



OHIO DEPARTMENT OF HEALTH
SICKLE CELL SERVICES PROGRAM
STANDARDS AND CRITERIA

For Ohio Regional Sickle Cell Projects

PREFACE

The Standards and Criteria document serves to outline service and administrative components required of facilities that are requesting consideration by the Ohio Department of Health (ODH) Sickle Cell Services Program to become a state-funded Regional Sickle Cell Project (RSCP) under the Direct Service Initiative.

The purpose and intent of the Standards and Criteria document is threefold:

1. To assist ODH in carrying out its mission of protecting and improving the health of all Ohioans, in this case, through grant funding support for sickle cell¹ services.
2. To inform, guide and facilitate required “best” practices related to the provision of sickle cell services in Ohio.
3. To serve as the foundation for quality assurance of Ohio RSCPs.

Funding consideration shall be given to those applicant facilities that **meet or **exceed** ODH Sickle Cell Services Program Standards and Criteria. In conjunction, the Standards and Criteria will serve as the basis for monitoring and evaluation of each state-funded RSCP.**

Anyone requesting additional information on the contents of this document or services provided through the ODH Sickle Cell Services Program should direct inquires to:

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¹The terms sickle cell, sickle cell disease and hemoglobinopathies are used interchangeably in this document.



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OVERVIEW

Background

In 1972, the Ohio General Assembly passed legislation establishing services to individuals with sickle cell disease. Ohio House Bill 1024 (Section 3701.131 of the Ohio Revised Code) authorized the director of the Ohio Department of Health (ODH) 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.”

In 1974, ODH published the first State Plan for Genetic Services. The plan set forth the commitment, policy and rationale to assume a more progressive role in the prevention of genetic diseases in children, including children with sickle cell disease. The state plan also provided the foundation and conceptual framework for the development of a regional network of state-funded sickle cell projects. Regional Sickle Cell Projects have been funded by the ODH Sickle Cell Services Program since that time to ensure that comprehensive services and care are available to all Ohioans at risk or affected by sickle cell disease, sickle cell trait and other hemoglobinopathies.

In 1987, two federal agencies, the National Institutes of Health (NIH) and the Health Resources and Services Administration (HRSA), sponsored a *Consensus Development Conference on Newborn Screening for Sickle Cell Disease and Other Hemoglobinopathies*. Published recommendations from this conference called for universal hemoglobinopathy screening of newborns in most states. These recommendations brought significant changes in the direction of services provided by the ODH Sickle Cell Services Program. The same year, ODH initiated a pilot effort to develop protocols pertaining to newborn screening with a limited number of Ohio maternity and pediatric facilities.

In 1988, the Ohio Revised Code (ORC) governing tests on newborn infants (Chapter 3701-55) was revised to include screening for sickle cell disease and other hemoglobinopathies. Specific responsibilities of hospitals, primary care physicians and state-funded sickle cell projects were included and/or modified in the ORC.

By 1990, **statewide** universal newborn screening (NBS) for sickle cell disease and other hemoglobinopathies was mandated in Ohio along with Phenylketonuria (PKU), Homocystinuria, Galactosemia and Congenital Hypothyroidism. Ohio currently mandates testing of all newborns for 35 disorders.

The ODH Sickle Cell Services Program functions administratively in the Bureau for Children with Medical Handicaps within the Division of Family and Community Health Services. The Program works in partnership with the Newborn Screening Program, the Genetic Services Program, the Metabolic Formula Program and Ohio Connections for Children with Special Needs (OCCSN).

Purpose of the ODH Sickle Cell Services Program

As a public health program, the ODH Sickle Cell Services Program works to (1) ensure and enhance the availability and accessibility of quality, comprehensive sickle cell services and care for newborns, children and adults; (2) promote patient/consumer/family/professional education to increase awareness and knowledge about hemoglobinopathies and (3) increase collaboration, coordination and utilization of all sickle cell-related services/resources in Ohio.

Operational Description of a Regional Sickle Cell Project

A Regional Sickle Cell Project will operate as an identifiable, functional unit or program within a tertiary care or community-based facility. It must be organized for and capable of ensuring the provision of **regional** comprehensive sickle cell services to newborns, children and adults at risk or affected by sickle cell disease, sickle cell trait or other hemoglobinopathies in an ODH-defined multi-county service region (see **APPENDIX A**). Comprehensive services for the purpose of this document may include, but are not limited to:

- ◆ Tracking and follow up of abnormal hemoglobin results, including newborn and non-newborn test results
- ◆ Hemoglobinopathy counseling and/or disease education for patients/consumers/families
- ◆ Hemoglobinopathy education and resource materials, training, outreach and awareness activities for professionals and the public
- ◆ Care coordination and/or referral to specialized medical teams and resources for diagnostic, preventive, transition and evaluative management of sickling hemoglobinopathies

Components of a Regional Sickle Cell Project

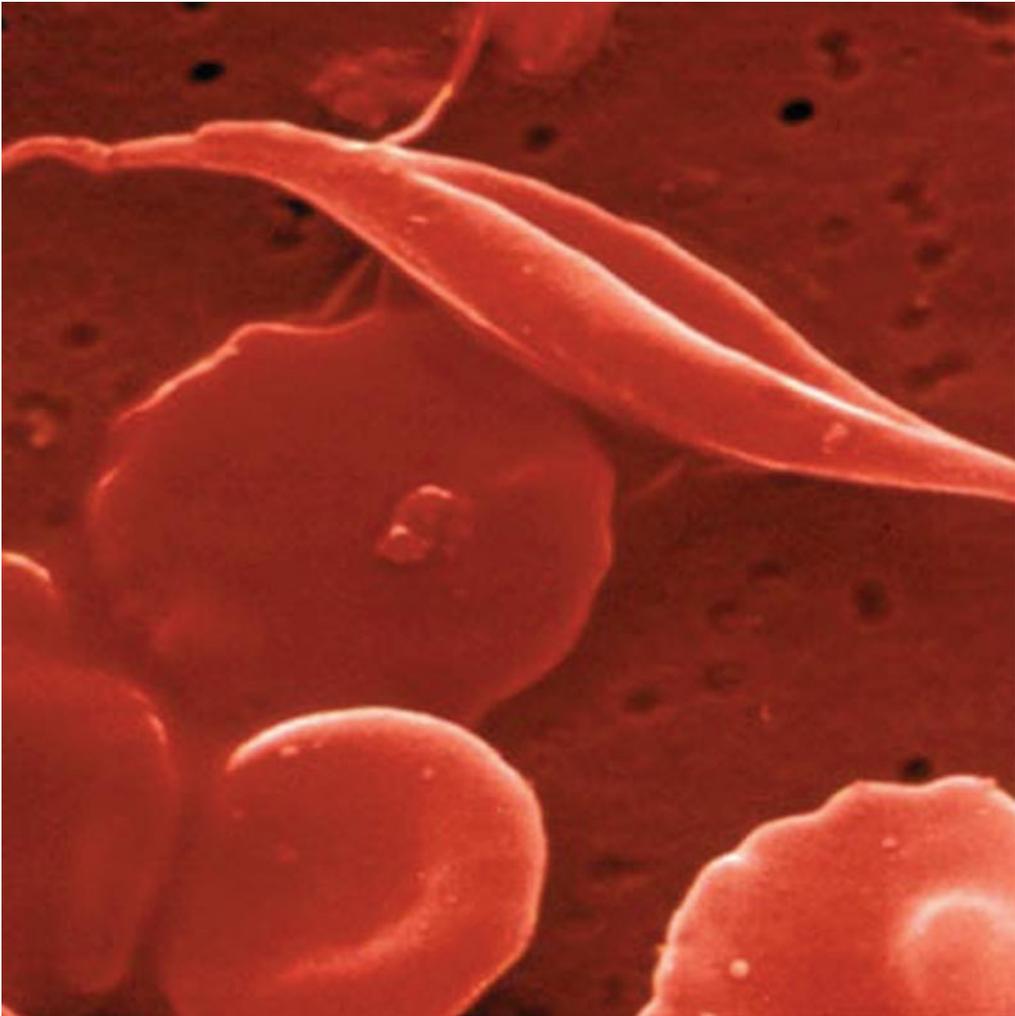
Each RSCP funded by ODH *must* meet or exceed the required (“*shall*”) Standards and Criteria and *may* meet many of the optional (“*should*”) Standards and Criteria outlined under the following five (5) major service and four (4) major administrative components:

Service Components

- ◆ Procedures of Care
- ◆ Education Activities
- ◆ Collaboration and Coordination Activities
- ◆ Outreach Activities
- ◆ Performance Improvement and Evaluation Activities

Administrative Components

- ◆ Facility Arrangements and Policies
- ◆ Staffing Composition and Administration
- ◆ Culturally and Linguistically Appropriate Services
- ◆ Guiding Operational Principles



COMPONENTS



SERVICE COMPONENTS

Procedures of Care for a RSCP shall include:

- A. "Follow-up" of any positive or potentially positive hemoglobin test result. This includes abnormal hemoglobin results received from the ODH Newborn Screening Program and other referral sources. Responsibilities and implementation of follow-up services should be assigned to a specific core team staff member (*see Staffing Composition and Administration*).
- B. Hemoglobinopathy counseling formats for all hemoglobin variants which are:
 - ◆ Non-directive and aimed at helping patients/consumers make informed decisions about health related and/or family planning issues that they believe are in their best interest.
 - ◆ Communicated accurately, thoroughly and clearly to the patient/consumer/family in a manner that is consistent with their primary language, literacy level, learning style and cultural needs (*see Education Activities and Culturally and Linguistically Appropriate Services*).
- C. Affiliations and/or working relationships with pediatric and adult primary care and hematology service providers in the region.
- D. An operational manual of protocol and responsibility related to the development, implementation and evaluation of the procedures of care component.

In addition, the RSCP should:

- A. Offer a program that identifies adolescents/young adults with sickle cell disease and coordinates the transition of their medical care from pediatric to adult care and services.
- B. Record information via documentation forms and/or data systems related to the provision of comprehensive sickle cell care and services to include, but not limited to the following:
 - ◆ Patients/consumers race, ethnicity and language
 - ◆ Diagnostic/confirmatory test results
 - ◆ Physician/provider of record
 - ◆ Source of referral
 - ◆ Follow-up services provided
 - ◆ Treatment interventions, if applicable

Education Activities of an Ohio RSCP shall include:

- A. **Patient/consumer/family education** consisting of:
1. Up-to-date information related to all aspects of the diagnosis (including complications and management, if applicable) communicated accurately, thoroughly and clearly to the patient/consumer/family in a manner consistent with their:
 - ◆ primary language (or other mode of communication)
 - ◆ literacy level
 - ◆ learning style
 - ◆ cultural needs (*see Culturally and Linguistically Appropriate Services*).
- B. **Community education and public awareness** consisting of:
1. Regional outreach strategies that focus on the dissemination of hemoglobinopathy education and information to targeted unserved, under-served and emerging population groups and venues including schools, faith-based groups, social, cultural and civic organizations and the general public.
 2. Culturally sensitive, age-appropriate programs and written materials designed and utilized for diverse audiences including those with various language and literacy levels (*see Culturally and Linguistically Appropriate Services*).
 3. A plan for public awareness which informs residents of the availability of services and promotes community understanding of sickle cell services and interventions.
- C. **Professional education and training** consisting of:
1. Strategies to increase the knowledge and sensitivity of health care and other professional groups and providers about the special health care needs and services related to individuals with hemoglobinopathies.
 2. Integrating hemoglobinopathy education into medical training and continuing education curriculums of other professional groups.
- D. Compliance with ownership copyright and verbiage/logo requirements on all RSCP-designed/produced education materials (e.g. media, brochures, audio-visual, translated documents) in accordance with ODH guidelines. All material(s) must clearly state:
- Funded in whole or part by the Ohio Department of Health
Bureau for Children with Medical Handicaps
Sickle Cell Services Program
<http://www.odh.ohio.gov/odhPrograms/cmh/scell/scell1.aspx>
- E. A regional resource clearinghouse of public, professional and patient/consumer hemoglobinopathy education materials that are current, of professional quality, culturally, age, language and literacy appropriate and available upon request (*see Culturally and Linguistically Appropriate Services*).

- F. An operational manual of protocol and responsibility related to the development, implementation and evaluation of the education component.

In addition, the RSCP *should*:

- A. Offer educational opportunities to increase patient/consumer knowledge about their disorders and promote self-care and empowerment.

Collaboration and Coordination Activities of an Ohio RSCP shall include:

- A. Networking and linkages established and maintained with appropriate medical health services and health information providers to maximize resources and prevent/minimize duplication of services.
- B. Active participation and/or collaboration with community, state and national programs and organizations/leaders to enhance patient/consumer/family education about specific disorders and to increase availability of peer support resources. Peer support resources include, but are not limited to: Family Voices, Ohio Sickle Cell Affected Families Association, March of Dimes (Ohio Chapter/National), Sickle Cell Disease Association of America, Inc. National Organization for Rare Disorders and Genetic Alliance.
- C. A single contact telephone number and project brochure that is widely publicized (e.g. 211 Ohio information system) for coordinated information and referral purposes (*see Facility Arrangements and Policies*).
- D. Referral policies and procedures that facilitate entry of the population to be served. Procedures must include information on referrals to ODH public health programs including, but not limited to:
 1. **Bureau for Children with Medical Handicaps (BCMh)** — A health care program (Diagnostic, Treatment and Service Coordination) which links families of children with special health care needs (age 0-21) to a network of quality providers and assists eligible families in obtaining payment for required services.
 2. **Help Me Grow (HMG)** — A program that provides health and developmental services to Ohio's expectant parents, newborns, infants and toddlers (age 0-3) with eligible conditions.
 3. **Ohio Connection for Children with Special Needs** — A birth defects information services program designed to ensure that those children and families (age 0-5) with specific birth defects are connected with appropriate medical providers and other support services.
 4. **Genetic Services Program** — A program to help individuals learn about birth defects and genetic disorders. The program also helps individuals who have these disorders get information about treatment and services through a regional network of genetic centers and clinics located throughout Ohio.

In addition, the RSCP *should*:

- A. Maintain a database of regional pediatric and adult primary care and sub-specialists to increase access to medical support and sub-specialty services necessary for the diagnosis, prevention, transition, evaluation and management of sickling hemoglobinopathies.
- B. Maintain an RSCP specific web page to increase patient/consumer/professional access to information on hemoglobinopathies, NBS and regional programs/services (see *Facility Arrangements and Policies*).

Outreach Activities of an Ohio RSCP *should* include:

A. **Satellite Clinic Site** that:

- 1. Increases the accessibility and availability of **community-based** hemoglobinopathy follow-up to unserved, under-served and emerging population groups through **regularly** scheduled clinics and educational outreach services.
- 2. Is coordinated and staffed by credentialed health care professionals based at the site.
- 3. Operate under the auspices of a larger health care institution or community-based organization (as the primary facility) through which its funding flows and to which referrals can be made for the full range of diagnostic and therapeutic services as needed.

And, or:

A. **Outreach Clinic Site** that:

- 1. Increases the accessibility and availability of **community-based** hemoglobinopathy follow-up to unserved, under-served and/or emerging population groups through periodically scheduled clinics and educational outreach services.
- 2. Are operated by a primary facility (hospital or community-based) and convened in various "host" facilities located outside of the primary facility's home county.
- 3. Is coordinated locally (usually by an employee of the host facility) and staffed by a medical professional and/or other visiting credentialed professionals (see *Staffing Composition and Administration*).
- 4. Offer a limited range of hemoglobinopathy follow-up services but through which referrals can be made to a primary facility for the full range of diagnostic and therapeutic services as needed.

Performance Improvement and Evaluation Activities of an Ohio RSCP *shall* include:

Project Level Activities

- A. Implementation of appropriate methods to monitor, evaluate and improve the quality of patient/consumer and RSCP services/programs.
- B. A process for identifying and resolving individual patient/consumer, as well as RSCP staff member complaints and/or problems.
- C. Evaluation mechanism(s) in place to assess the level of patient/consumer understanding of information subsequent to hemoglobinopathy counseling and/or education services.
- D. Participation in a project self-evaluation and/or monitoring site visit process as specified by ODH.
- E. Development and maintenance of a **functional Regional Sickle Cell Advisory Committee** which meets, at a minimum three (3) times during the state fiscal year (July through June), and whose purpose is to assist and advise the RSCP in formal interagency planning, evaluation, policy development (in accordance with ODH standards) and implementation of a coordinated, comprehensive and multi-disciplinary system of **regional** sickle cell supports and services (see **APPENDIX B**).

ODH Data Collection and Reporting Requirements

- A. Maintenance of computer hardware and software as specified by ODH to allow linkage and data entry in designated information systems.
- B. Setup, collection and reporting of RSCP newborn screening, hemoglobinopathy counseling and education event data in accordance with ODH data fields and definitions.
- C. Monitoring and reporting of performance indicators as defined by ODH to measure regional/statewide program results and impact.
- D. Compliance with all state and federal data collection and other reporting requirements.
- E. Participation in research and evaluation activities as recommended by the director of health, ODH Advisory Councils (e.g. NBS, OCCSN) and/or the Statewide Sickle Cell Advisory Committee.

ADMINISTRATIVE COMPONENTS

Facility Arrangements and Policies for an Ohio RSCP *shall* include:

- A. Identification with an ODH-defined multi-county sickle cell service region in the state of Ohio.
- B. Location in a tertiary care or community-based facility with an identifiable, functional unit or program organized for and capable of ensuring the provision of **regional** comprehensive sickle cell services.
- C. Proper licensure/certification (if required for operation) by ODH or any other licensing/certifying agency.
- D. Compliance with Federal and State Assurances for Subgrantees and other documentation as required by ODH.
- E. Adequate and appropriate space designated for administrative tasks, record keeping, data management, storage of supplies and educational materials and the provision of private counseling services.
- F. Designated telephone number(s) through which all services can be accessed and for contacting the RSCP core team staff during regular work hours.
- G. A secure fax machine, e-mail and web service in compliance with the Health Insurance Portability and Accountability Act (HIPAA) guidelines.
- H. Linkage with the ODH web site on RSCP-specific web sites. The site can be accessed at: <http://www.odh.ohio.gov/odhPrograms/cmh/scell/scell1.aspx>
- I. Permission for access and review of facility records (including those of project contractors, if applicable) by ODH staff in compliance with the Ohio Public Records Law, Section 149.43 of the ORC.

Staffing Composition and Administration of an Ohio RSCP *shall* include:

- A. The necessary administrative, professional and technical staff in place for the effective operation of the project. The **core team staff** must have experience and/or expertise in the provision of sickle cell services and, at a minimum, include:

1. **Project Director** — This person is responsible for organization, implementation and administration of the service and administrative components of the RSCP (see **APPENDIX C**). The person in this position will also be expected to maintain close contact with the ODH Sickle Cell Program Coordinator and the Grant Administration Unit (GAU) Grant Consultants. Depending on the funding resources, this position may be combined with other core team staff functions.
 2. **Newborn Screening Coordinator** — This person is responsible for the planning, coordination and implementation of newborn hemoglobin screening/testing follow-up and hemoglobinopathy counseling services (see **APPENDIX D**). This is a one hundred percent grant-funded position.
 3. **Regional Outreach Educator** — This person is responsible for the overall planning, coordination, implementation and evaluation of public and professional hemoglobinopathy education services (see **APPENDIX E**). Depending on the funding resources, this position may be combined with other core team staff functions.
 4. **Medical Director/Medical Advisor** — This person is responsible for providing guidance and leadership to the team regarding the five (5) service components and four (4) administrative components of the RSCP. The position of Medical Director is associated with hospital-based applicants. The Medical Advisor position is associated with community-based applicants (see **APPENDIX F**).
- B. Documented completion of a Hemoglobinopathy Training Program within **one year of employment** for applicable RSCP core team staff.
- C. Administrative staff meetings that are convened at least quarterly and include core RSCP team staff.
- D. RSCP staff members who continuously update their knowledge and skill level with respect to hemoglobinopathies and culturally and linguistically appropriate service delivery through documented attendance/participation in conferences, seminars, workshops, webinars and/or in-service education programs.
- E. **Current** biographical sketches/resume/curricula vitae on file with the ODH Sickle Cell Program Coordinator or submitted within 30 days of hire for new employees.
- F. Maintenance of written contracts/agreements (with specific deliverables) for all core professional services not directly provided by project personnel.
- G. Participation/attendance at all requested and/or required ODH meetings, conference calls, trainings and/or webinars.

In addition, the RSCP *should*:

- A. Have an **extended multi-disciplinary team** comprised of areas of expertise readily available and accessible as needed for referral and/or consultation, including but not limited to:
 - 1. Hemoglobinopathy Nursing (pediatric and adult)
 - 2. Psycho-Social (e.g. psychology, social work)
 - 3. Counseling (e.g. genetic, financial, education/vocational/rehabilitation)
 - 4. Pain Management (pediatric and adult)
 - 5. Other Physician Specialties (e.g. surgery, radiology, ophthalmology, nephrology, pulmonary, psychology, psychiatry, dental, obstetrics/gynecology)
 - 6. Other Allied Health Disciplines (e.g. nutrition, occupational, physical, recreational, massage therapy)

Culturally and Linguistically Appropriate Services of an Ohio RSCP shall include:

Language Access Services

- A. Language assistance services including bilingual staff and interpreter services, at no cost to each patient/consumer with limited English proficiency (LEP) at all points of contact, in a timely manner during all hours of operation (Culturally and Linguistically Appropriate Services (CLAS) Standard 4).
- B. Both verbal and written notices, to inform patients/consumers, in their preferred language, of their right to receive language services (CLAS Standard 5).
- C. Language assistance services to limited English proficient patients/consumers that are provided by competent interpreters and bilingual staff. Family and friends should not be used to provide interpretation services (except on request by the patient/consumer) (CLAS Standard 6).
- D. Easily understood patient-related materials and post signage made available in the languages of the commonly encountered groups and/or groups represented in the service area (CLAS Standard 7).

In addition, the RSCP *should*:

Culturally /Competent Care

- A. Ensure that patients/consumers receive from all staff members' effective, understandable and respectful care that is provided in a manner compatible with their cultural health beliefs and practices and preferred language (CLAS Standard 1).
- B. Implement strategies to recruit, retain and promote at all levels of the organization a diverse staff and leadership that are representative of the demographic characteristics of the service area (CLAS Standard 2).
- C. Ensure that staff at all levels and across all disciplines receives ongoing education and training in culturally and linguistically appropriate service delivery (CLAS Standard 3).

Organizational Support for Cultural Competence

- D. Develop, implement and promote a written strategic plan that outlines clear goals, policies, operational plans and management accountability/oversight mechanisms to provide culturally and linguistically appropriate services (CLAS Standard 8).
- E. Conduct initial and ongoing organizational self-assessments of CLAS-related activities and are encouraged to integrate cultural and linguistic competence-related measures into their internal audits, performance improvement programs, patient satisfaction assessments and outcome-based evaluations (CLAS Standard 9).
- F. Ensure that data on the individual patient/consumer race, ethnicity, spoken and written language are collected in health records, integrated into the organization's information system and periodically updated (CLAS Standard 10).
- G. Maintain a current demographic cultural and epidemiological profile of the community as well as a needs assessment to accurately plan for and implement services that respond to the cultural and linguistic characteristics of the service area (CLAS Standard 11).
- H. Develop participatory, collaborative partnerships with communities and utilize a variety of formal and informal mechanisms to facilitate community and patient/consumer involvement in designing and implementing CLAS-related activities (CLAS Standards 12).
- I. Ensure that conflict and grievance resolution processes are culturally and linguistically sensitive and capable of identifying, preventing and resolving cross-cultural conflicts and complaints by patient/consumers (CLAS Standard 13).

The ODH Sickle Cell Services Program also suggests the following CLAS recommendation for voluntary adoption:

- A. Health care organizations are encouraged to regularly make available to the public information about their progress and successful innovations in implementing the CLAS standards and to provide public notice in their communities about the availability of this information.

Policy, Procedure and Practices of an Ohio RSCP shall be developed based on the following *Guiding Operational Principles*:

- A. RSCP services are available, accessible, family-centered and culturally and linguistically appropriate.
- B. No individual is denied RSCP services on the basis of age, gender, sexual orientation, race, color, religion, ancestry, national origin, language difference, disability, medical condition, educational level, veteran status, ability to pay or any other factor specified in legislation pertaining to civil rights.
- C. Individuals and their families requiring and/or receiving hemoglobinopathy services shall have the freedom to utilize the RSCP of their choice and actively participate in decision-making regarding their own health care.
- D. Patient/consumer/family privacy and confidentiality is maintained and practiced by RSCP staff, interns and volunteers as outlined by HIPAA guidelines.
- E. A policy and procedure in place to deal with ethical/legal issues, especially those related to confidentiality, discrimination and informed consent.

REFERENCES

1. *Sickle Cell Act*. Amended House Bill No.1024, July 1972.
2. *State Plan for Genetic Services*. Ohio Department of Health (Coordinating Agency), September, 1974.
3. *Consensus Conference*. Newborn Screening for Sickle Cell Disease and Other Hemoglobinopathies. JAMA 1987; 258:1205-9.
4. *Guidelines for Clinical Genetic Services for the Public's Health*. Council of Regional Networks for Genetic Services (CORN). Edited by Sallie B. Freeman, Ph.D., Cynthia F. Hinten, M.S., M.P.H., Louis J. Elsas, II, M.D., April 1997.
5. *Ohio Hemophilia Treatment Center Standards and Criteria*. Ohio Department of Health, Columbus, Ohio, revised 1999.
6. *Consumer Indicators of Quality Genetic Services*. Alliance of Genetic Support Groups, 4301 Connecticut Avenue, Washington, D.C., 1999.
7. *National Standards for Culturally and Linguistically Appropriate Services in Health Care: Final Report*. Produced for the Office of Minority Health, U.S. Department of Health and Human Services, OPHS, 2001.
8. *Ohio Regional Comprehensive Genetic Centers Standard and Criteria*. Ohio Department of Health, Columbus, Ohio, revised 2004.
9. *Advisory Councils*. Nancy Axelrod, Board Source, 2004.
10. *U.S. Newborn Screening System Guidelines: Statement of the Council of Regional Networks for Genetic Services*. BL. Therrell, et al., February, 1992.

DOCUMENT WEB SITES

Culturally and Linguistically Appropriate Services

<http://minorityhealth.hhs.gov/assets/pdf/checked/finalreport.pdf>

Family Voices of Ohio

www.familyvoicesohio.org

Genetic Alliance

www.geneticalliance.org

Health Resources and Services Administration

www.hrsa.gov/index.html

HIPPA Safeguards

<http://www.hhs.gov/ocr/privacy/hipaa/understanding/special/healthit/safeguards.pdf>

March of Dimes, National

www.marchofdimes.com

March of Dimes, Ohio Chapter

www.marchofdimes.com/ohio/

National Commission for Health Education Credentialing, Inc

www.nchec.org

National Institutes of Health

www.nih.gov

ODH Bureau for Children with Medical Handicaps

www.odh.ohio.gov/odhPrograms/cmh/cwmh/bcmh1.aspx

ODH Help Me Grow

www.ohiohelpmegrow.org

ODH Metabolic Formula Program

<http://www.odh.ohio.gov/odhPrograms/cmh/metaform/metaform1.aspx>

ODH Newborn Screening Program

www.odh.ohio.gov/odhPrograms/phl/newbrn/nbrn1.aspx

ODH Genetics Program

www.odh.ohio.gov/odhPrograms/cmh/genserv/genserv1.aspx

ODH Sickle Cell Services Program

www.odh.ohio.gov/odhPrograms/cmh/scell/scell1.aspx

Ohio Administrative Code for Genetic, Endocrine or Metabolic Screening of Newborn Infants

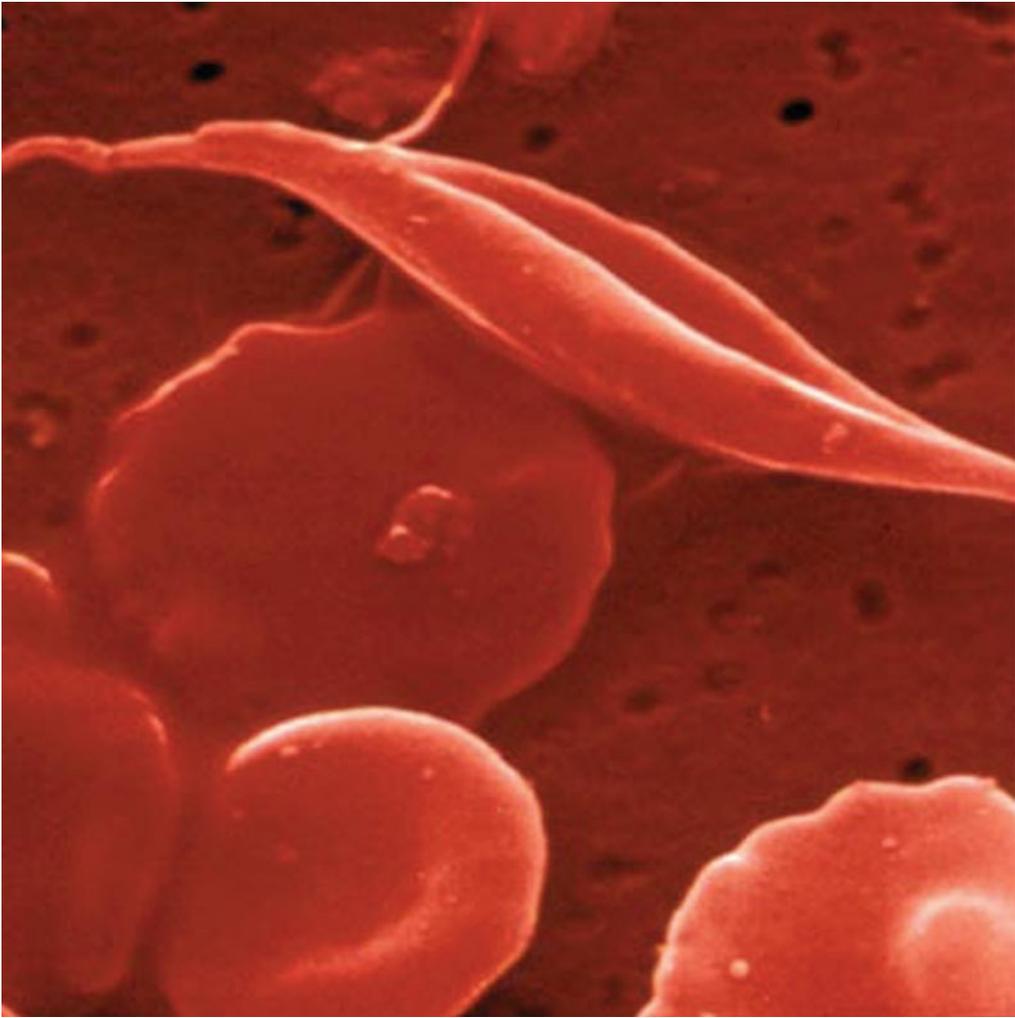
www.odh.ohio.gov/rules/final/f3701-55.aspx

Ohio Public Record Law ORC 149.43

<http://codes.ohio.gov/orc/149.43>

Sickle Cell Disease Association of America, Inc. (SCDAA)

www.sicklecelldisease.org/

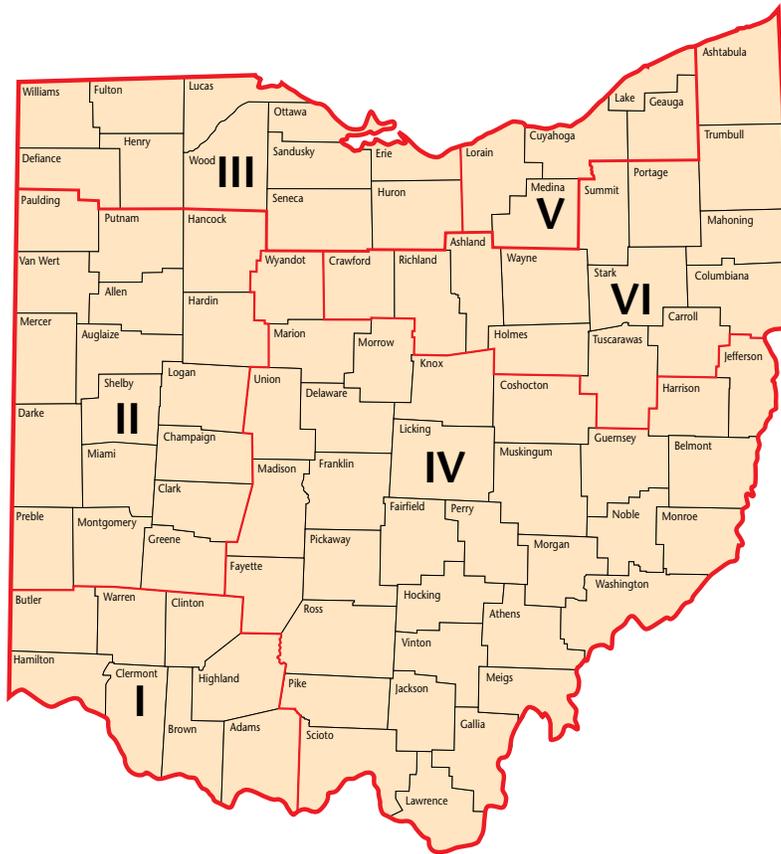


APPENDIX



APPENDIX A

MAP OF THE OHIO SICKLE CELL REGIONS



REGION I

Adams, Brown, Butler, Clermont, Clinton, Hamilton, Highland, and Warren

REGION II

Allen, Auglaize, Champaign, Clark, Darke, Greene, Hancock, Hardin, Logan, Mercer, Miami, Montgomery, Paulding, Preble, Putman, Shelby, and Van Wert

REGION III

Defiance, Erie, Fulton, Henry, Huron, Lucas, Ottawa, Sandusky, Seneca, Williams, and Wood

REGION IV

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, and Wyandot

REGION V

Cuyahoga, Geauga, Lake, Lorain, and Medina

REGION VI

Ashland, Ashtabula, Carroll, Columbiana, Crawford, Holmes, Mahoning, Portage, Richland, Stark, Summit, Trumbull, Tuscarawas, and Wayne

APPENDIX B

REGIONAL SICKLE CELL ADVISORY COMMITTEE

PURPOSE

As the designated advisory group, the purpose of the **Regional Sickle Cell Advisory Committee** is to assist and advise the RSCP in formal interagency planning, evaluation, policy development (in accordance with ODH standards), and implementation of a coordinated, comprehensive and multi-disciplinary system of regional sickle cell supports and services.

AUTHORITY

The development and maintenance of a **Regional Sickle Cell Advisory Committee** is required by the Ohio Department of Health, Sickle Cell Services Program under the Direct Service Initiative.

FUNCTIONS

By way of illustration and not limitation, the functions of the **Regional Sickle Cell Advisory Committee** include:

1. Advise and assist the RSCP in development and implementation of policies (in accordance with ODH standards).
2. Advise and assist the RSCP in achieving the full participation, coordination and cooperation of all appropriate providers and agencies in the region.
3. Advise and assist the RSCP in its administration duties, including identification and preparation of external funding application(s) for fiscal and other support.
4. Advise and assist the RSCP in the promotion and implementation of strategies that support better hemoglobinopathy information dissemination, education and service delivery to individuals from unserved, under-served and/or emerging population groups and professionals/providers in the region.
5. Advise and assist the RSCP in the development and implementation of an internal/external evaluation process.
6. Advise and assist the RSCP and the ODH in matters pertaining to transition of children/youth/young adults with special health needs from pediatric to adult medical care and other appropriate specialized services, resources and supports.

MEMBERSHIP

Membership composition of the **Regional Sickle Cell Advisory Committee** must reflect a broad spectrum of the regional community who are knowledgeable about the community/agency they represent and who have insight into the recommended “best” practice standards for hemoglobinopathies and the provision of sickle cell services in Ohio. This should include the recommended **organizational** and **consumer representation** as follows:

1. A representative from a Regional Blood Program in Ohio
2. A representative from a Federally Qualifying Health Center (FQHC)
3. A representative from an organization that has a mission or goal of addressing health disparities for unserved, underserved and/or emerging population groups
4. A representative (genetic counselor) from the Regional Comprehensive Genetics Center
5. A representative from a faith-based group or ministerial alliance
6. A representative (nursing director or designee) from the Local Health Districts in the region with the largest estimated carrier population(s)
7. A representative from a pediatric health care facility in the region serving children with sickle cell disease (community-based applicants)
8. A representative from an adult health care facility (or service agency) in the region serving adults with sickle cell disease (hospital and community –based applicants)
9. A representative from the regional school system
10. A representative from the volunteer or advocacy community
11. One representative (project director or designee) from the local Help Me Grow project
12. At least 10 percent consumer representation from parents of children with sickle cell disease age 18 years or younger
13. At least 10 percent consumer representation from adults (age 18 or older) affected with sickle cell disease

The Regional Sickle Cell Advisory Committee must be established outside the administrative or governing boards of the applicant agency or program.

STRUCTURE

The Chairperson of the **Regional Sickle Cell Advisory Committee** shall be selected by the RSCP Project Director or by members of the committee through a nomination and selection process.

With the approval/discretion of the RSCP Project Director and/or Chairperson, the committee may establish standing and/or ad-hoc subcommittees, task forces and other groups necessary to the operation of the committee. These groups, which shall be comprised of members of the parent committee, may also include other individuals who have expertise regarding issues of minority health (including racial and ethnic health disparities) and/or provision of sickle cell services.

MEMBERSHIP TERM

The term of membership is to be determined by the RSCP Project Director and Chairperson.

MEETINGS

A **functional Regional Sickle Cell Advisory Committee** is expected to meet, at a minimum, three (3) times during the state fiscal year (July through June). This includes tele-meetings.

With advance notification to the RSCP Project Director and/or the Chairperson, meetings should be open to the public.

MEMBER RESPONSIBILITIES

Each Committee member is expected to:

- ◆ Attend a minimum two (2) meeting per state fiscal year
- ◆ Actively participate in the functions of the Advisory Committee
- ◆ Be available for consultation with the RSCP
- ◆ Be available to accompany (occasionally) RSCP staff on outreach activities to increase visibility and support of sickle cell services and resources

COMPENSATION

Based on funding resources, mileage reimbursement (at state rates) for **patients/consumers** that actively participate as a member of the **Regional Sickle Cell Advisory Committee** is an allowable cost to the RSCP.

APPENDIX C

POSITION DESCRIPTION TEMPLATE

PROJECT DIRECTOR

POSITION TITLE: Project Director

SUMMARY OF RESPONSIBILITY:

Responsible for the overall organization, implementation and administration of a RSCP which provides and/or coordinates procedures of care (e.g. newborn hemoglobin screening follow-up and hemoglobinopathy counseling) and regional outreach education in a multi-county service area defined by the Ohio Department of Health (ODH), Bureau for Children with Medical Handicaps, **Sickle Cell Services Program**. Components of this position include administration, regional outreach, professional development and research.



PRINCIPAL DUTIES AND RESPONSIBILITIES

A. Administration

1. Administer day to-day internal operations and components of the RSCP in accordance and compliance with the ODH Grants Administration Policies and Procedures (GAPP) Manual and required and recommended “best” practice Standards and Criteria.
2. Keep ODH State Program Coordinator apprised of activities in the fiscal, education, outreach, hemoglobinopathy counseling, and newborn screening components of the Project.
3. Interact with GAU Grant Consultants and work in the Grant Management Information System (GMIS) 2.0 on-line grant application environment.
4. Comply with all ODH programmatic and fiscal timelines and reporting requirements.
5. Administrate and monitor ODH grant funds and other revenues to ensure adherence to expenditure guidelines in the implementation of program activities.
6. Maintain records system and data/statistics on RSCP components for ODH data collection, program evaluation and other reporting requirements.
7. Participate as a member of ODH sponsored meetings and other relevant committees.
8. Prepare, write and submit RSCP grant applications, reports and other documents as required by ODH and/or other external funding resources.
9. Supervise and evaluate RSCP staff and conduct performance evaluations. Make recommendations regarding recruitment, hiring and termination of personnel.
10. Aid in planning and delivery of newborn screening hemoglobin follow-up, educational programming, outreach and hemoglobinopathy counseling services as arranged by RSCP staff.

B. Regional Outreach

1. Recruit and select members for the **Regional Sickle Cell Advisory Committee** and other ad-hoc interest groups. Conduct/facilitate meetings.
2. Act as a liaison and resource consultant regarding hemoglobinopathies and RSCP services with regional agencies and organizations, health and allied health professionals/providers, patients/consumers and the public.
3. Participate in outreach strategies to increase patient referrals, compliance and access to comprehensive sickle cell services in conjunction with pediatric and adult hematology and primary care service providers in the region.

C. Professional Development

1. Review professional literature and attend educational venues to continuously advance knowledge in the area of hemoglobinopathies, program management, supervision and culturally and linguistically appropriate service delivery.
2. Maintain involvement in regional, state and national groups and organizations related to academic field of study or professional interests.

D. Research

1. Support and participate in research and other activities to evaluate, monitor and modify RSCP services and programs.

QUALIFICATIONS

Education

Graduate from an accredited college or university with a B.A. /B.S. minimum, M.A. /M.S. preferred in a field of study commensurate with the duties and responsibilities of the position.

Experience

A minimum of two (2) years of college intern or professional administrative or supervisory experience with a social agency, community based program or health related institution.

Skills and Knowledge

1. Strong leadership and organizational skills.
2. Working knowledge of hemoglobinopathies and/or chronic disease.
3. Knowledge of grant proposal and contract writing and budget preparation highly desirable.
4. Familiarity with community planning and organization, program planning and evaluation techniques.
5. Demonstrated oral and written communication skills.
6. Capable of functioning independently/self-motivated.

Training

1. Documented completion of a Hemoglobinopathy Training Program required within *one year of employment*.

Additional Requirements

1. Must be able to provide own transportation.
2. Must be able to travel and work flexible hours, including some evenings and weekends.
3. Must be able to work closely with diverse populations (various racial/ethnic, socioeconomic and educational backgrounds) and professionals from other disciplines.
4. Must be able to develop and maintain collaborative relationships with pediatric and adult hematology and primary care service providers in the region and work as part of an integrated team.
5. Must be able to lift within weight allowances specified by applicant.

APPENDIX D

POSITION DESCRIPTION TEMPLATE

NEWBORN SCREENING COORDINATOR

POSITION TITLE: Newborn Screening Coordinator

REPORT TO: Project Director

SUMMARY OF RESPONSIBILITY:

Responsible for the planning, coordination and implementation of newborn hemoglobin screening/testing follow-up and hemoglobinopathy counseling services in a multi-county service region defined by the Ohio Department of Health, Bureau for Children with Medical Handicaps, **Sickle Cell Services Program**. Components of this grant-funded position include newborn hemoglobin screening follow-up, hemoglobinopathy counseling, regional outreach, professional development, administration and research.



PRINCIPAL DUTIES AND RESPONSIBILITIES

A. Newborn Hemoglobin Screening Follow-up

1. Track and follow-up all newborns identified with a positive or potentially positive hemoglobin **trait** result via the ODH NBS Program and other referral sources to assure confirmation of results and hemoglobinopathy counseling services (see hemoglobinopathy counseling below).
2. Track and follow-up all newborns identified with a positive or potentially positive hemoglobin **disease** result via the ODH NBS Program and other referral sources to assure confirmation of results, hemoglobinopathy counseling, disease education and/or referral to specialized medical teams and resources for diagnostic, preventive and evaluative management of sickling hemoglobinopathies.
3. Report confirmatory/diagnostic test results and other case disposition to ODH.

B. Hemoglobin-Counseling

1. Provide on and off site (if applicable) hemoglobinopathy counseling services to parents of newborns and/or non-newborn individuals identified with an abnormal hemoglobin test result.
2. Coordinate and facilitate reciprocal referrals for hemoglobinopathy counseling services in conjunction with primary care providers, Regional Hematology-Oncology Centers and Regional Comprehensive Genetic Centers.
3. Participate as a team member in external and internal case conferences with regional partners.

4. Participate in regional outreach activities for the purpose of identification and referral of individuals for hemoglobinopathy counseling services.
5. Coordinate and/or co-facilitate education sessions and/or activities for patient/parent/affected family group audiences.

C. Regional Outreach

1. Participate as a member of the **Regional Sickle Cell Advisory Committee** and other regional ad-hoc interest groups.
2. Act as a liaison and resource consultant regarding hemoglobinopathies, newborn screening and hemoglobinopathy counseling services to regional agencies and organizations, health and allied health professionals/providers, patients/consumers and the public.
4. Participate in outreach strategies to increase patient referrals, compliance and access to comprehensive sickle cell services in conjunction with Regional Hematology-Oncology Centers.

D. Professional Development

1. Review professional literature and attend educational venues to continuously advance knowledge in the area of hemoglobinopathies, newborn screening, hemoglobinopathy counseling and culturally and linguistically appropriate service delivery.
2. Maintain involvement in regional, state and national groups and organizations related to academic field of study or professional interests.

E. Administration

1. Participate in the preparative writing and submission of RSCP reports and grant proposals in conjunction with the Project Director.
2. Maintain records system and data/statistics on RSCP newborn screening and hemoglobinopathy counseling services for ODH data collection, program evaluation and other reporting requirements.
3. Comply with required and recommended "best" practices related to the provision of sickle cell services as outlined in the Standards and Criteria document.
4. Participate in ODH sponsored meetings and other relevant committees.

F. Research

1. Support and participate in research and other activities to evaluate, monitor and modify RSCP services and programs.

QUALIFICATIONS

Education

Graduate from an accredited college or university with a minimum B.A. /B.S., M.A. /M.S. preferred in a field of study commensurate with duties and responsibilities of the position.

Experience

A minimum of two (2) years of college intern or professional experience with a social service agency, community based program or health related institution.

Skills and Knowledge

1. Working knowledge of hemoglobinopathies and/or chronic disease.
2. Training or experience in counseling techniques essential.
3. Demonstrated proficiency in oral and written communication skills.
4. Capable of functioning independently/self motivated.

Additional Requirements

1. Must be able to provide own transportation.
2. Must be able to travel and work flexible hours, including some evenings and weekends.
3. Must be able to work closely with diverse populations (various racial/ethnic, socioeconomic and educational backgrounds) and professionals from other disciplines.
4. Must be able to develop and maintain collaborative relationships with pediatric and adult hematology and primary care service providers in the region and work as part of an integrated team.
5. Must be able to lift within weight allowances specified by the applicant.

APPENDIX E

POSITION DESCRIPTION TEMPLATE

REGIONAL OUTREACH EDUCATOR

POSITION TITLE: Regional Outreach Educator

REPORT TO: Project Director

SUMMARY OF RESPONSIBILITY:

Responsible for the overall planning, coordination, implementation and evaluation of public and professional hemoglobinopathy education services in a multi-county service region defined by the Ohio Department of Health (ODH), Bureau for Children with Medical Handicaps, **Sickle Cell Services Program**. Components of this grant-funded position include education/training, resource management, regional outreach, professional development, administration and research.



PRINCIPAL DUTIES AND RESPONSIBILITIES

A. Education/Training

1. Plan, implement and evaluate educational programming and in-service training for patients/consumers, health care providers/professionals and other specified audiences in the regional service area.
2. Design, prepare and oversee exhibits and participatory activities for educational outreach activities. Coordinate and train volunteer assistants.
3. Develop and implement hemoglobinopathy education programs for school systems in the region; both in student and teacher curriculum.
4. Collaborate with Ohio RSCPs, Comprehensive Regional Genetics Centers, Regional Hematology-Oncology Centers and other regional resources to facilitate joint educational ventures.
5. Coordinate and/or co-facilitate education sessions and/or activities for parent/affected family group audiences.
6. Demonstrate leadership in hemoglobinopathy education through presentations at workshops, seminars, in-services, orientations, and continuing education programs at the regional, state and/or national levels.

B. Resource Management

1. Maintain a regional resource clearinghouse of educational materials (e.g. print and audiovisual) for distribution to professional and consumer audiences. Materials must be current and of professional quality and culturally, age, language and literacy appropriate.

C. Regional Outreach

1. Participate as a member of the **Regional Sickle Cell Advisory Committee** and other regional ad-hoc interest groups.
2. Act as a liaison and resource consultant regarding hemoglobinopathies and education services to regional agencies and organizations, health and allied health professional/providers, patients/consumers and the public.
3. Participate in outreach strategies to increase patient referrals, compliance and access to comprehensive sickle cell services in conjunction with Regional Hematology-Oncology Centers.

D. Professional Development

1. Review professional literature and attend educational venues to continuously advance knowledge in the area of hemoglobinopathies, educational programming and culturally and linguistically appropriate service delivery.
2. Maintain involvement in regional, state and national groups and organizations related to academic field of study or professional interests.

E. Administration

1. Participate in the preparative writing and submission of RSCP reports and grant proposals in conjunction with the Project Director.
2. Maintain records system and data/statistics on RSCP education activities for ODH data collection, program evaluation and other reporting requirements.
3. Comply with required and recommended “best” practice Standards and Criteria related to the provision of sickle cell services.
4. Participate as a member of ODH sponsored meetings and other relevant committees.

F. Research

1. Support and participate in research and other activities to evaluate, monitor and modify RSCP services and programs.

QUALIFICATIONS

Education

Graduate from an accredited college or university with a minimum B.A. /B.S. minimum, M.A. /M.S. preferred in a field of study commensurate with the duties and responsibilities of the position.

Experience

A minimum of two (2) years of college intern or professional experience with a social agency, community based program or health related institution.

Skills and Knowledge

1. Working knowledge of hemoglobinopathies and/or chronic disease.
2. Familiarity with community planning and organization preferred.
3. Demonstrated proficiency in oral and written communication skills including presentation skills for small and large groups.
4. Knowledge of educational, teaching and evaluation techniques desirable.
5. Skilled in use of information technology (IT) and various communications media (e.g. power point).
6. Capable of functioning independently/self motivated.

Certification

1. Health Education Specialist Certification (CHES) through the National Commission for Health Education Credentialing (NCHEC) highly desirable.

Additional Requirements

1. Must be able to provide own transportation.
2. Must be able to travel and work flexible hours, including some evenings and weekends.
3. Must be able to work closely with diverse populations (various racial/ethnic, socioeconomic and educational backgrounds) and professionals from other disciplines.
4. Must be able to develop and maintain collaborative relationships with pediatric and adult hematology and primary care service providers in the region and work as part of an integrated team.
5. Must be able to lift within weight allowances specified by the applicant.

APPENDIX F

ROLE OF THE MEDICAL DIRECTOR/MEDICAL ADVISOR

PURPOSE

The purpose of the Medical Director/Medical Advisor is to provide guidance and leadership to the RSCP regarding the five (5) service components and the four (4) administrative components as outlined in the Standards and Criteria document.

RESPONSIBILITIES OF THE MEDICAL DIRECTOR/ADVISOR

Pursuant to the purpose of the ODH Sickle Cell Program, the Medical Director/Advisor functions directly or consultatively as follows:

- ◆ Facilitate the medical, referral and follow-up process for patients/consumers diagnosed with a hemoglobinopathy.
- ◆ Serve as a consultant to RSCP staff regarding interpretation of laboratory test results for hemoglobinopathies.
- ◆ Participate/serve as a active member of the **Regional Sickle Cell Advisory Committee** and other administrative/governing boards (if applicable).
- ◆ Provide medical expertise about hemoglobinopathies and represent the RSCP, when appropriate, within the medical community.
- ◆ Review and approve (in accordance with ODH) materials for educational presentations.
- ◆ Provide education, upon request and as necessary, to regional professionals/providers and the public on hemoglobinopathies.
- ◆ Attend ODH RSCP Medical Director/Medical Advisor meetings (as requested/required).
- ◆ Serve as a liaison between the RSCP and the community of individuals affected by hemoglobinopathies.

QUALIFICATIONS

- ◆ Preferably, the medical director/medical advisor should be a board-certified hematologist with expertise in the management of persons with sickle cell disease/ and treatment-related complications, and for hospital-based direct service projects, based on-site.
- ◆ If the medical director/medical advisor is not a board-certified hematologist based at the project site, at a minimum, he/she must be a licensed physician with experience/expertise in the management of persons with sickle cell disease.
- ◆ For an on-site or off-site medical director/medical advisor, there must be documentation of the relationship, including roles and responsibilities, of the medical director/medical advisor to the project.

TERM

The term of responsibility should be determined by the RSCP Project Director and the Medical Director/Advisor.

GENERAL PROVISIONS

There is no monetary compensation for the Medical Director/Medical Advisor to the RSCP.

APPENDIX G

GLOSSARY OF TERMS

At-Risk: includes persons of African ancestry and also persons with heritage from Spanish-speaking regions in the Western Hemisphere (South America, Cuba and Central America), Saudi Arabia, India and Mediterranean countries such as Turkey, Greece and Italy.

Culturally and Linguistically Appropriate Services (CLAS): are health care services that are respectful of and responsive to cultural and linguistic needs.

Emerging Population: defined as individuals that are affected by sickle cell disease or sickle cell trait in the project's geographic catchment area that are not receiving adequate care due to the lack of information or outreach to these individuals and families. Emerging populations can include racial and ethnic communities not previously viewed as having significant rates of sickle cell disease or sickle cell trait, persons affected by sickle cell disease or trait that do not speak English or who speak sign language and individuals who are illiterate or have low literacy in any language (*Source: HRSA: Sickle Cell Disease Newborn Screening RFP, 2010*).

Family Member: includes parents/legal guardians, siblings and other extended family relationships (e.g. aunts, cousins).

Follow-Up: active case surveillance on any positive or potentially positive result from the point of physician/hospital/parent/patient/consumer notification to the point of resolution/disposition. (*Source: U.S. Newborn Screening System Guidelines — Statement of the Council of Regional Networks for Genetic Services, 1992*).

Follow-Up Services: services provided by the RSCP or non-RSCP provider that includes, but are not limited to confirmatory testing, hemoglobinopathy counseling, disease education, resource referrals and/or applicable treatment management.

Hemoglobinopathies: a group of disorders passed down (inherited) through families in which there is abnormal production or structure of the hemoglobin molecule. These disorders include hemoglobin C disease, hemoglobin SC disease, hemoglobin SS disease (sickle cell anemia) and various types of thalassemia (*Source: HRSA: Sickle Cell Disease Newborn Screening RFP, 2010*).

Hemoglobinopathy Counseling: refers to the entire process of interpreting/communicating accurate test results to individuals screened by a competent laboratory. This counseling process involves genetic, medical and psychosocial counseling.

Non-Newborn: an individual with a birth date prior to the *beginning* of the SFY reporting period (June through July) that receives follow-services from an RSCP or non-RSCP provider *during* the reporting period..

Non-RSCP Provider: a service provider in the region that is *external* to the RSCP core team or the extended team members.

Patient/Consumer: individuals, including family members, guardians or companions that seek physical, mental or other health-related services.

APPENDIX H

ACRONYMS AND ABBREVIATIONS

BCMH: Bureau for Children with Medical Handicaps

CLAS: Culturally and Linguistically Appropriate Services

GAPP: Grants Administration Policies and Procedures

GAU: Grants Administration Unit

GMIS: Grants Management Information System

HIPPA: Health Insurance Portability and Accountability Act

HMG: Help Me Grow

HRSA: Health Resources and Services Administration

IT: Information Technology

LEP: Limited English Proficiency

NBS: Newborn Screening

NIH: National Institutes of Health

NORD: National Organization for Rare Disorders

OCCSN: Ohio Connection for Children with Special Needs

ODH: Ohio Department of Health

ORC: Ohio Revised Code

PKU: Phenylketonuria

RSCP: Regional Sickle Cell Project

SCDAA: Sickle Cell Disease Association of America, Inc.



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