SICKLE CELL
Annual Report 2024

This report includes data from
State Fiscal Years 2021–2022

Ohio Department of Health

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 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 ..."*

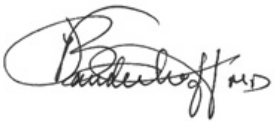
This section of the Ohio Revised Code also requires the director of health to submit a written report to the General Assembly each year outlining the receipt and disbursement of funds and the implementation and progress of various programs undertaken pursuant to this section during the preceding fiscal year. Due to disruptions caused by the COVID-19 pandemic, data analysis and reporting for State Fiscal Years (SFY) 2021 and 2022 was delayed and are being combined into one report. Data for SFY 2023 are being actively analyzed.

The ODH Sickle Cell Services Program works to:

- Ensure and enhance the availability and accessibility of quality, comprehensive sickle cell services and care for newborns, children, and adults.
- Promote public/patient/consumer/family/professional education to increase awareness and knowledge about sickle cell disease, sickle cell trait, and other hemoglobinopathies.
- Increase strategies to maximize collaboration, coordination, and utilization of all sickle cell-related services and resources in Ohio.

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

Sincerely,



Bruce Vanderhoff, MD, MBA
Director of Health

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 both SFY 2021 and SFY 2022 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, (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.
- 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:

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

For SFY 2021 and SFY 2022, 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 per SFY (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 each year.
- The sickle cell project located in Columbus was awarded $90,000 to provide services/activities (see Program Background) under the Statewide Family Support Initiative each year.

Funding to the RSCPs for SFY 2021 and SFY 2022 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

Sickle Cell Initiative				
Region	**Agency Name**	**City/County**	**SFY 2021**	**SFY 2022**
I	Cincinnati Children's Hospital Medical Center	Cincinnati/Hamilton	$125,957	$125,957
II	Children's Medical Center-Dayton	Dayton/Montgomery	$72,932	$72,932
III	Neighborhood Health Association of Toledo	Toledo/Lucas	$54,743	$54,743
IV	Nationwide Children's Hospital	Columbus/Franklin	$171,595	$171,595
V	American Sickle Cell Anemia Association	Cleveland/Cuyahoga	$188,164	$188,164
VI	Children's Hospital Medical Center-Akron	Akron/Summit	$96,609	$96,609
Statewide Family Support Initiative				
	Ohio Sickle Cell and Health Association	Columbus/Statewide	$90,000	$90,000

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*https://codes.ohio.gov/ohio-administrative-code/rule-3701-55-20

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 the 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 to 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 of 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 (RSCP), 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.

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.

Hemoglobinopathy Diagnostic 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 RSCPs may also provide diagnostic testing services to individuals at risk[†] for hemoglobinopathies. These individuals, referred to as non-newborns, include:

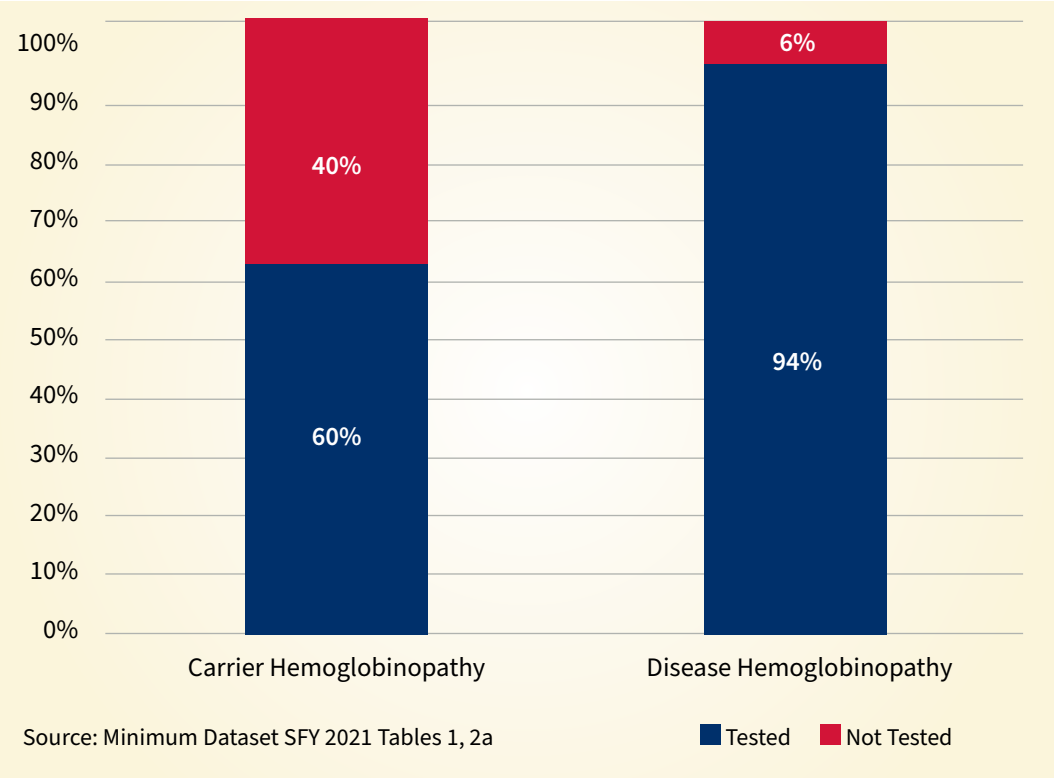
- Parents and family members of infants identified with abnormal newborn hemoglobin screening results.
- Adults (not associated with an abnormal newborn screening result) unaware of their hemoglobin status.
- Individuals of childbearing age (representing various racial and ethnic populations) considered 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).

Newborn Hemoglobinopathy Confirmatory Testing

During SFY 2021, the RSCPs received notification of 3,350 abnormal newborn hemoglobinopathy screening results from the ODH Public Health Laboratory. This number accounts for 2.5% of all Ohio births (n=128,899) during the reporting period. A total of 3,212 (96% of abnormal screening results) had a carrier hemoglobinopathy screening result. Of these newborns, the RSCPs reported that 2,032 (61%) received confirmatory testing (See Figure 1).

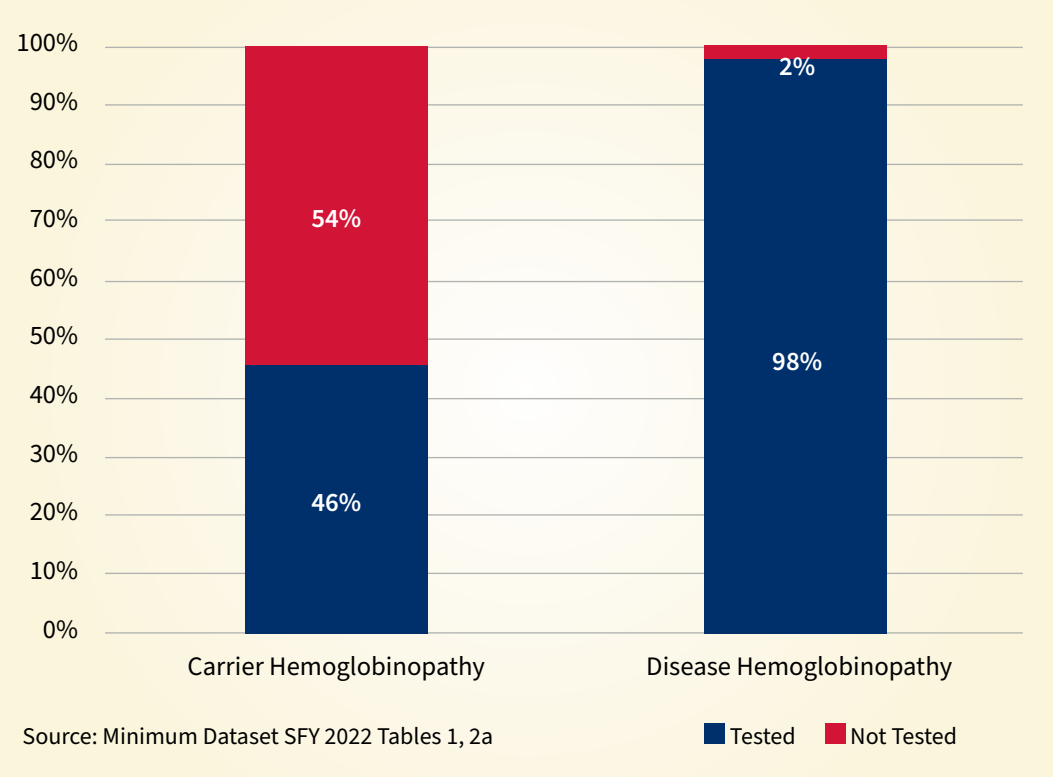
There were 138 (4% of abnormal screening results, <1% of the total births in SFY 2021) newborns that had a disease hemoglobinopathy screening result. Of these disease hemoglobinopathy screening results, 108 (79%) received confirmatory testing within the first two months of life and 20 (15%) received confirmatory testing after two months. A total of 10 (6%) disease hemoglobinopathy screening results did not receive confirmatory testing.

Figure 1. Newborns: Abnormal Screening Notification and Confirmatory Testing SFY 2021



[†] 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.

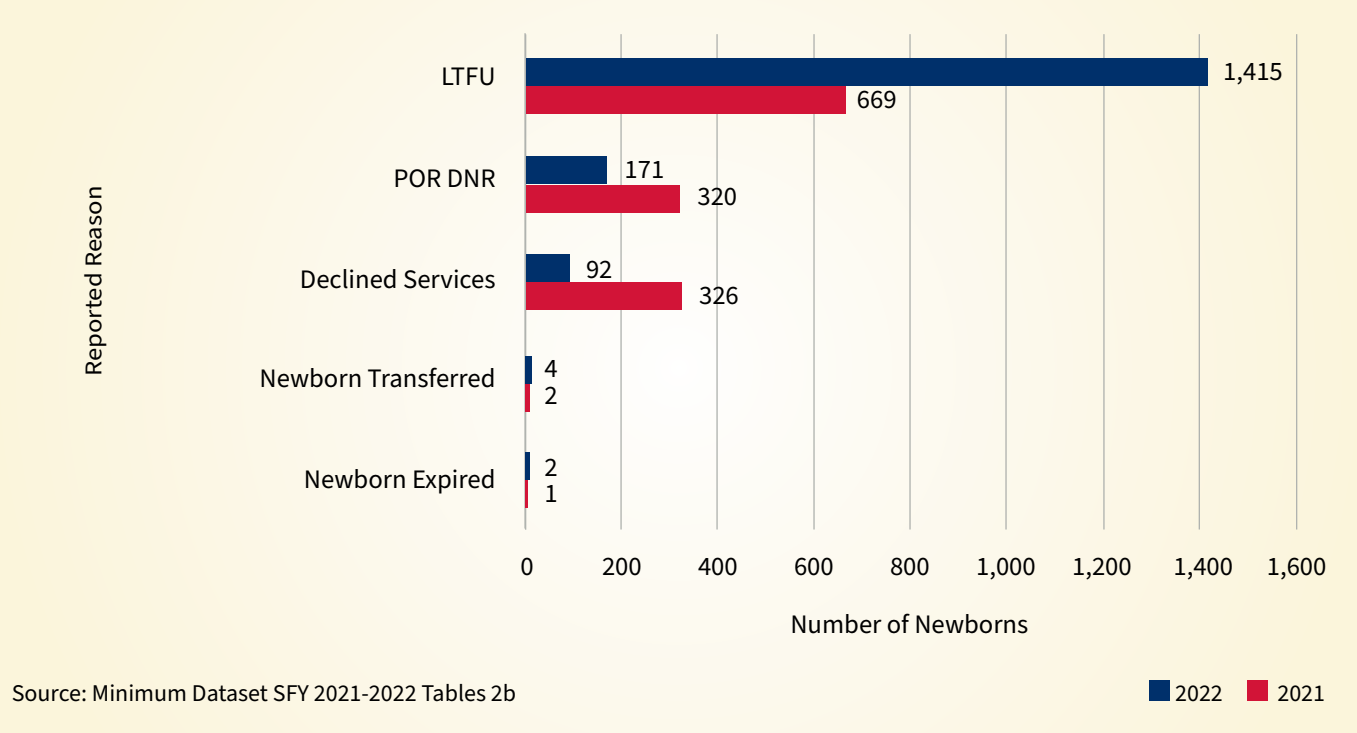
Figure 2. Newborns: Abnormal Screening Notification and Confirmatory Testing SFY 2022



During SFY 2022, the RSCPs received notification of 3,270 abnormal newborn hemoglobinopathy screening results from the ODH Public Health Laboratory. This number accounts for 2.5% of all Ohio births (n=129,254) during the reporting period. A total of 3,119 (95% of abnormal screening results, 2.4% of the total births in SFY 2022) had a carrier hemoglobinopathy screening result. Of these newborns, the RSCPs reported that 1,586 (55%) received confirmatory testing (See Figure 2).

There were 151 (5% of abnormal screening results, <1% of the total births in SFY 2022) newborns that had a disease hemoglobinopathy screening result. Of these disease hemoglobinopathy screening results, 122 (81%) received confirmatory testing within the first two months of life and 26 (17%) received confirmatory testing after two months. A total of three (2%) disease hemoglobinopathy screening results did not receive confirmatory testing.

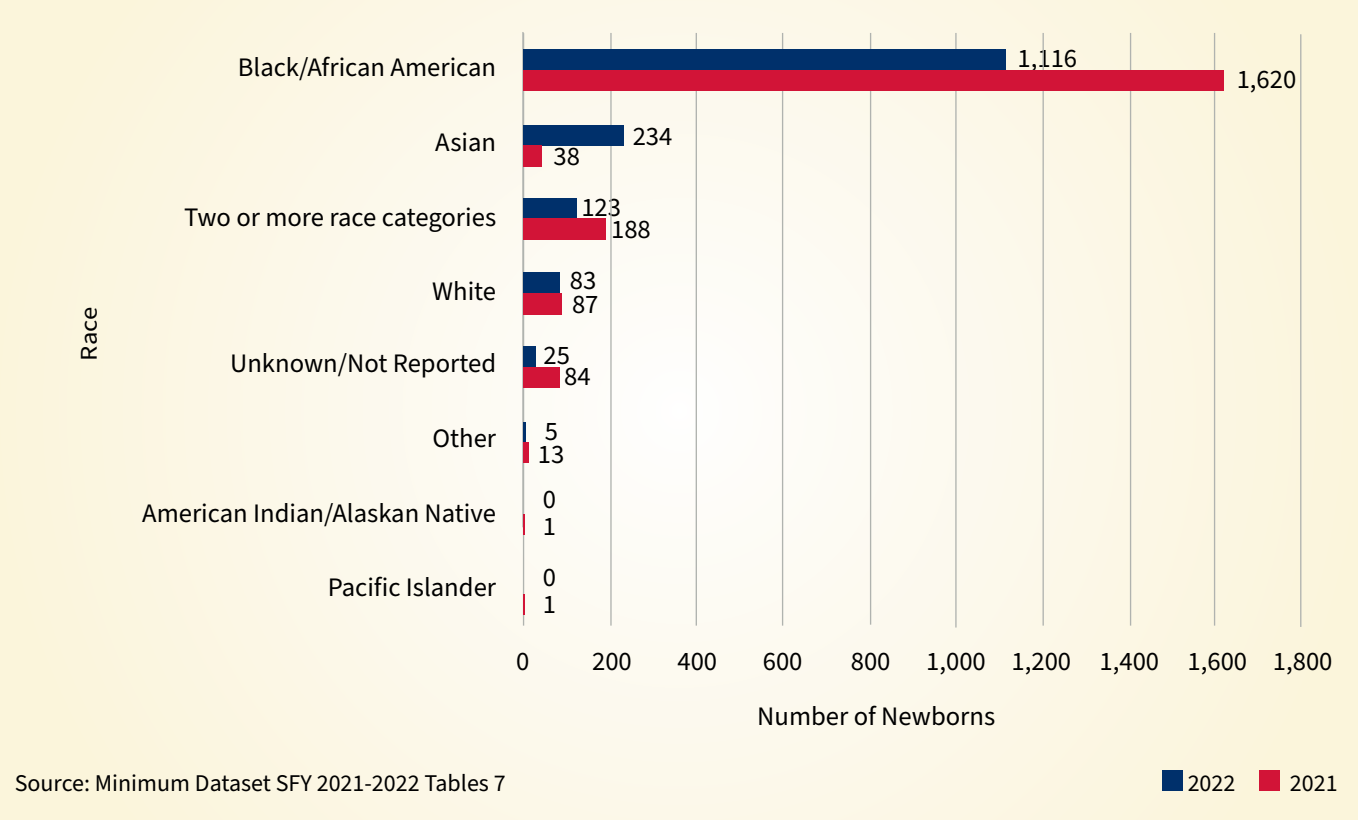
Figure 3. Reasons Newborns were not Documented as Having Confirmatory Testing (n_{2021}=1,318; n_{2022}=1,684)



The factors contributing to newborns not having confirmatory testing documented in SFY 2021 and SFY 2022 are outlined in Figure 3. In Figure 3, "POR DNR" indicates newborns for whom their designated physician did not respond to RSCP outreach. Furthermore, "LTFU" refers to newborns who were lost to follow-up, encompassing those who relocated out of state, lacked a primary care provider, had outdated contact information, or had caregivers who did not engage with RSCPs.

In SFY 2021, a total of 669 newborns were lost to follow-up, 320 were not referred to RSCPs by the physician of record, and 326 declined services. In SFY 2022, there were 1,415 newborns lost to follow-up, representing a significant increase of 112% compared to the previous year. Additionally, 171 newborns were not referred to RSCPs by the physician of record, reflecting a decrease of 47%, while 92 newborns declined services, indicating a decrease of 72%.

Figure 4. Newborns with Documented Confirmatory Testing by Race (n_{2021}=2,032; n_{2022}=1,586)



During SFY 2021, 1,620 (80%) of newborns who underwent confirmatory testing were Black or African American, while 188 (9%) were two or more races, and 87 (4%) were White.

During SFY 2022, 1,116 (70%) of tested newborns were Black or African American, with 123 (8%) were two or more races, and 83 (5%) were White. (See Figure 4.)

During SFY 2021, out of the newborns tested, 1,935 (95%) were Non-Hispanic, 24 (1%) were Hispanic, and 73 (4%) were of unknown ethnicity.

During SFY 2022, out of the newborns tested, 1,504 (95%) were Non-Hispanic, 53 (3%) were Hispanic, and 29 (2%) were of unknown ethnicity.

Newborns and infants diagnosed with treatable hemoglobinopathies should promptly receive treatment, which may include the initiation of penicillin prophylaxis for sickle cell disease as recommended in standard care protocols, within the first three months of life.

During SFY 2021, out of 138 newborns who underwent hemoglobinopathy confirmatory testing, RSCPs reported that 79 (57%) infants received treatment within the specified timeframe, with none receiving treatment after three months. Additionally, 59 (43%) newborns did not receive treatment, either due to being identified as carriers or having conditions that did not require treatment.

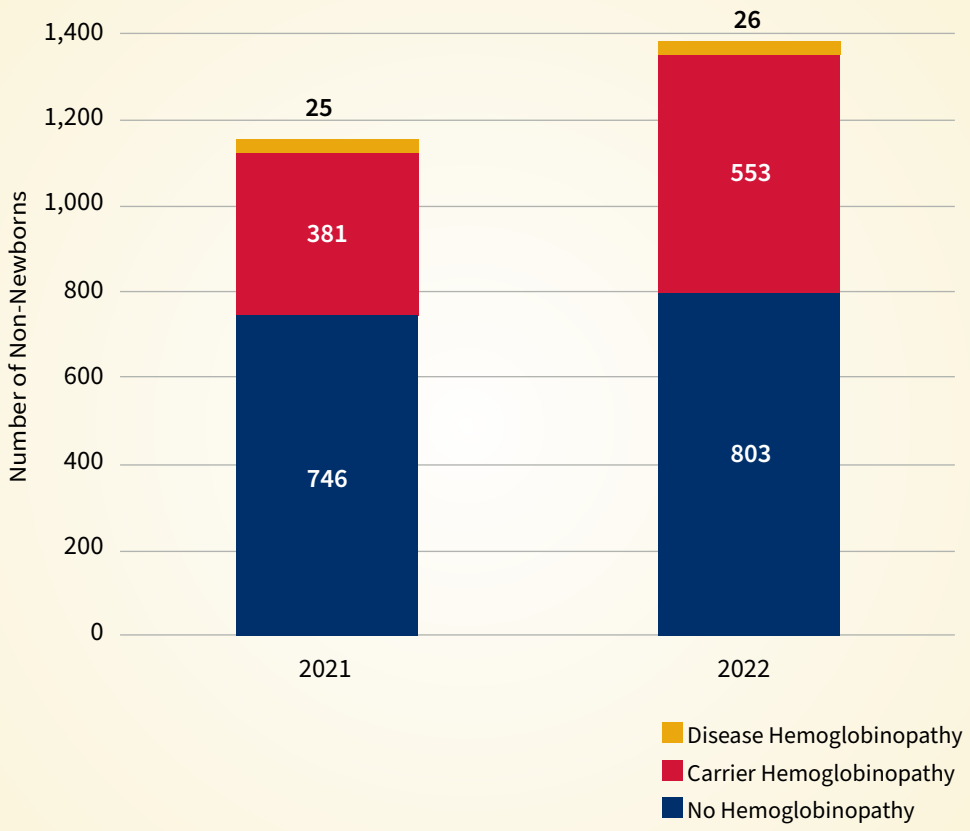
During SFY 2022, out of the 151 newborns who underwent hemoglobinopathy confirmatory testing, RSCPs reported that 84 (56%) newborns received treatment within three months of birth. None of the newborns received treatment after three months. Additionally, 67 (44%) newborns did not receive treatment, either because they were confirmed as carriers or because their diagnosis did not require treatment.

Non-Newborn Hemoglobinopathy Diagnostic Testing

During SFY 2021, 1,152 non-newborns* received hemoglobinopathy confirmatory testing services through a RSCP, with 25 (2%) identified with a disease hemoglobinopathy and 381 (33%) identified with a carrier hemoglobinopathy. A total of 746 (65%) non-newborns were identified with no hemoglobinopathy. (See Figure 5.)

During SFY 2022, 1,382 non-newborns received hemoglobinopathy confirmatory testing services through a RSCP, with 26 (2%) identified with a disease hemoglobinopathy and 553 (40%) identified with a carrier hemoglobinopathy. A total of 803 (58%) non-newborns were identified with no hemoglobinopathy. (See Figure 5.)

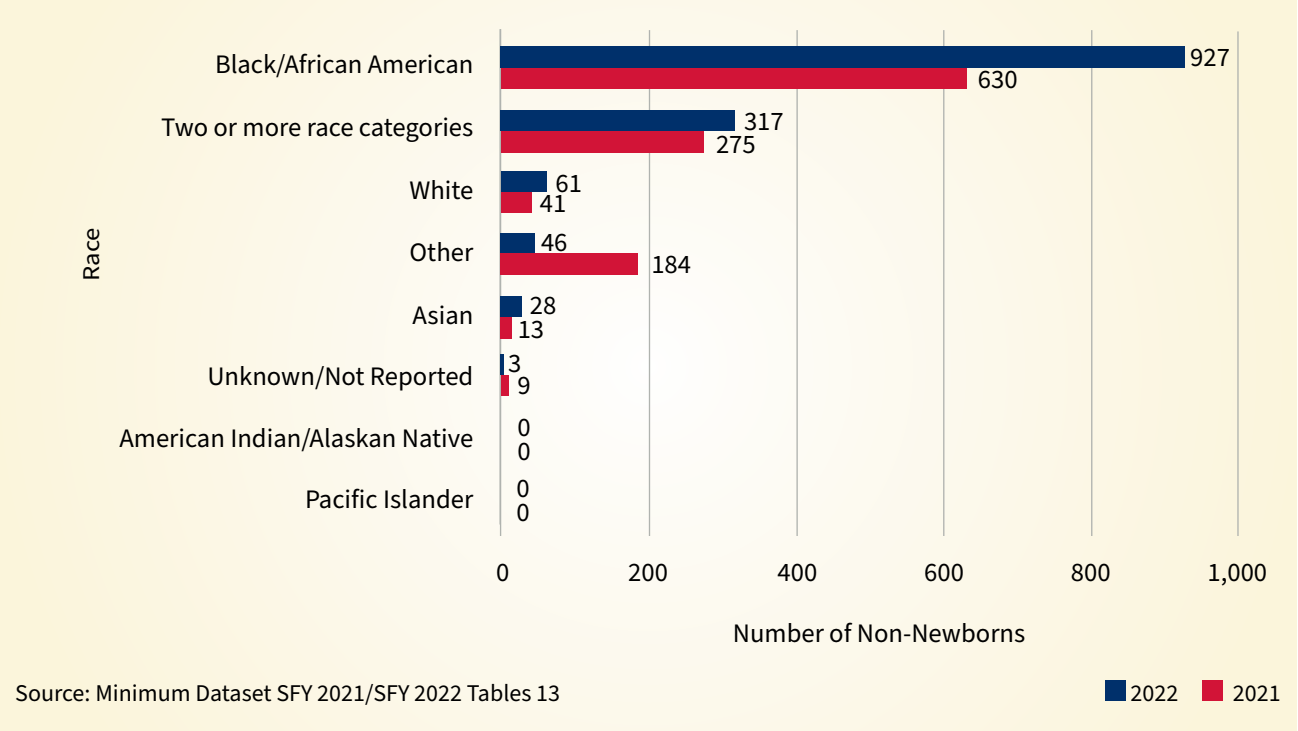
Figure 5. Non-Newborns with Hemoglobinopathy Testing (n_{2021}=1,152; $_{n2022}$=1,382)



Source: Minimum Dataset SFY 2021-2022 Tables 9

*Non-newborn is defined as an individual born before SFY 2021 (07/01/20 - 06/30/21) who received hemoglobinopathy follow-up services through an RSCP during SFY 2021.

Figure 6. Non-Newborns with Hemoglobinopathy Testing by Race (n_{2021}=1,152; n_{2022}=1,382)



During SFY 2021, 630 (55%) of non-newborn individuals undergoing hemoglobinopathy testing were Black or African American, 275 (24%) were classified under two or more race categories, and 41 (4%) were White.

During SFY 2022, 927 (67%) of non-newborn individuals receiving hemoglobinopathy testing were Black or African American, 317 (23%) were listed under two or more race categories, and 61 (4%) were White. (Refer to Figure 6.)

During SFY 2021, 965 (84%) of non-newborn individuals undergoing hemoglobinopathy testing were Non-Hispanic, 180 (16%) were Hispanic, and 7 (<1%) had unknown ethnicity.

During SFY 2022, 1,104 (80%) of non-newborn individuals receiving hemoglobinopathy testing were Non-Hispanic, 275 (20%) were Hispanic, and 3 (<1%) had unknown ethnicity.

In SFY 2021, a total of 3,184 individuals received hemoglobinopathy testing services, with 64% being newborns from 59 counties and 36% being non-newborns from 24 counties. In SFY 2022, a total of 2,968 individuals received hemoglobinopathy testing services, with 53% being newborns from 59 counties and 47% being non-newborns from 24 counties. Please refer to Figures 7a and 7b for more detailed information.

Figure 7a. Newborns with Confirmed Sickle Cell Disease by County

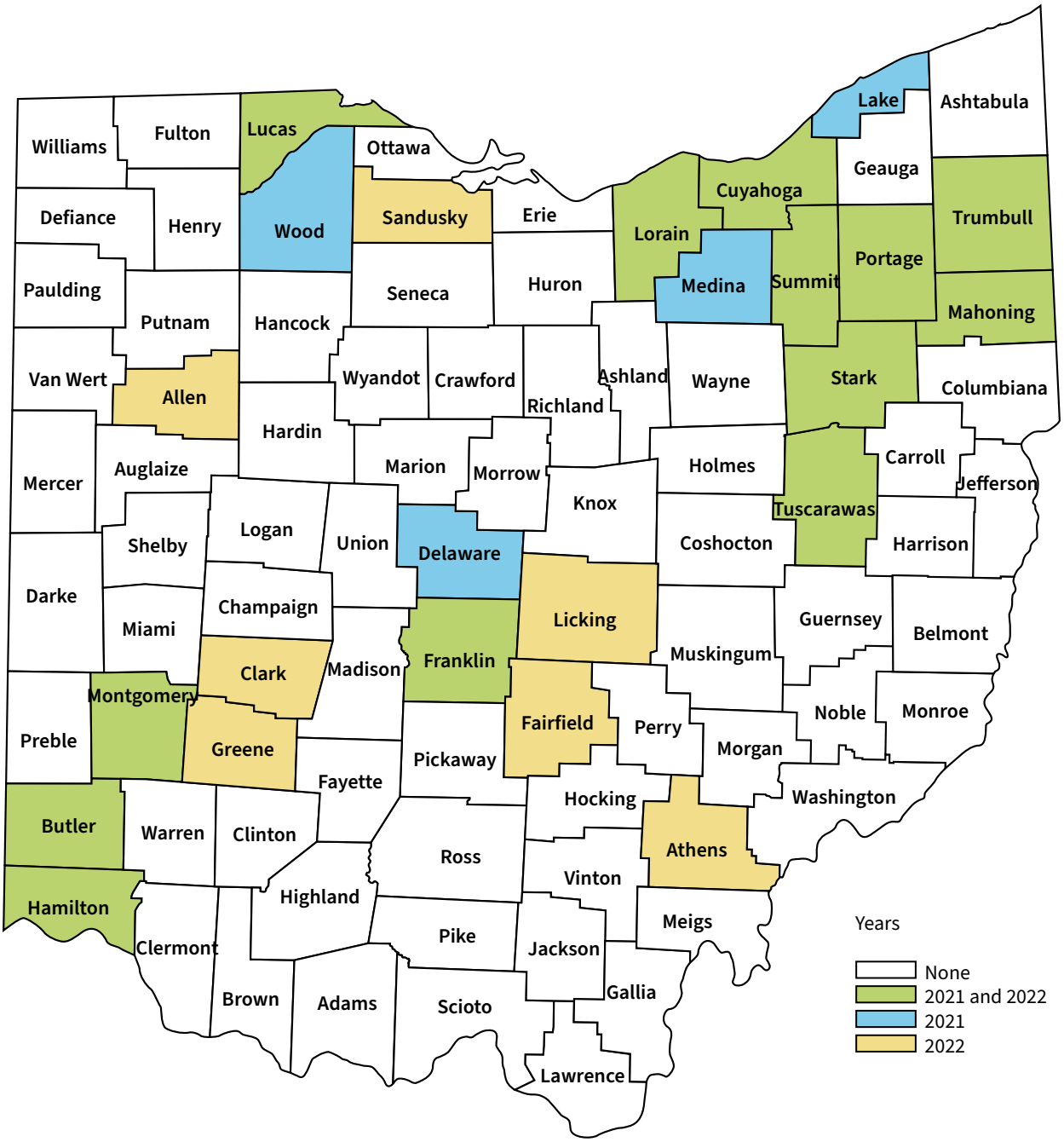


Figure 7b. Non-Newborns with Confirmed Sickle Cell Disease by County

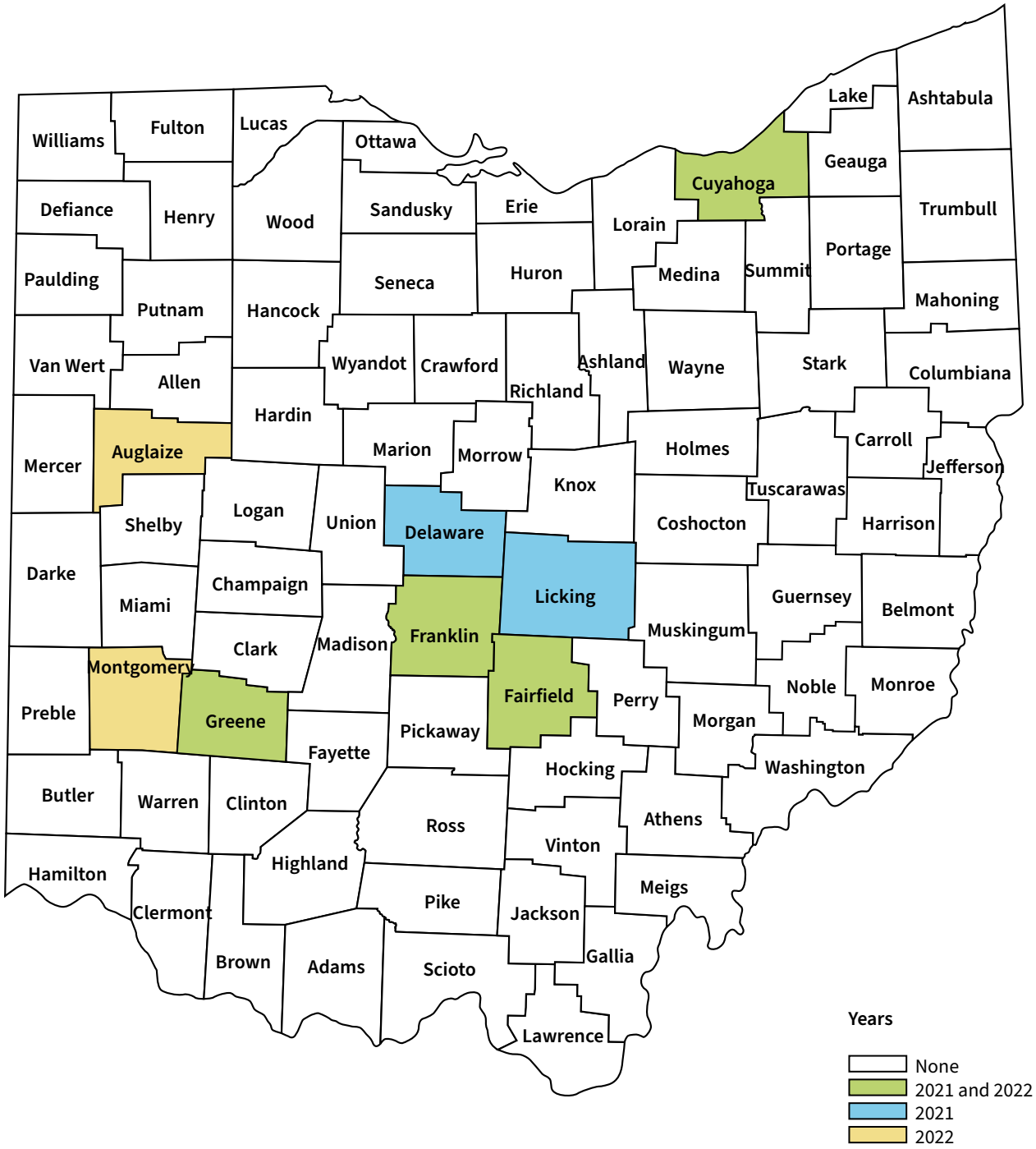


Figure 7c. Newborns with Confirmed Sickle Cell Trait by County

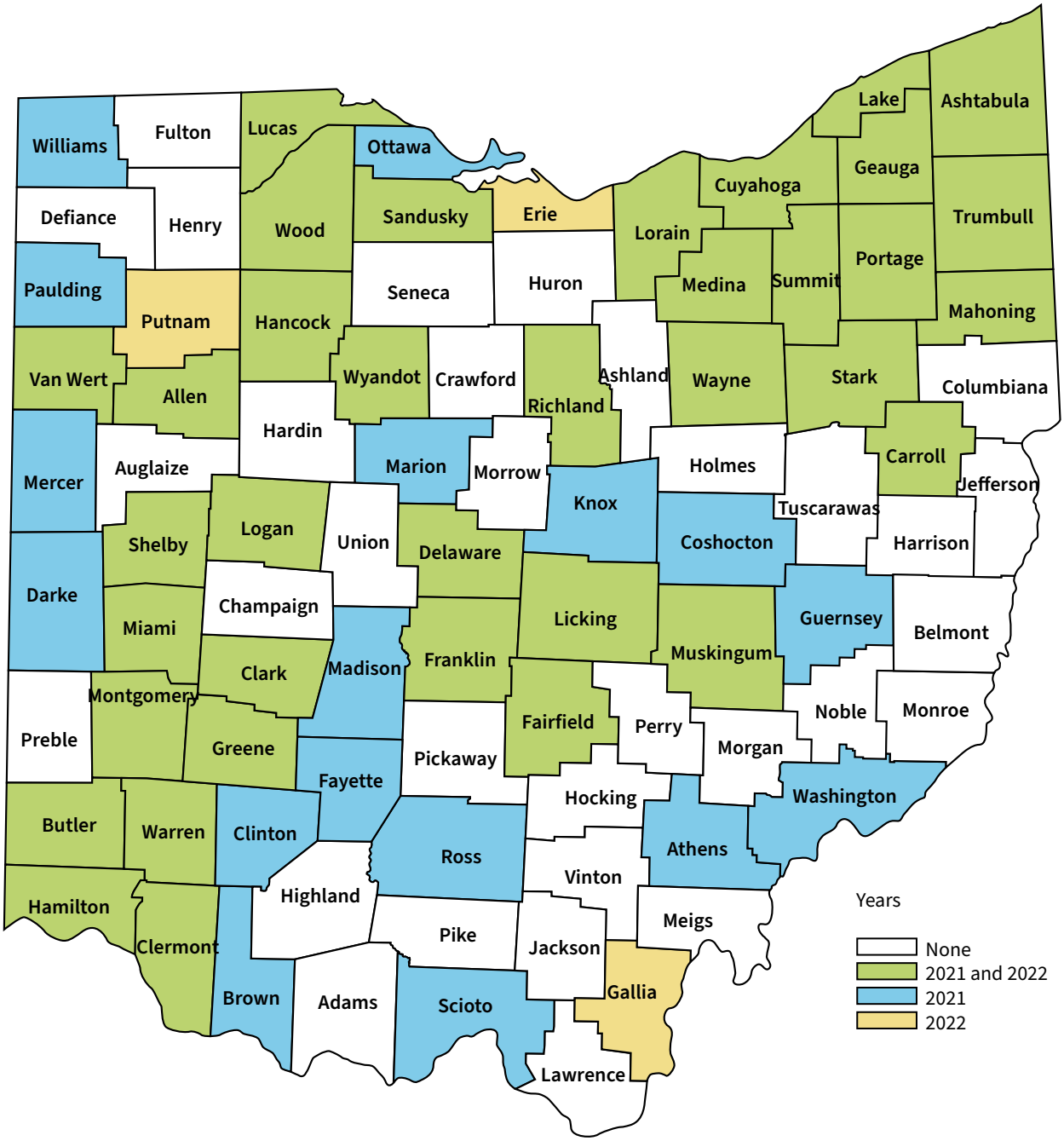
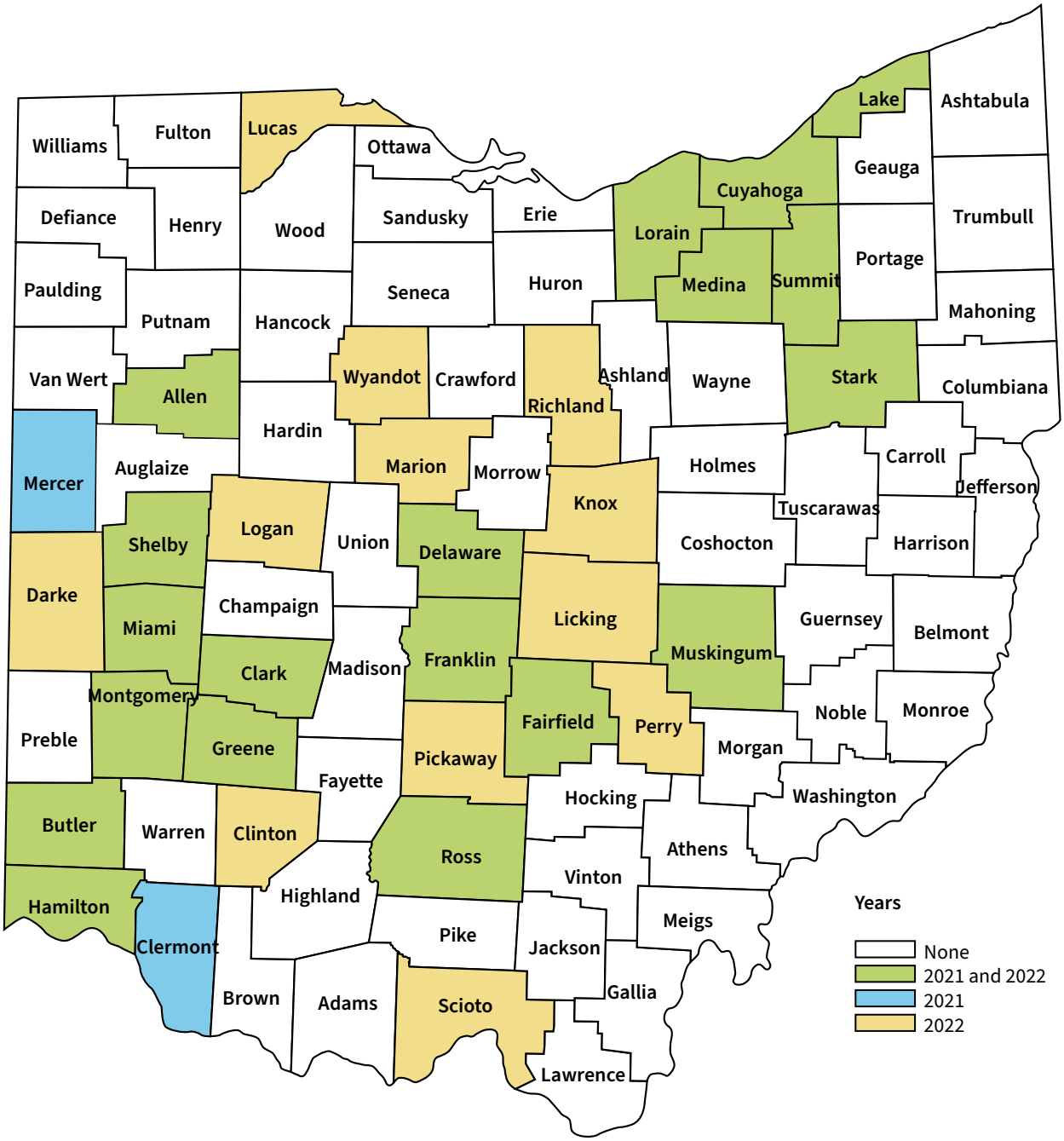


Figure 7d. Non-Newborns with Confirmed Sickle Cell Trait by County



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 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 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, non-RSCP providers may choose to counsel parents of newborns with a confirmed abnormal hemoglobin result.

Newborns

During SFY 2021, out of the 2,032 newborns born in SFY 2021 who underwent confirmatory testing, 1,797 (88%) had parents or guardians participate in hemoglobinopathy counseling. There were 188 (10%) of confirmed newborns whose parents or guardians did not receive counseling due to declined counseling or lost to follow-up.

During SFY 2022, out of the 1,586 newborns who underwent confirmatory testing, 1,417 (79%) had their parents or guardians receive hemoglobinopathy counseling. Of the 1,586 newborns who received confirmatory testing, 169 (11%) of confirmed newborns did not receive counseling as their parents or guardians either declined or were lost to follow-up.

Non-Newborns

During SFY 2021, hemoglobinopathy counseling services were provided to the parents or guardians of 1,109 non-newborns. Of these, 331 (30%) were parents of non-newborn infants and 582 (52%) were other non-newborns directly tested. All parents and guardians of non-newborns who received testing were subsequently counseled.

During SFY 2022, hemoglobinopathy counseling services were provided to the parents or guardians of 1,329 non-newborns. Of these, 412 (31%) were parents of non-newborn infants and 667 (50%) 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

One of the main goals of the Sickle Cell Services Program is to collaborate with state-funded Regional Sickle Cell Projects and the Statewide Sickle Cell Project in order to educate and provide information about hemoglobinopathies and related services to healthcare professionals, 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 play a vital role in educating professionals, patients, and the public about sickle cell disease and related hemoglobinopathies to minimize risks and effects. The Regional and Statewide Sickle Cell Projects conduct awareness activities during National Sickle Cell Awareness Month (September) and other nationally recognized health observance months (e.g., April/National Minority Health Month; May/Stroke Awareness Month; November/American Diabetes Month). These initiatives aim to:

- Educate the public about sickle cell disease and promote awareness of available services and resources.
- Emphasize the connection between hemoglobinopathies and other health issues.

Throughout the year, RSCPs collaborate with organizations and stakeholders interested in sickle cell disease to enhance awareness of the disease. This is achieved through the dissemination of current, up-to-date information and key messages aimed at improving health outcomes and reducing sickle cell disease health disparities among various racial, ethnic, and age groups.

During the SFY 2021, RSCPs conducted a total of 458 educational events, reaching approximately 19,085 individuals. The primary attendees at these events included members of faith-based communities, individuals from various professional backgrounds, and members of the public. These events collectively provided over 1,132 hours of direct education. For awareness events, funded projects conducted a total of 384 events, which had an estimated reach of 4,266,700 individuals.

During SFY 2022, RSCPs conducted a total of 453 education events, which provided education to an estimated 14,129 individuals. The most common attendees of these events were people in mixed disciplines and members of the general public. In total, the projects reported over 1,312 hours of direct education. For awareness events, funded projects conducted a total of 258 events, which had an estimated reach of 2,294,850 individuals. The general public made up more than 99% of these individuals.

References

1. 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.

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

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6. 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.

APPENDIX A: Sickle Cell Facts

Sickle cell disease (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 red blood. As a result of this mutation, individuals with SCD experience life-long complications including anemia, infections, stroke, tissue damage, organ failure, 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]

SCD 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.

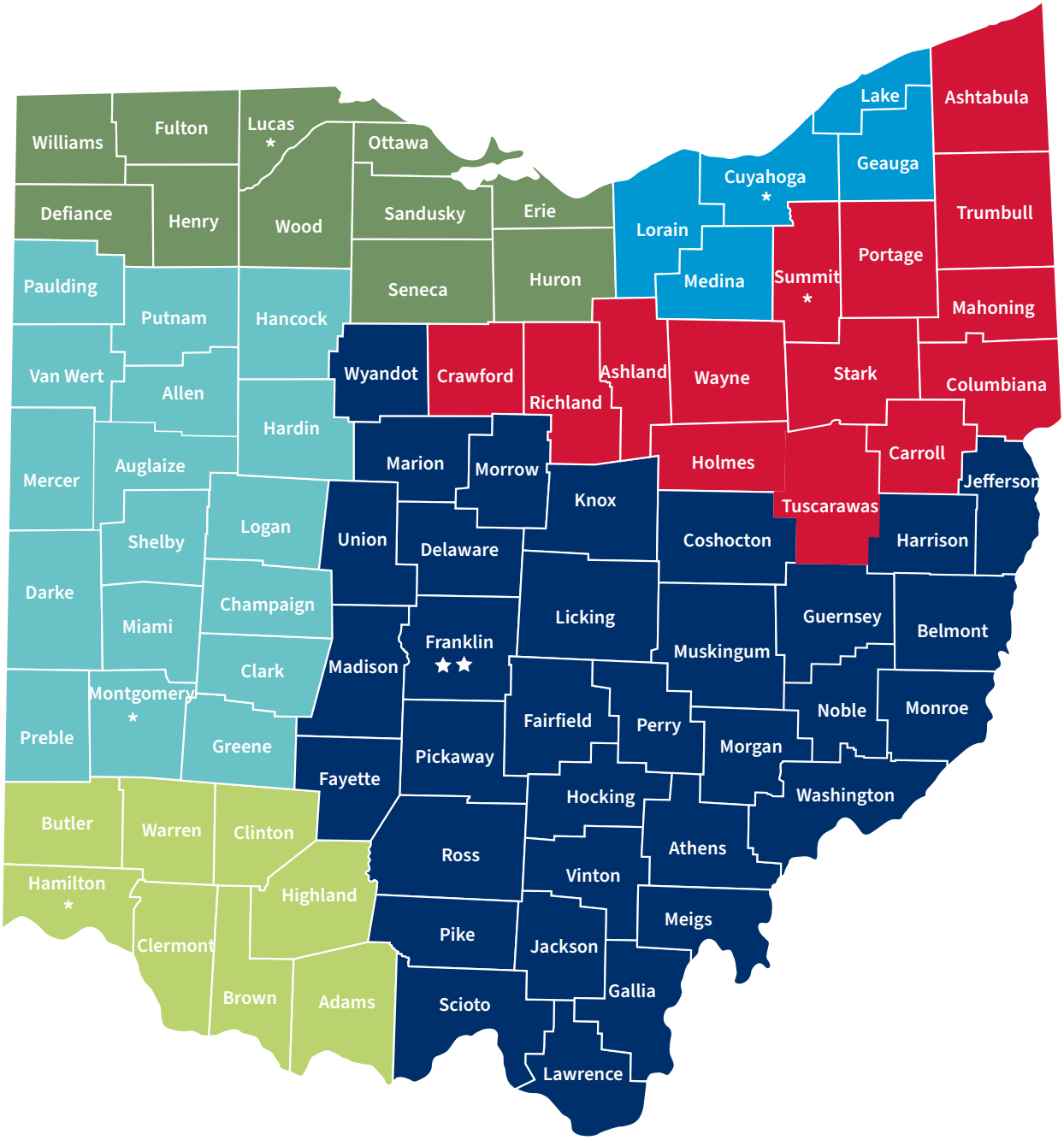
- **Hemoglobin sickle beta (b) thalassemia syndromes (HbSb$^+$and HbSb°-thalassemia)**
  People who have this form of SCD inherit one gene for HbS from one parent and one gene for b thalassemia, another type of anemia, from the other parent. There are two types of b thalassemia:
  HbSb$^+$-thalassemia and HbSb°-thalassemia. Those with HbSb°-thalassemia usually have a clinical course similar to HbSS. People with HbSb$^+$-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.[5]

APPENDIX B: Sickle Cell Regional Project Map



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* The asterisks 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 2021/2022 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 2021/2022 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 2021/2022 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, 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 2021/2022 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 2021/2022 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, X, 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 2021/2022 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 ages 6-16 and Counselor in Training Program for patients aged 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 2021/2022 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)