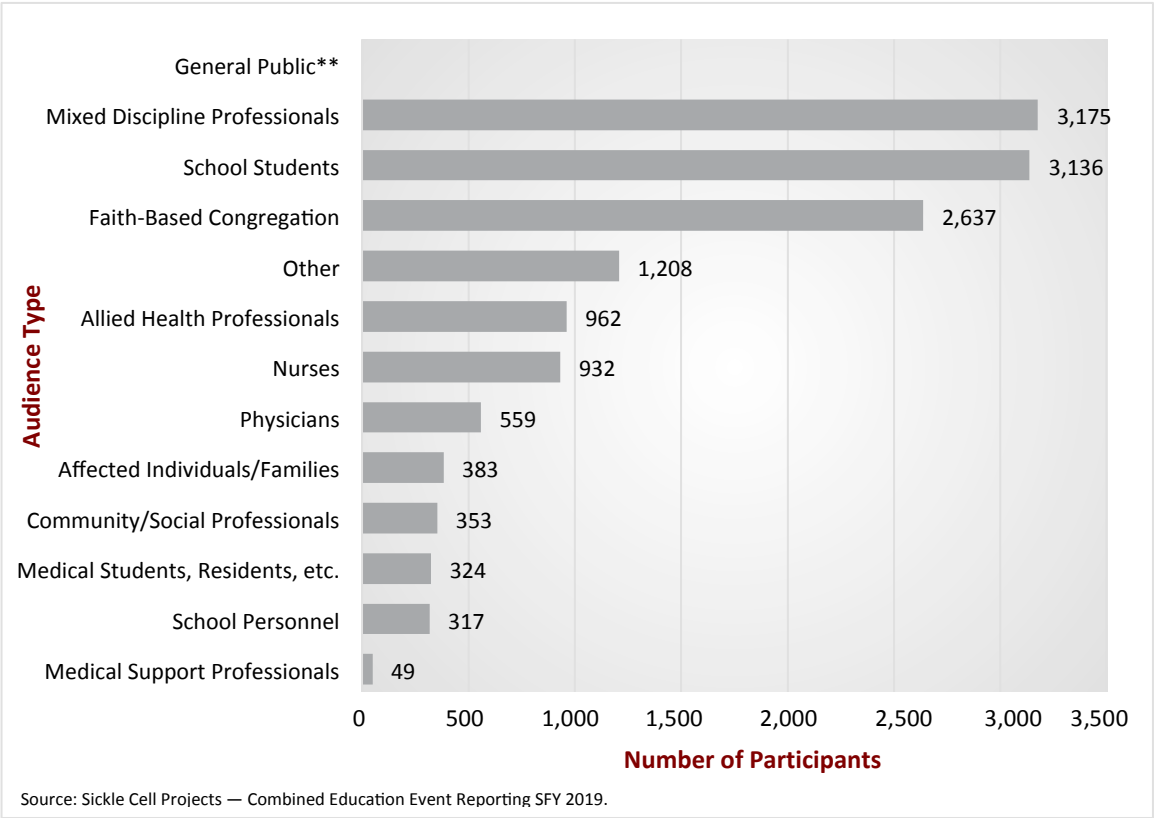
Source: Sickle Cell Projects — Combined Education Event Reporting SFY 2019.

Table 2. Other Education Event Attendees

Other Audience Type	Count
Federal Employees	159
Hematology/Oncology Specialist	100
Pregnant Inmates	30
Motorcycle Club Members	30
Medical Scientists	20
Librarians	8
Disability Specialists	6
Program Directors	6
Graphic Designer	1
Public Relations Coordinator	1

During SFY 2019, funded projects conducted a total of 314 awareness events, which had an estimated reach of 4,392,856 individuals. (See Figure 9.) The general public** made up more than 99% (4,378,821) of these individuals. Audience types listed as "Other" are displayed in Table 3. In total, the projects reported more than 1,667 hours of awareness. In addition to these events, Sickle Cell Sabbath events occurred at 17 churches.

Figure 9. Awareness Events by Audience Type (n=4,392,856)



Source: Sickle Cell Projects — Combined Education Event Reporting SFY 2019.

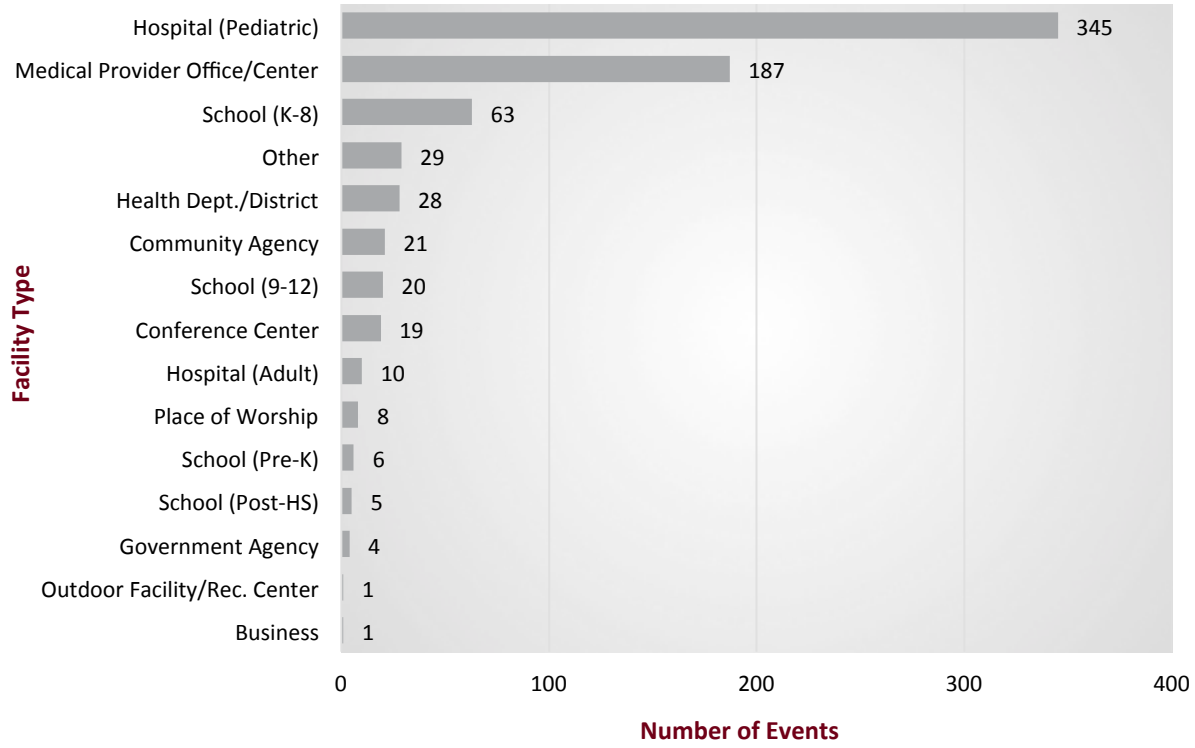
Table 3. Other Awareness Event Attendees

Other Audience Type	Count
Inmates	450
Employees	300
Religious Organizations	300
Legislators/Politicians	128
Community Club Members	30

** 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 10 shows the primary facilities for which education events were reported. Pediatric hospitals held 345 events (46%) and medical provider's offices held 187 events (25%). The remaining facility types each make up less than 10% of the total. Table 4 shows the facilities specified by those who selected "Other."

Figure 10. Education Events by Facility Type (n=747)



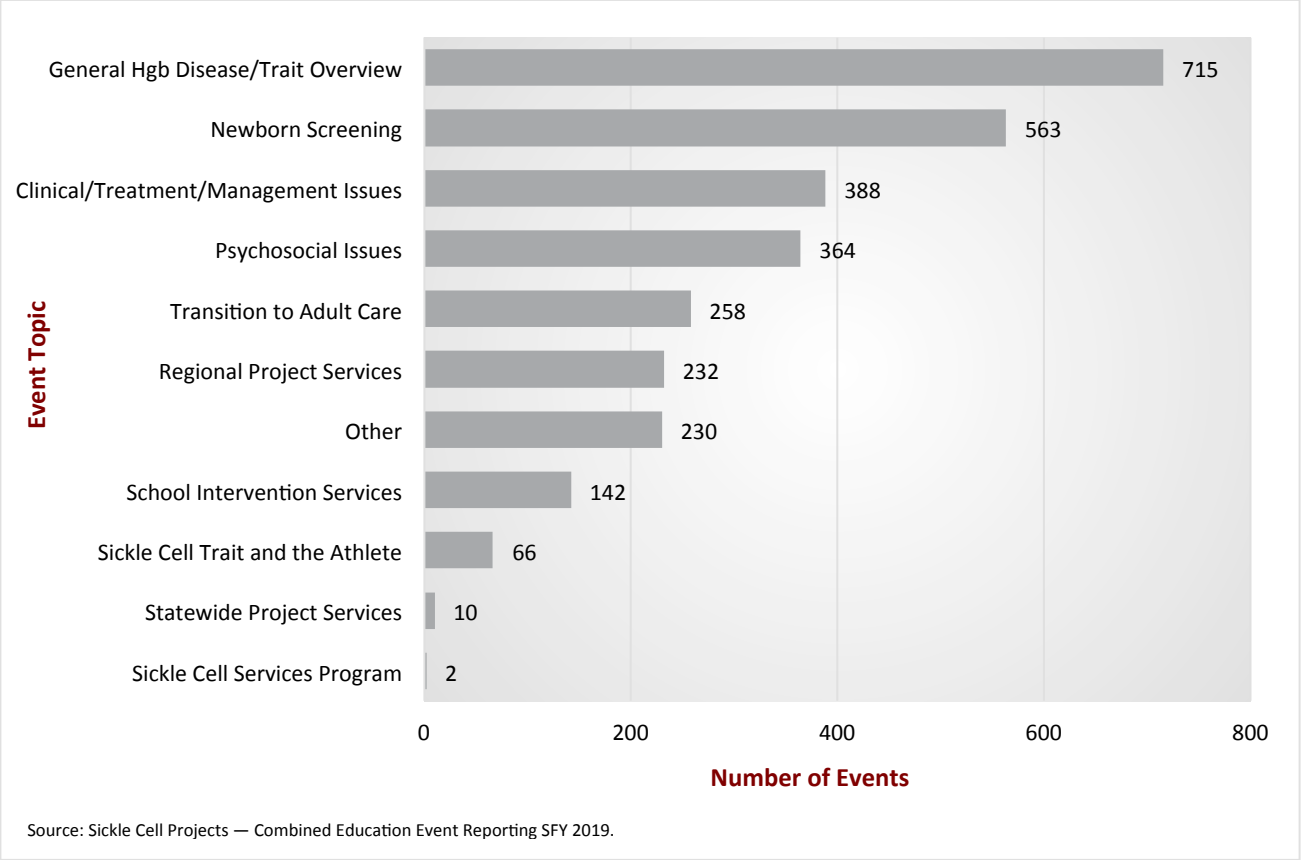
Source: Sickle Cell Projects — Combined Education Event Reporting SFY 2019.

Table 4. Other Education Event Facilities

Other Facility	Count
Satellite Location	22
Dentistry Office	2
Corrections Facility	1
Library	1
School District Central Office	1
Bowling Alley	1

Education events focused on multiple topics, ranging from information about hemoglobin disease and hemoglobin trait, to treatment and management. Figure 11 shows the primary categories for which education events were reported. General overviews of hemoglobinopathy made up 715 events (24%) and newborn screening was the topic of 563 events (19%). Table 5 shows the topics specified by those who selected "Other."

Figure 11. Education Events by Topic (n=2,970)



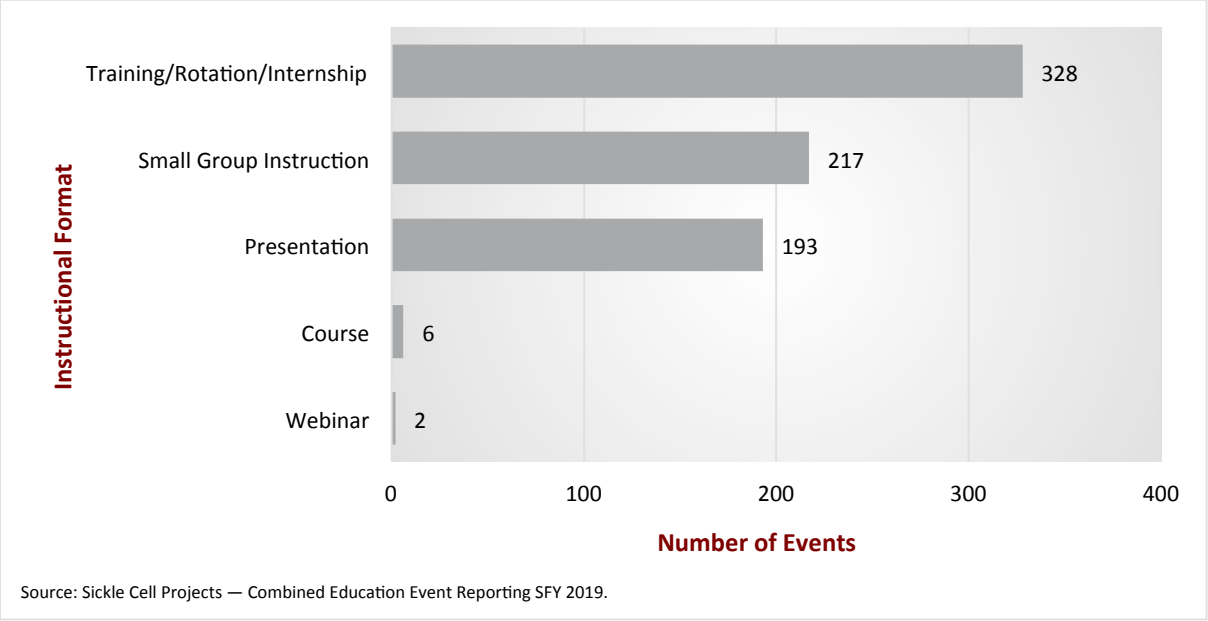
Source: Sickle Cell Projects — Combined Education Event Reporting SFY 2019.

Table 5. Other Education Event Topics

Other Topic	Count	Other Topic	Count
Specific Hemoglobin Disorder	200	Community Engagement	2
Recruitment of Minority Blood Donors	8	STORM	2
Human Genetics	5	Blood Donation Information	1
Gene Therapy	3	Cultural Competency	1
Oral Considerations of SCD	3	Primary Care	1
Research	3	State Advocacy Initiatives	1

Figure 12 shows the instructional format of education events. There were 328 (44%) education events classified as trainings, rotations, or internships; 217 (29%) were classified as small group instruction sessions; 193 (26%) events were classified as presentations; six (<1%) events were classified as courses (<1%); and two (<1%) were classified as webinars. All formats were conducted in person, with the sole exception of the webinars.

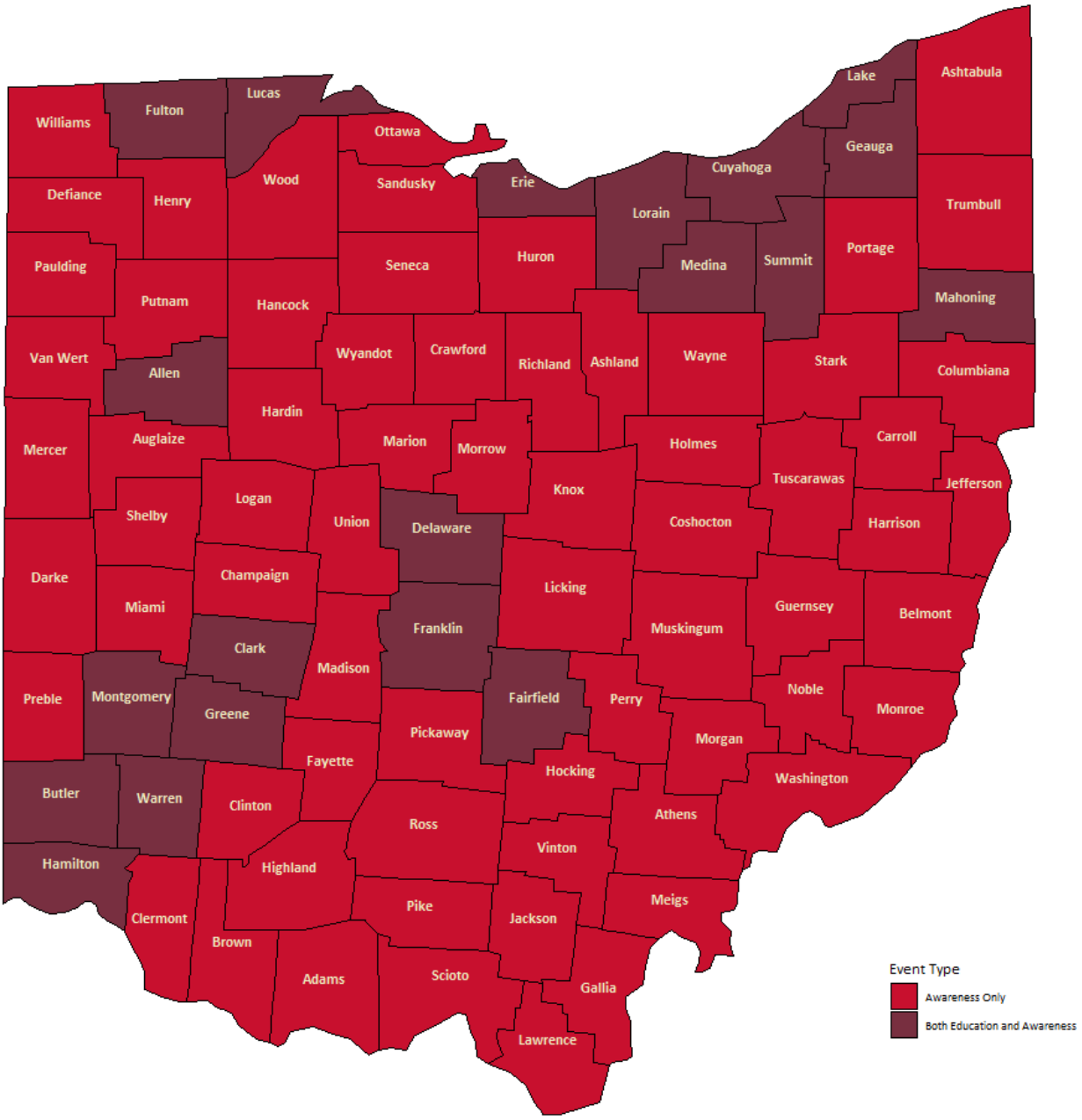
Figure 12. Education Events by Instructional Format (n=746)



Source: Sickle Cell Projects — Combined Education Event Reporting SFY 2019.

Education events took place in 20 Ohio counties. (See Figure 13.) This included the five counties with the highest proportion of African American residents (Cuyahoga, Hamilton, Franklin, Montgomery, and Lucas).[5] Two education events were web-based and may have affected more than their target county. Awareness events often extended beyond county borders and the events held impacted all 88 counties in Ohio.

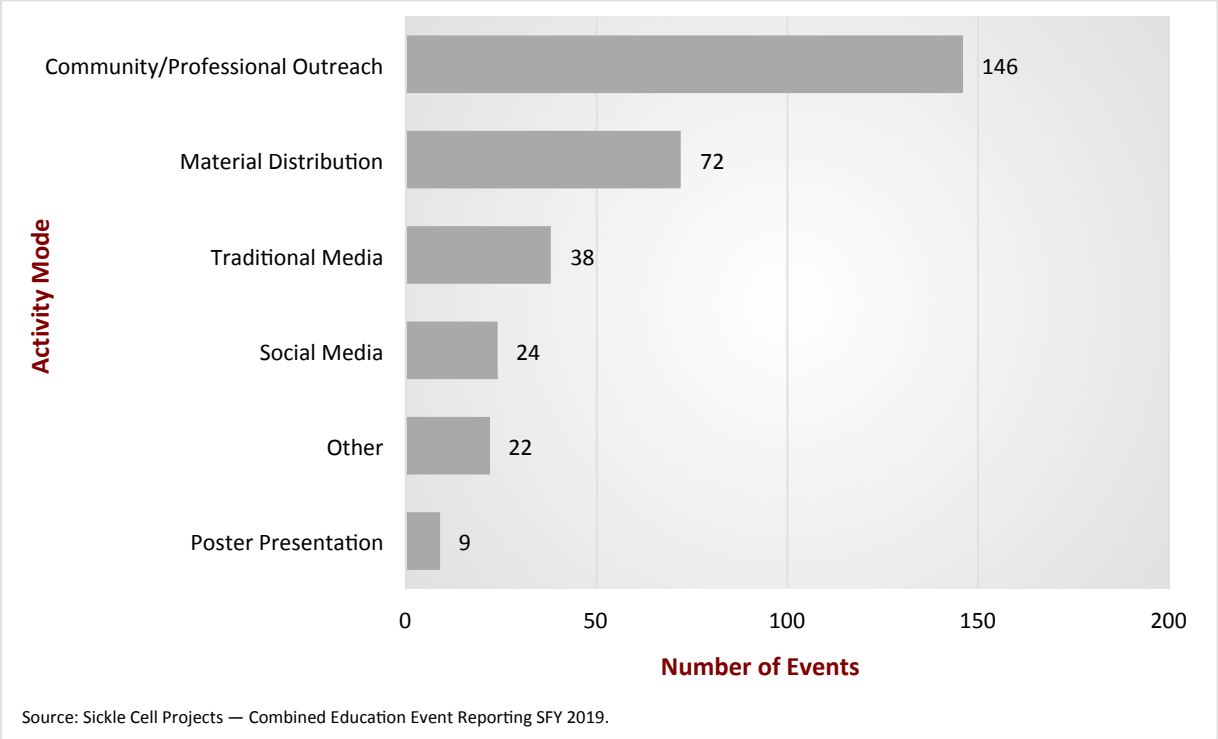
Figure 13. Education and Awareness Events by County (n=1,060)



Source: Sickle Cell Projects — Combined Education Event Reporting SFY 2019.

The sickle cell projects conducted 314 awareness activities during SFY 2019. These activities were estimated to have made 4,392,856 contacts through a variety of modes. In Figure 14, the 146 (47%) community or professional outreach events included walks, health fairs, exhibits, and blood and bone marrow drives. There were 72 (23%) material distribution events. Traditional media engagement (38 activities, 12%) included newspaper, television, radio, and electronic newsletter activities. Finally, social media engagement (24 events, 8%) included Facebook, Twitter, and Instagram. Three sickle cell projects did not report awareness activity mode.

Figure 14. Awareness Activity by Mode (n=314)



Source: Sickle Cell Projects — Combined Education Event Reporting SFY 2019.

Table 6. Other Awareness Event Modes

Other Mode	Count	Other Mode	Count
Phone	9	Planning Meeting	1
Legislative Awareness	2	Fundraiser	1
Email Response	2	Fashion Show	1
Exhibit	2	Conference	1
Baseball Game	1	Speaker	1
Attended Meeting	1		

References

Newborn Hemoglobinopathy Screening

1. King, L., Knight-Madden, J., & Reid, M. (2014). Newborn screening for sickle cell disease in Jamaica: A review – past, present and future. *West Indian Medical Journal, 63*(2), 147–150. https://doi.org/10.7727/wimj.2013.107

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*, 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. National Human Genome Research Institute. (2020 August). *About sickle cell disease*. NHGRI. https://www.genome.gov/Genetic-Disorders/Sickle-Cell-Disease

5. US-Places. *Ohio population by county—percentage of Black residents*. US-Places. https://us-places.com/Ohio/black-percentage-population-comparison.htm

Sickle Cell Facts

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

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

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

9. Ibid, p. 2.

APPENDICES

APPENDIX A:
Sickle Cell Facts

Sickle cell disease (SCD) is a term used to describe a group of inherited disorders characterized by the predominance of hemoglobin-S in red blood cells. 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°-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°-thalassemia. Those with HbSβ°-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 (SCT) 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.

[††] 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.[6]

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 100,000 Americans.
- SCD occurs among about one out of 365 Black or African American births.
- SCD occurs among about one out of every 16,300 Hispanic American births.
- About one in 13 Black or African American babies are born with SCT.[7]

SCD 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%.[8]

SCD, 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 blood. As a result of this mutation, individuals with SCD experience lifelong 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.[9]

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

APPENDIX B:
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 2019 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 and Sickle Cell Month (September) educational activities.

Expanded Services and Programs:

- Annual newsletter for regional healthcare providers.
- "Center Talk" newsletter for pediatric families.

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 six-state learning network (Sickle Treatment Outcomes Research in the Midwest – STORM).
- Annual summer camp program.
- Healthcare provider education programs, including the annual National Hemoglobinopathy Counselor Training Course.
- Training/rotation in hemoglobin disorders.

Project Director: Lisa Shook, DHPE, MCHES

Medical Director: Charles Quinn, MD

APPENDIX C:
Sickle Cell Project Profile - Region II

West Central Ohio Comprehensive Sickle Cell Center
Dayton Children's Hospital
One Children's Plaza
Dayton, OH 45404
937-641-3111 or 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 2019 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 (tutoring for patients who are admitted as inpatients).
- Patient assistance program (help with utilities, medications, rent, etc.).
- Special family events/activities.
- 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).
- Flying Horse Farms summer camp.
- Transition clinic to adult care at Five Rivers (725 South Ludlow St., Dayton).

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 and collaboration with adult healthcare providers.
- Nutrition assessment and counseling.
- Social work.
- Psychology referral (social assessment and intervention).
- Professional training/rotation/internship in hemoglobin disorders.
- Child life specialist.
- Genetic counseling.
- Onsite 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 D:
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
1415 Jefferson Ave. (location address)
Toledo, OH 43604
419-214-5700, ext. 6240
http://nhainc.org/sickle-cell-project-nwo

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

ODH SFY 2019 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, and community audiences.
- Regional resource center for hemoglobinopathy educational materials.
- Sickle Cell Sabbath and Sickle Cell Month (September) activities.

Expanded Services and Programs:

- Patient and family disease education.
- School outreach and interventions.
- Hemoglobin testing (in collaboration with Toledo Children's Hospital and Mercy Children's Hospital).
- Genetic counseling (in collaboration with/referral to the University of Toledo Division of Genetics).
- Annual awareness 5K walk/run (September Sickle Cell Matters 5K Walk/Run).
- Summer camp (Flying Horse Farms).
- Sickle Cell Awareness of Toledo Support Group (SCAT).
- External community advisory committees.
- Certified Community Health Worker Program (in affiliation with the Sickle Cell Disease Association of America Inc.).

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 (with incorporated social work services, pharmacy and laboratory, WIC services, 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).
- Community engagement activities (in collaboration with Ohio Sickle Cell and Health Association).

Project Director: La'Shardae Scott, BS, CHW

Medical Advisors: Crawford Strunk, MD (Toledo Children's Hospital) and Melisa Mullins, MD (Mercy Children's Hospital)

APPENDIX E:
Sickle Cell Project Profile - Region IV

Comprehensive Sickle Cell Disease and Thalassemia Program
Nationwide Children's
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 2019 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/day care 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 Center with Urgent Care (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.
- Genetic counseling and extended family testing.
- Case management.
- Dental evaluations.
- Psychological testing and evaluations.
- Apheresis program.
- Psychological/clinical research trials.
- Student training.

Project Director: Tanica Jeffries, MS, LPC, LSW

Medical Director: Anthony Villella, MD

APPENDIX F:
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
http://www.ascaa.org

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

ODH SFY 2019 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, and Medina County Health Department).
- Resource center for hemoglobinopathy education materials.
- Sickle Cell Sabbath/Sunday and Sickle Cell Month (September) activities.

Expanded Services and Programs:

- Hispanic community direct services and outreach.
- Global/international education and referral initiative.
- School/home intervention program.
- Supportive services/crisis intervention/community referrals.
- Collaborative relationships with Region V hospitals.
- CBS Cares public service announcement for sickle cell disease (local and national airing).
- Website (in over 80 pull-down languages).
- Facebook, Twitter, YouTube, and Instagram.

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).
- National Caucus and Center on Black Aging senior community service (clerical) program.
- Summer Cleveland Clinic Science Internship Program for high school students.
- Cleveland Clinic resident physician rotation program.
- Bryant & Stratton College pre-graduate internship program (science and administration).
- Sickle Talk podcast.

Project Director: Ira Bragg-Grant, LSW

Medical Advisor: Grace Onimoe, MD (MetroHealth Hospital)

APPENDIX G:
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 2019 Funding Allocation: $96,609

Standard Services:

- 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 healthcare professionals/providers, consumers, and the public.
- Sickle Cell Sabbath/Sunday and Sickle Cell Awareness Month (September) activities.

Expanded Services and Programs:

- School intervention services.
- Patient and family disease education.
- Adolescent transition program.
- Holiday events for patients and their families.
- Monthly parent/patient support group meetings.
- 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.

Project Director: LaTonya Lewis

Medical Director: Prasad Bodas, MD

APPENDIX H:
Sickle Cell Project Profile - Statewide

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

Counties:
Statewide – 88 Ohio Counties

ODH SFY 2019 Funding Allocation: $90,000

Standard Services:

- Professional education and training.
- Statewide public awareness and media campaigns.
- Sickle Cell Month (September) and Sickle Cell Sabbath activities.

Expanded Services and Programs:

- Administrator of the Empowerment Scholarship Fund for educational events.
- Advisory organization to the Ohio Sickle Cell Affected Families Association.
- 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.
- 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: Payal Desai, MD (The Ohio State University Comprehensive Sickle Cell Clinic)

Ohio | Department of Health

Mike DeWine, Governor
Jon Husted, Lt.Governor

Stephanie McCloud, Director

An Equal Opportunity Employer/Provider
2020