

MEMO

Date: March 09, 2007

To: Prospective Sickle Cell Services Program Applicants

From: Karen F. Hughes, M.P.H., Chief *KFH*
Division of Family and Community Health Services
Ohio Department of Health

Subject: Notice of Availability of Funds – State Fiscal Year 2008
(July 1, 2007-June 30, 2008) Sickle Cell Services Program

The Ohio Department of Health (ODH), Division of Family and Community Health Services (DFCHS), Bureau for Children with Medical Handicaps (BCMh), announces the availability of grant funds to support activities of the Sickle Cell Services Program – Direct Service Initiative.

To obtain a grant application packet:

1. Go to the ODH website at www.odh.ohio.gov
2. From the home page, click on “About ODH”;
3. From the next page, click on “ODH Grants”;
4. Next click on “Grant Request for Proposals”. This will give you a pull down menu with current grant RFP’s by name;
5. Select and highlight the Sickle Cell Services Program RFP and click “Submit”. This process invokes Adobe Acrobat and will display the entire RFP. You can then review the RFP to determine your organization’s ability to meet the requirements of the grant and your intent to apply.

All grant applications must be submitted via the Internet, using GMIS 2.0. To be eligible for funding, all interested applicants must: 1) submit the attached *Notice of Intent to Apply for Funding* form no later than Monday, March 26, 2007 and 2) attend a mandatory GMIS 2.0 Training Session. Please complete and return the attached *GMIS 2.0 Training* form to schedule a specific training session date.

Should you have any questions, please contact Cheryl L. Jones, Sickle Cell Services Program Coordinator at (614) 728-6787, by e-mail at cheryl.jones@odh.ohio.gov, or by fax at (614) 728-3616.

NOTICE OF AVAILABILITY OF FUNDS

Ohio Department of Health
Division of Family and Community Health Services
Bureau for Children with Medical Handicaps

SICKLE CELL SERVICES PROGRAM

Competitive Grant Applications for State Fiscal Year 2008

Introduction/Background

The Ohio Department of Health (ODH), Division of Family and Community Health Services (DFCHS), Bureau for Children with Medical Handicaps (BCMh), announces the availability of grant funds to support activities of the Sickle Cell Services Program. Recipients will be expected to have an identifiable, functional unit or program organized for and capable of ensuring the provision of **regional** comprehensive sickle cell services to newborns, children and adults with or at-risk for sickle cell disease, sickle cell trait and related hemoglobin disorders. Comprehensive services for the purposes of this grant application, include but are not limited to: (1) tracking and follow-up of abnormal hemoglobin results, including newborn and non-newborn test results; (2) genetic, psychosocial and hemoglobinopathy counseling; (3) hemoglobinopathy education and resource materials, training, outreach and awareness activities and (4) care coordination and/or referral to specialized medical teams and resources for diagnostic, preventive, transition and evaluative hemoglobin disease management. **Support of clinical services is not a funding priority for this grant initiative.**

Authorization of funds of this program is contained in the Catalog of Federal Domestic Assistance (CFDA) Number 93-994 and in legislation enacted by the 126th General Assembly.

Qualified Applicants

Qualified applicants are tertiary care or community-based facilities with an identifiable, functional unit or program organized for and capable of ensuring the provision of **regional** comprehensive sickle cell services to newborns, children and adults with or at-risk for sickle cell disease, sickle cell trait and related hemoglobin disorders. Priority will be given to those applicant facilities that demonstrate capability, experience and expertise in the provision of services as described above and whose programmatic activities meet or exceed ODH Sickle Cell Program Standards and Criteria. **Only one agency will be funded in each of the six (6) multi-county sickle cell service regions listed below:**

- **Region I** - Adams, Brown, Butler, Clermont, Clinton, Hamilton, Highland, Warren (8)
- **Region II** - Allen, Auglaize, Champaign, Clark, Darke, Greene, Hancock, Hardin, Logan, Mercer, Miami, Montgomery, Paulding, Preble, Putnam, Shelby, Van Wert (17)
- **Region III** - Defiance, Erie, Fulton, Henry, Huron, Lucas, Ottawa, Sandusky, Seneca, Williams, Wood (11)
- **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, Wyandot (33)
- **Region V** - Cuyahoga, Geauga, Lake, Lorain, Medina (5)
- **Region VI** - Ashland, Ashtabula, Carroll, Columbiana, Crawford, Holmes, Mahoning, Portage, Richland, Stark, Summit, Trumbull, Tuscarawas, Wayne (14)

All applicants must 1) be a governmental or non-profit agency; 2) attend GMIS 2.0 training and 3) have the capacity to set up an electronic funds transfer (EFT).

Applicants must **also** meet the additional requirements listed below to qualify for funding:

1. be able to provide required services across county lines within their identified target area;
2. be able to provide required services across institutional boundaries within a variety of health systems;
3. have a history of effective collaboration and cooperation within their communities; and

NOTICE OF AVAILABILITY OF FUNDS

Page 2

4. have demonstrated acceptable performance during previous grant periods if currently receiving ODH funds.

Applicants that apply for funds under this initiative may not apply for additional grant funding under the ODH Sickle Cell Services Program - Statewide Family Support Initiative.

Program Period and Award Amounts

This is a competitive grant application. The program period for this application will be four (4) years, beginning July 1, 2007 and ending June 30, 2011. The budget period will be twelve (12) months beginning July 1, 2007 and ending June 30, 2008. A maximum of six (6) SCSP grants (one applicant per region) will be awarded. The total grant funds available will be approximately \$710,000. Eligible applicants for each region may apply for initial awards ranging from \$53,037 up to \$197,025. All awards are contingent on the availability of funds for this purpose.

To Obtain a Grant Application Packet

1. Go to the ODH website at www.odh.ohio.gov
2. From the home page, click on "About ODH";
3. From the next page, click on "ODH Grants";
4. Next click on "Grant Request for Proposals (RFP)". This will give you a pull down menu with current grant RFP's by name;
5. Select and highlight the Sickle Cell Services Program RFP and click "Submit". This process invokes Adobe Acrobat and will display the entire RFP. You can then review the RFP to determine your organization's ability to meet the requirements of the grant and your intent to apply.

All interested applicants must submit a *Notice of Intent to Apply for Funding* form (attached), no later than Monday, March 26, 2007 to be eligible to apply for funding. Upon receipt of your completed *Notice of Intent to Apply for Funding* form, ODH will:

- a. create the grant application account for your organization. This account number will allow you to submit an application via the Internet using GMIS 2.0. All grant applications must be submitted via the Internet using GMIS 2.0.
- b. assess your organizations' GMIS 2.0 training needs and contact you regarding those needs. GMIS 2.0 training is mandatory for all interested applicants.

Once ODH receives your completed *Notice of Intent to Apply for Funding* form, creates the grant application account for your organization, and finalizes all GMIS 2.0 training requirements, you may proceed with the application process as outlined in the RFP.

Technical Assistance Session

A Technical Assistance (TA) Session may be scheduled to provide guidance and answer questions related to programmatic sections of the RFP. The dates and location for this meeting is to be determined (TBD) and will be sent to applicants subsequent to GMIS 2.0 Training. Participation in the TA meeting is not a substitution for attendance at the GMIS 2.0 Training Session.

NOTICE OF INTENT TO APPLY FOR FUNDING

Ohio Department of Health
Division of Family and Community Health Services
Bureau for Children with Medical Handicaps

ODH Program Title: Sickle Cell Services Program

ALL INFORMATION REQUESTED MUST BE COMPLETED
(Please Print Clearly or Type)

County of Applicant Agency _____

Federal Tax Identification Number _____

NOTE: The applicant agency/organization name must be the same as that on the IRS letter. This is the legal name by which the tax identification number is assigned.

Type of Applicant Agency (Check one) County Agency Hospital Local Schools
 City Agency Higher Education Not-for Profit

Applicant Agency/Organization _____

Applicant Agency Address _____

Agency Contact Person/Title _____

Telephone Number _____

E-mail Address _____

Please Check One: _____ Yes – Our agency will need GMIS 2.0 training
_____ No – Our agency has already had GMIS 2.0 training

Mail, E-Mail, or Fax To: Cheryl L. Jones, Program Coordinator
Ohio Department of Health
246 N. High Street
Sickle Cell Services Program
Columbus, Ohio 43215
E-mail: cheryl.jones@odh.ohio.gov
Fax: (614) 728-3616

NOTICE OF INTENT TO APPLY FOR FUNDING MUST BE RECEIVED BY MARCH 26, 2007

**Ohio Department of Health
GMIS 2.0 Training**

**ALL INFORMATION REQUESTED MUST BE COMPLETED for EACH EMPLOYEE FROM
YOUR AGENCY WHO WILL ATTEND A GMIS 2.0 TRAINING SESSION.
(Please Print Clearly or Type)**

Grant Program _____ **RFP Due Date** _____

County of Applicant Agency _____

Federal Tax Identification Number _____

NOTE: The applicant agency/organization name must be the same as that on the IRS letter. This is the legal name by which the tax identification number is assigned and as listed, if applicable, currently in GMIS.

Applicant Agency/Organization _____

Applicant Agency Address _____

Agency Employee to attend training _____

Telephone Number _____

E-mail Address _____

GMIS 2.0 Training Authorized by: _____
(Signature of Agency Head or Agency Fiscal Head Required)

Please Check One: _____ **Yes – I ALREADY have access to the ODH Gateway (SPES, ODRS, LHIS, etc.)**

_____ **No – I DO NOT have access to the ODH Gateway**

Please indicate your training date choices: 1st choice _____, 2nd choice _____, 3rd choice _____

Mail, E-mail or Fax To: **GAIL BYERS**
Grants Administration Unit
Ohio Department of Health
246 N. High Street
Columbus, Ohio 43215
E-mail: gail.byers@odh.ohio.gov
Fax: 614-752-9783

CONFIRMATION OF YOUR GMIS 2.0 TRAINING SESSION WILL BE E-MAILED TO YOU



ALL APPLICATIONS MUST BE SUBMITTED VIA THE INTERNET

OHIO DEPARTMENT OF HEALTH

**Division of Family and Community Health Services
Bureau for Children with Medical Handicaps**

SICKLE CELL SERVICES PROGRAM
REQUEST FOR PROPOSALS (RFP)
FOR
FISCAL YEAR 2008
(07/01/07-06/30/08)

**Local Public Applicant Agencies
Non-Profit Applicants**

COMPETITIVE GRANT APPLICATION INFORMATION

**OHIO DEPARTMENT OF HEALTH
DIVISION OF FAMILY AND COMMUNITY HEALTH SERVICES
BUREAU FOR CHILDREN WITH MEDICAL HANDICAPS**

SFY 2008 Anticipated Timetable

April 23, 2007	Deadline for Internet Submission of Grant Applications and Materials Not Electronically Filed
July 1, 2007	SFY 2008 Project Funding Period Begins
October 15, 2007	SFY 2008 Quarterly Expenditure Report due via Internet 1 st Quarter Education Event Forms due to Program (July-September 2007) SFY 2008 Advisory Committee Membership Form due via Internet
January 15, 2008	SFY 2008 Quarterly Expenditure Report due via Internet SFY 2008 Mid-Year Program Performance (Activity) Report due via Internet 2 nd Quarter Education Event Forms due to Program (October-December 2007)
April 15, 2008	SFY 2008 Quarterly Expenditure Report due via Internet 3 rd Quarter Education Event Forms due to Program (January-March 2008) SFY 2007 Minimum Data Set Packet due via Internet
July 15, 2008	SFY 2008 Quarterly Expenditure Report due via Internet SFY 2008 Year-End Program Performance (Activity) Report due via Internet 4 th Quarter Education Event Forms due to Program (April-June 2008)
August 15, 2008	SFY 2008 Final Expense Report due via Internet

SAVE FOR FUTURE REFERENCE

TABLE OF CONTENTS

I. <u>APPLICATION SUMMARY and GUIDANCE</u>	
A. Policy and Procedure.....	1
B. Application Name.....	1
C. Purpose	1
D. Qualified Applicants	1-2
E. Service Area	2
F. Number of Grants and Funds Available.....	2
G. Due Date.....	2
H. Authorization	3
I. Goals	3
J. Program Period and Budget Period.....	3
K. Local Health Districts Improvement Standards.....	3
L. Public Health Impact Statement	3
M. Appropriation Contingency	4
N. Programmatic, Technical Assistance & Authorization for Internet Submission.....	4
O. Acknowledgement	4
P. Late Applications	4
Q. Successful Applicants.....	4
R. Unsuccessful Applicants.....	5
S. Review Criteria	5
T. Freedom of Information Act	5
U. Ownership Copyright	5
V. Reporting Requirements.....	6
W. Special Condition(s).....	7
X. Unallowable Costs	7
Y. Audit.....	8
Z. Submission of Application.....	8
II. <u>APPLICATION REQUIREMENTS AND FORMAT</u>	
A. Application Information	10
B. Annual Assurances.....	10
C. Budget	10
D. Budget Certification	11
E. Program Narrative	12
F. Attachments.....	13
G. Electronic Funds Transfer (EFT) Form	14
H. Internal Revenue Service (IRS) W-9 Form	14
I. Public Health Impact Statement Summary.....	14
J. Public Health Impact/Response Statement	14
K. Liability Coverage	14
L. Non-Profit Organization Status.....	14
M. Declaration Regarding Material Assistance/Non-Assistance to a Terrorist Organization (DMA) Questionnaire.....	14
N. EEO Survey	15
O. Attachments as Required By Program	15
III. <u>APPENDICES</u>	
APPENDIX #1 – ODH Sickle Cell Program Standards and Criteria	
Sub – Appendix #1 – Position Description Template – Project Director	
Sub – Appendix #2 – Position Description Template – Newborn Screening Coordinator	
Sub – Appendix #3 – Position Description Template – Regional Outreach Educator	

APPENDIX #2 – Funding Allocation by Region
APPENDIX #3 – Sickle Cell Target Population Projections – Region I
APPENDIX #4 - Sickle Cell Target Population Projections – Region II
APPENDIX #5 - Sickle Cell Target Population Projections – Region III
APPENDIX #6 - Sickle Cell Target Population Projections – Region IV
APPENDIX #7 - Sickle Cell Target Population Projections – Region V
APPENDIX #8 - Sickle Cell Target Population Projections – Region VI
APPENDIX #9 – Application Summary Review Form
APPENDIX #10 – RSCP Goals, Expected Results and Performance Indicators

I. APPLICATION SUMMARY and GUIDANCE

An application for an ODH grant consists of a number of required parts - an electronic component submitted via an Internet Website (**which is sent with electronic acknowledgement in lieu of Signature Page**), various paper forms and attachments. All the required parts of a specific application must be completed and submitted by the application due date. **Any required part that is not submitted on time will result in the entire application not being considered for review.**

The application summary information is provided to assist your agency in identifying funding criteria:

- A. Policy and Procedure:** Uniform administration of all ODH grants is governed by the Ohio Department of Health, Grants Administration Policies and Procedures Manual (GAPP). This manual must be followed to assure adherence to the rules, regulations and procedures for preparation of all Subgrantee applications. The GAPP manual is available on the ODH web-site <http://www.odh.ohio.gov> (Click on "About ODH", click on "ODH Grants" and then click on "GAPP Manual").
- B. Application Name: SICKLE CELL SERVICES PROGRAM (SCSP)**
- C. Purpose:** To fund a network Regional Sickle Cell Projects (RSCP), who in partnership with the ODH Sickle Cell Services Program (under the Direct Services Initiative), work to ensure and enhance the availability and accessibility of quality, comprehensive services to Ohioans (newborns, children and adults) with or at-risk for sickle cell disease, sickle cell trait and related hemoglobin disorders. Comprehensive services for the purpose of this grant application, include but is not limited to:
1. Tracking and follow-up of abnormal hemoglobin results (including newborn and non-newborn test results);
 2. Genetic, psychosocial and hemoglobinopathy counseling;
 3. Hemoglobinopathy education and resource materials, training, outreach and awareness activities; and
 4. Care Coordination and/or referral to specialized medical teams and resources for diagnostic, preventive, transition and evaluative hemoglobin disease management.

Support of clinical services is not a funding priority of this grant initiative.

- D. Qualified Applicants:** All applicants must be a local public or non-profit agency. Qualified applicants for grant funds under the Direct Service Initiative are tertiary care or community-based facilities with an identifiable, functional unit or program organized for and capable of ensuring the provision of **regional** comprehensive sickle cell services for newborns, children and adults identified with or at-risk for sickle cell disease, sickle cell trait and related hemoglobin disorders. Priority will be given to those applicant facilities that demonstrate capability, experience and expertise in the provision of services as described above and whose programmatic activities meet or exceed ODH Sickle Cell Services Program Standards and Criteria (see **APPENDIX #1**). **All applicants must attend GMIS 2.0 training.**

Applicants must **also** meet the additional requirements listed below to qualify for funding:

1. be able to provide services across county lines within their identified target area;
2. be able to provide services across institutional boundaries within a variety of health systems;
3. have a history of effective collaboration and cooperation within their communities. Shared or cooperative projects involving more than one agency/organization which enhances the ability to cut across geographic or service system boundaries are encouraged; and
4. have demonstrated acceptable performance during previous grant periods if currently receiving ODH funds.

Note: Applicants that apply for funds under this Initiative MAY NOT apply for additional grant funding under the ODH Sickle Cell Services Program-Statewide Family Support Initiative.

The following entities are ineligible for funding consideration:

- Individuals;
- National organizations;
- Facilities applying for the sole purpose of acquiring funds to supplement existing program without any plans for enlarging their scope of practice;
- Facilities in the process of creating or starting a “functional unit” for the sole purpose of applying for a grant under this Initiative;
- Facilities requesting funds to replicate activities currently funded by ODH or other funding sources; and
- Facilities requesting funds under this Initiative to pay for medical services and/or personnel that can be covered by 3rd party payers or other resources.

E. Service Area: Applicants will be required to provide services within one (1) of six (6) ODH defined multi-county sickle cell service regions listed below:

- Region I – Adams, Brown, Butler, Clermont, Clinton, Hamilton, Highland, Warren (8)
- Region II – Allen, Auglaize, Champaign, Clark, Darke, Greene, Hancock, Hardin, Logan, Mercer, Miami, Montgomery, Paulding, Preble, Putnam, Shelby, Van Wert (17)
- Region – Defiance, Erie, Fulton, Henry, Huron, Lucas, Ottawa, Sandusky, Seneca, Williams, Wood (11)
- 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, Wyandot (33)
- Region V – Cuyahoga, Geauga, Lake, Lorain, Medina (5)
- Region VI – Ashland, Ashtabula, Carroll, Columbiana, Crawford, Holmes, Mahoning, Portage, Richland, Stark, Summit, Trumbull, Tuscarawas, Wayne (14)

F. Number of Grants and Funds Available: A maximum of six (6) SCSP grants (**one applicant per region**) will be funded for the SFY 2008 competitive grant cycle. The total grant funds available will be approximately \$710,000. Eligible applicants for each region may apply for initial awards ranging from \$53,037 to \$197,025 (see **APPENDIX #2**).

Note: Recipients may subcontract with other agencies for implementation of parts of the grant. Collaboration between agencies providing sickle cell services in the region is strongly encouraged. Applicant agencies must assume an oversight role for those agencies with whom they subcontract.

No grant award will be issued for less than \$30,000. The minimum amount is exclusive of any required matching amount and represents only ODH funds granted. Applications submitted for less than the minimum amount will not be considered for review.

G. Due Date: Applications including any required forms and required attachments mailed or electronically submitted via GMIS 2.0 are due by **Monday, April 23, 2007**. Attachments and/or forms sent electronically must be transmitted by the application due date. Attachments and/or forms mailed that are non-Internet compatible must be postmarked or received on or before the application due date.

Please contact Cheryl L. Jones, State Sickle Cell Program Coordinator at (614) 728-6787 or by e-mail at cheryl.jones@odh.ohio.gov with any questions.

- H. Authorization:** Funding authorization for this program is contained in the Catalog of Federal Domestic Assistance (CFDA) Number 93-994 and in legislation enacted by the Ohio 126th General Assembly, Am. Sub. H.B. 66.
- I. Goals:** In releasing funds for this Initiative, the goals of the Sickle Cell Services Program are as follows:
- A. Promote the early identification of children and adults with sickle cell disease and related hemoglobin disorders and facilitate their integration into systems of service and care (which include treatment interventions) that are accessible, continuous, comprehensive, family-centered, coordinated and culturally sensitive.
 - B. Increase the awareness, knowledge and skill level of Ohio's health care professionals and providers about the special health care needs and services related to sickle cell disease and other hemoglobin disorders through the promoted use of education, training and outreach.
 - C. Expand public and community awareness and access to information on sickle cell disorders and related programs/services with special emphasis on meeting the needs and culture of unserved and/or under-served at-risk population groups.
- J. Program Period and Budget Period:** This is a competitive grant application. The program period for this application will be four (4) years beginning July 1, 2007 and ending June 30, 2011. The budget period for this application will be twelve (12) months beginning July 1, 2007 and ending June 30, 2008.
- K. Local Health District Improvement Standards:** This grant program will address two (2) Local Health District Improvement Goals:
- Goal 3701-36-07 – “Promote Healthy Lifestyles”, Standard 3701-36-07-03 – *Prevention, health promotion, early intervention and outreach services are provided directly*, **AND**
 - Goal 3701-36-08 – “Address the Need for Personal Health Services”, Standard 3701-36-08-04 – *Plans to reduce specific gaps in access to critical health services being developed and implemented through collaborative efforts.*
- The Local Health District Improvement Goals/Standards/Measures are available on the ODH website <http://www.odh.ohio.gov> (At the top of the page, click on “Local Health Districts”, then “Local Health Districts Improvement Standards”; and then click the link “Local Health District Improvement Goals/Standards/Measures”).
- L. Public Health Impact Statement:** All applicant agencies that are not local health districts must communicate with local health districts regarding the impact of the proposed grant activities on the Local Health District Improvement Standards.
1. Public Health Impact Statement Summary - Applicant agencies are required to submit a summary statement of the project to local health districts prior to submitting the grant application to ODH. The project summary, not to exceed one page, must include:
 - (1) The Local Health District Improvement Standard(s) to be addressed by grant activities;
 - (2) A description of the specific target population(s) affected by hemoglobinopathies to be served;
 - (3) A summary of the regional services (county-specific) to be provided or programs to be conducted.
 - (4) A plan to coordinate and share information with appropriate local health districts (regional).

The applicant must submit the above summary as part of their grant application to ODH. This will document that a written summary of the proposed activities was provided to the local health districts with a request for their support and/or comment about the activities as they related to the Local Health Districts Improvement Standards.

Note: A complete listing of contact information for the Ohio Local Health Districts by county and city is available on the ODH web-site <http://www.odh.ohio.gov> (At the top of the page, click on “Local Health Districts” then “Ohio Local Health Districts Directory”).

2. *Public Health Impact Statement of Support* - Include with the grant application a statement of support from the local health district(s), if available. If a statement of support from the local health district is not obtained, indicate that when the project summary is submitted with the grant application.

If an applicant agency has a regional focus, a statement of support must be submitted from the local health district(s) in the region with the largest estimated number of sickle cell (HbAS) carriers. See **APPENDIX #3 through APPENDIX #8** for Sickle Cell Target Population Projections for each Region.

- M. Appropriation Contingency:** Any award made through the Sickle Cell Services Program is contingent upon the availability of funds for this purpose.
- N. Programmatic, Technical Assistance and Authorization for Internet Submission:** Please contact: Cheryl L. Jones, State Sickle Cell Program Coordinator at (614) 728-6787 or by e-mail at cheryl.jones@odh.ohio.gov.

Initial authorization for Internet submission will be distributed after your GMIS 2.0 Training Session.

Note: A Technical Assistance (TA) meeting may be scheduled to provide guidance and answer questions related to programmatic sections of the RFP. The date and location for this meeting is to be determined (TBD) and will be sent to applicants subsequent to GMIS 2.0 Training. Participation in the TA meeting is not a substitution for attendance at the GMIS 2.0 Training Session.

- O. Acknowledgement:** An electronic message will appear in GMIS 2.0 that acknowledges ODH receipt of the Internet submission.
- P. Late Applications:** Applications are dated the time of actual submission via the Internet utilizing GMIS 2.0 with an Electronic Signature. Required attachments and/or forms sent electronically must be transmitted by the application due date. Required attachments and/or forms mailed that are non-Internet compatible must be postmarked or received on or before the application due date of **Monday, April 23, 2007.**

Applicants should request a legibly dated postmark, or obtain a legibly dated receipt from the U.S. Postal Service, or a commercial carrier. Private metered postmarks shall **not** be acceptable as proof of timely mailing. Applicants can hand deliver attachments to ODH, Grants Administration, Central Master Files; but they must be delivered by 4:00 p.m. on the application due date. FAX attachments will not be accepted. **GMIS 2.0 applications and required application attachments received late will not be considered for review.**

- Q. Successful Applicants:** Successful applicants will receive official notification in the form of a “Notice of Award” (NOA). The NOA, issued under the signature of the Director of Health, allows for expenditure of grant funds.

- R. Unsuccessful Applicants:** Within 30 days after a decision to disapprove or not fund a grant application for a given program period, written notification, issued under the signature of the Director of Health, or his designee, shall be sent to the unsuccessful applicant.
- S. Review Criteria:** All proposals will be judged on the quality, clarity and completeness of the application. Applications will be judged according to the extent to which the proposal:
1. Contribute to the advancement and/or improvement of the health of Ohioans;
 2. Is responsive to policy concerns and programs objectives of the initiative/program/activity for which grant dollars are being made available;
 3. Is well executed and is capable of attaining program objectives;
 4. Describes specific measurable objectives, activities, milestones and outcomes with respect to timelines and resources;
 5. Estimates reasonable cost to the Ohio Department of Health, considering the anticipated results;
 6. Demonstrates that program personnel are well qualified by training and/or experience for their roles in the program and the applicant organization had adequate facilities and personnel;
 7. Provides an evaluation plan, including a design for determining program success;
 8. Is responsive to the special concerns and program priorities specified in the request for proposals; and
 9. Has demonstrated acceptable past performance (during previous grant periods if currently receiving ODH funds).

Program-Specific Review Criteria

In addition to the criteria listed above, applications will be reviewed based on the degree to which they specifically address the requirements of the Direct Service Initiative. Responses to the RFP, which are determined to be complete and in compliance with these requirements, will be reviewed in accordance with the Point Values contained on the Application Review Summary Form (see **APPENDIX #9**).

The Ohio Department of Health will make the final determination and selection of successful/unsuccessful applicants and reserves the right to reject any or all applications for any given request for proposals. There will be no appeal of the Department's decision.

- T. Freedom of Information Act:** The Freedom of Information Act and the associated Public Information Regulations (45 CFR Part 5) of the U.S. Department of Health and Human Services require the release of certain information regarding grants requested by any member of the public. The intended use of the information will not be a criterion for release. Grant applications and grant-related reports are generally available for inspection and copying except that information considered to be an unwarranted invasion of personal privacy will not be disclosed. For specific guidance on the availability of information, refer to 45 CFR Part 5.
- U. Ownership Copyright:** Any work produced under this grant will be the property of the Ohio Department of Health. This includes all print and audio-visual materials. The Department's ownership will include copyright. The content of any material developed under this grant **must** be approved in advance by the awarding office of the Ohio Department of Health. All material(s) must **clearly** state:

FUNDED BY OHIO DEPARTMENT OF HEALTH
BUREAU FOR CHILDREN WITH MEDICAL HANDICAPS
SICKLE CELL SERVICES PROGRAM

- V. **Reporting Requirements:** Successful applicants are required to submit subgrantee program and expenditure reports. Reports must adhere to the Ohio Department of Health, Grants Administration Policy and Procedure (GAPP) Manual. Reports must be received before the Department will release any additional funds.

Note: Failure to assure quality of reporting such as submitting incomplete and/or late program or expenditure reports will jeopardize the receipt of your agency flexibility status and/or further payments.

Submit reports as follows:

1. **Program Reports:** Subgrantee Program Reports **must** be completed and submitted via the Internet by the following dates:

- SFY 2008 Advisory Committee Membership Form due: **October 15, 2007**
- SFY 2008 Mid-Year Program Performance Report due: **January 15, 2008**
- SFY 2007 Minimum Data Set (MDS) Collection Packet due: **April 15, 2008**
- SFY 2008 Year-End Program Performance Report due: **July 15, 2008**

Additional required attachments associated with a Program Report may be sent electronically as part of an e-mail. Any paper non-Internet compatible report attachments must be submitted to Central Master Files by the specific report due date.

- SFY 2008 Education Event Forms due: **October 15, 2007; January 15, 2008; April 15, 2008 and July 15, 2008.**

Note: The formats for the SFY 2008 Mid-Year and Year-End Performance Reports, the Education Event Forms and the SFY 2007 MDS Collection Packet will be provided to successful applicant subsequent to official notification from ODH.

Submission of Subgrantee Program Reports via the Ohio Department of Health's GMIS 2.0 system indicates acceptance of ODH Grants Administration Policy and Procedure (GAPP). Clicking the "submit" button signifies your authorization of this submission as an agency official and constitutes your electronic acknowledgement and acceptance of GAPP rules and regulations.

2. **Subgrantee Program Expenditure Reports:** Subgrantee Program Expenditure Reports **must** be completed and submitted **via the Internet** by the following dates: **October 15, 2007; January 15, 2008; April 15, 2008 and July 15, 2008**

Submission of Subgrantee Program Expenditure Reports via the Ohio Department of Health's GMIS 2.0 system indicates acceptance of ODH Grants Administration Policy and Procedure (GAPP). Clicking the "submit" button signifies your authorization of this submission as an agency official and constitutes your electronic acknowledgement and acceptance of GAPP rules and regulations.

3. **Final Expense Reports:** A Subgrantee Final Expense Report reflecting total expenditures for the fiscal year must be completed and submitted **via the Internet** within 45 days after the end of each budget period – by 08/15/08. The information contained in this report must reflect the project's accounting records and supportive documentation. Any cash balances must be returned with the Subgrantee Final Expense Report. The Subgrantee Final Expense Report serves as invoice to return unused funds.

Submission of Subgrantee Final Expense Report via the Ohio Department of Health's GMIS 2.0 system indicates acceptance of ODH Grants Administration Policy and

Procedure (GAPP). Clicking the “submit” button signifies your authorization of this submission as an agency official and constitutes your electronic acknowledgement and acceptance of GAPP rules and regulations.

4. **Inventory Report:** A listing of all equipment purchased in whole or in part with **current** grant funds (Equipment Section of the approved budget) must be submitted via the Internet as part of the Subgrantee Final Expense Report. At least once every two years, inventory must be physically inspected by the subgrantee. Equipment purchased with ODH grant funds must be tagged as property of ODH for inventory control. Such equipment may be required to be returned to ODH at the end of the grant program period.

- W. Special Condition(s):** Responses to all special conditions **must be submitted via the Internet within 30 days of receipt of the first quarter payment.** A Special Conditions link is available for viewing and responding to special conditions. This link is viewable only after the issuance of the subgrantee’s first payment. The 30-day time period, in which the subgrantee must respond to special conditions, will begin when the link is viewable. Failure to submit satisfactory responses to the special conditions or a plan describing how those special conditions will be satisfied will result in the withholding of any further payments until satisfied.

Submission of response to grant special conditions via the Ohio Department of Health’s GMIS 2.0 system indicates acceptance of ODH Grants Administration Policy and Procedure (GAPP). Clicking the “submit” button signifies your authorization of the submission as an agency official and constitutes your electronic acknowledgement and acceptance of GAPP rules and regulations.

- X. Unallowable Costs:** Funds **may not** be used for the following:

1. To advance political or religious points of view, or for fund raising or lobbying, but must be used solely for the purpose as specified in this announcement;
2. To disseminate factually incorrect or deceitful information;
3. Consulting fee for salaried program personnel to perform activities related to grant activities;
4. Bad debts of any kind;
5. Lump sum indirect or administrative costs;
6. Contributions to a contingency fund;
7. Entertainment;
8. Fines or penalties;
9. Membership fees– unless related to the program and approved by ODH;
10. Interest or other financial payments;
11. Contributions made by program personnel;
12. Costs to rent equipment or space owned by the funded agency;
13. Inpatient services;
14. The purchase or improvement of land; the purchase, construction, or permanent improvement of any building;
15. Satisfying any requirement for the expenditure of non-federal funds as a condition for the receipt of federal funds;
16. Travel and meals over the current state rates (see OBM Website <http://www.obm.ohio.gov/mppr/travel.asp>);
17. All costs related to out-of-state travel, unless otherwise approved by ODH, and described in the budget narrative;
18. Training longer than one week in duration, unless otherwise approved by ODH;
19. Contracts for compensation, with advisory board members;
20. Grant-related equipment costs greater than \$300, unless justified and approved by ODH;
21. Payments to any person for influencing or attempting to influence members of Congress or the Ohio General Assembly in connection with awarding of grants.
22. Reduce, replace or supplant existing applicant agency funds for sickle cell disease.

Use of grant funds for prohibited purposes will result in the loss or recovery of those funds.

- Y. Audit:** An independent audit must be completed no later than nine (9) months after the end of the agency's fiscal year.

Subgrantees that have an agency fiscal year that ends on or after January 1, 2004 which expend \$500,000 or more in Federal awards in its fiscal year are required to have a single audit (\$300,000 for fiscal years that end on or before December 31, 2003). The fair share of the cost of the single audit is an allowable cost to Federal awards provided that the audit was conducted in accordance with the requirements of OMB Circular A-133.

Subgrantees that have an agency fiscal year that ends on or after January 1, 2004 which expend less than the \$500,000 threshold require a financial audit conducted in accordance with Generally Accepted Government Auditing Standards (\$300,000 for fiscal years ending on or before December 31, 2003). **The financial audit is not an allowable cost to the program.**

Once the audit is completed, a copy must be sent to the ODH, Grants Administration, Central Master Files address within 30 days. Reference GAPP Chapter 100, Section 108 and OMB Circular A-133, Audits of States, Local Governments and Non-Profit Organizations for additional audit requirements.

Z. Submission of Applications:

The Internet application submission must consist of the following:

**Complete &
Submit
Via
Internet**

1. Application Information
2. Assurances
3. Budget
 - Cover Page
 - Personnel
 - Other Direct Costs
 - Equipment
 - Contracts
 - Confirmation of Contractual Agreements
 - Section D
 - Summary
4. Budget Certification
5. Program Narrative
6. EEO Survey
7. Attachments as required by Program
 - Attachment #1 – C.V./Resumes and Position Descriptions
 - Attachment #2 – Project Activities Timeline
 - Attachment #3 – Letters of Support and Documentation
 - Attachment #4 – Advisory Committee Membership

An original and one (1) copy of the following forms, available on the Internet, must be completed, printed, signed in blue ink with original signatures and mailed to the ODH address listed below:

**Complete,
Sign &
Mail
To
ODH**

1. Electronic Funds Transfer (EFT) Form **(Required if new agency, thereafter only if banking information has changed)**
2. IRS W-9 Form **(Required if new agency, thereafter only if tax or agency address information has changed)**

Two (2) copies of the following documents must be mailed to the ODH address listed below:

**Copy
&
Mail To
ODH**

1. Public Health Impact Statement (**for competitive cycle only**)
2. Statement of Support from the Local Health Districts (**for competitive cycle only**)
3. Liability Coverage (**Non-Profit Organizations only; proof of current liability coverage and thereafter at each renewal period**)
4. Evidence of Non-Profit Status (**Non-Profit Organizations only; for competitive cycle only**)

One (1) copy of the following documents must be mailed to the ODH address listed below:

**Complete,
Copy &
Mail To
ODH**

1. Current Independent Audit (latest completed organizational fiscal period)
2. Declaration Regarding Material Assistance/Non-Assistance to a terrorist Organization (DMA) Questionnaire (**Required by ALL Non-Governmental Applicant Agencies**)
3. An original and one (1) copy of Attachments (non-Internet compatible) as required by Program: **None**

**Ohio Department of Health
Grants Administration
Central Master Files, 4th Floor
246 N. High Street
Columbus, Ohio 43215**

II. APPLICATION REQUIREMENTS AND FORMAT

Access to the on-line Grants Management Information System 2.0 (GMIS 2.0), will be provided after your GMIS 2.0 training session.

All applications must be submitted via the Internet. Submission of all parts of the grant application via the Ohio Department of Health's GMIS 2.0 system indicates acceptance of ODH Grants Administration Policy and Procedure (GAPP). Checking the Acknowledgement Button signifies your authorization of this submission as an agency official and constitutes your electronic acknowledgement and acceptance of GAPP rules and regulations in lieu of an executed Signature Page document.

- A. **Application Information:** Information on the applicant agency and its administrative staff must be accurately completed in its entirety. Include e-mail addresses for receipt of acknowledgements. This information will serve as the basis for necessary communication between the agency and the ODH.
- B. **Annual Assurances:** Each subgrantee must submit the "Federal and State Assurances for Subgrantees" form. This form is submitted automatically with each application via the Internet.
- C. **Budget:** Prior to completion of the budget section, please review page 7 of the RFP for unallowable costs.

Match or Applicant Share is not required by this program. Do not include match or applicant share in the budget and/or the Applicant Share column of the Budget Summary. **Only the narrative may be used to identify additional funding information from other resources.**

The funded applicant must **also** adhere to the following budgetary restrictions:

- No more than 50% of the total personnel costs may be allocated for clerical support.
- No more than 10% of the total personnel cost may be allocated for administrative positions (e.g. Grant Manager).
- No more than 10% of the total personnel cost may be allocated for a R.N. to do follow-up (e.g. parental disease education) with infants identified via Newborn Screening (NBS) with a positive hemoglobin disease result.
- No funds may be allocated for the position of Medical Director/Medical Advisor associated with the project. Refer to the Staffing Composition and Administration Section of the ODH Standards and Criteria for information on the position of Medical Director/Medical Advisor.
- No funds may be allocated for clinical services. This is not a funding priority of this grant initiative.

In addition, for the SFY 2008 budget period (07/01/07 to 06/30/08), of the total grant allocation anticipated for each project, funds must be allocated to support travel (to Columbus) and per diem expenses (if applicable) for attendance at the following **required** ODH meetings/educational venues:

- Sickle Cell Project Directors/Coordinators Meetings – Four (4) quarterly meeting during SFY 2008. Dates TBD.
- RSCP NBS Coordinators Meetings – Two (2) times during SFY 2008. Dates TBD.
- RSCP Educators Meetings – Two (2) times during SFY 2008. Dates TBD.

1. **Cover Page:** Provide a detailed narrative budget justification that describes how the categorical costs are derived. Discuss the necessity, reasonableness, and allocability of the proposed costs. Describe the specific functions of the personnel, consultants, and collaborators. Explain and justify equipment, travel, supplies and training costs. If you have joint cost(s), refer to GAPP Chapter 100, Section 103 and Section D (9) of the application for additional information.

2. **Personnel, Other Direct Costs, Equipment, Contracts & Confirmation of Contractual Agreement (CCA) Form(s):** Submit a budget with these sections and form(s) completed as necessary to support costs for the period 07/01/07 to 06/30/08.

Funds may be used to support personnel; their training, travel (see OBM website <http://www.obm.ohio.gov/mppr/travel.asp>) and supplies directly related to planning, organizing, and conducting the initiative/program/activity described in this announcement.

Submit as an attachment with this application, an original and one (1) copy of the following documents:

1. Curricula Vitae/Resumes for all project staff listed on the GMIS 2.0 Personnel Page (see **ATTACHMENT #1**).

Note: References to the curricula vitae/resume information “being on file or submitted with a previous ODH grant application” is not acceptable.

2. Position descriptions for all project staff in which a Curricula Vitae/Resume is submitted (see **ATTACHMENT #1**). A listing of core staffing and position description templates is provided in the Staffing Composition and Administration and Appendix Section of the Standards and Criteria. All position descriptions must encompass the duties and responsibilities as outlined in the templates (excluding Medical Director/Medical Advisor). *If staff has not been selected for a vacant position, a description of the recruitment strategies for filling the position must be submitted.*

Where appropriate, retain all contracts on file. The contracts should not be sent to ODH. A completed “Confirmation of Contractual Agreement” (CCA) form must be submitted via the Internet for each contract. The submitted CCA must be approved by ODH before contractual expenditures are authorized.

Submission of the “Confirmation of Contractual Agreement” (CCA) via the Ohio Department of Health’s GMIS 2.0 system indicates acceptance of ODH Grants Administration Policy and Procedure (GAPP). Clicking the “submit” button signifies your authorization of this submission as an agency official and constitutes your electronic acknowledgement and acceptance of GAPP rules and regulations.

Where appropriate, itemize all equipment (**minimum \$300.00 unit value cost**) to be purchased with grant funds in the Equipment Section.

3. **Section D:** Answer each question on this form as accurately as possible. Completion of the form ensures your agency’s compliance with the administrative standards of ODH and Federal grants.
4. **Budget Summary:** Enter information about the funding sources, budget categories and forecasted cash needs for the project. Distribution should reflect the best estimate of need by quarter. Failure to complete this section will cause delays in receipt of grant funds.

- D. Budget Certification:** The Budget Certification sets forth standards of financial conduct relevant to receipt of grant funds and is provided for informational purposes. The listing is not all-inclusive and any omission of other statutes does not mean such statutes are not assimilated under this certification. Complete the form by entering the State and Congressional Districts. By clicking the Acknowledge box when submitting an application, the subgrantee agency agrees by electronic acknowledgement to the financial standards of conduct as stated therein.

E. Program Narrative:

(Each Program Narrative point must have a response. The responses should be referenced by the bulleted point to which they correspond. All responses {unless otherwise indicated} should be submitted via GMIS 2.0).

1. Executive Summary:

- Describe the public health problem/need that the project will address.
- Identify the specific target population(s) affected by hemoglobinopathies to be served.
- Identify the services and programs to be offered.
- Identify other agencies or subcontractors will be involved in the provision of these services and programs.

2. Description of Applicant Agency/Documentation of Eligibility/Personnel:

- Briefly describe the applicant's eligibility to apply for funds (see requirements listed under Qualified Applicants in Section I).
- Summarize the agency's structure as it relates to this project and, as the lead agency, how it will manage the program.
- Note any personnel or equipment deficiencies that will need to be addressed in order to carry out this grant. Describe plans for hiring and training, as necessary.
- Delineate all personnel or positions (grant funded and non-grant funded) who will be directly involved in project activities. Include curricula vitae/resumes and positions descriptions as outlined in this Section under Personnel, Other Direct Costs, Equipment, Contracts & Confirmation of Contractual Agreement Form(s).
- Describe the relationship between project staff members, staff members of the applicant agency and other partners and agencies that will be working on the project. Include letters of support and documentation as outlined in this Section under Additional Requirements.

3. Problem/Need:

- Identify and describe the local/regional health status concern(s) that supports the need for the project. Do not restate national and state data. The specific health status concerns that the program intends to address may be stated in terms of health status (e.g. morbidity and/or mortality) or health system (e.g. accessibility, availability, affordability, appropriateness of health services) indicators. The indicators should be measurable in order to serve as baseline data upon which the evaluations will be based.
- Clearly indicate the specific target population(s), affected by this health status concern(s) that will be served by the project.
- Describe other agencies/organizations also addressing this problem/need and how collaboration/coordination efforts will occur.

4. Methodology:

- In lieu of submitting a narrative identifying the program goals, objectives and activities, each applicant is required to complete a **Project Activities Timeline Form** (see instructions for completion of the Form on **ATTACHMENT #2**) to identify specific project objectives, expected results, action implementation steps and timeline (start/finish) dates for the SFY 2008 grant period.
- Applicants must utilize the RSCP Goals, predetermined or "core" Expected Results (the ultimate outcomes expected as a result of funding the RSCP) and Performance Indicators (how Projects will be monitored) listed on **APPENDIX #10** to complete their Timeline Form.

5. Additional Requirements

(This section is to be submitted as an attachment via GMIS 2.0).

- **Letters of Support and Documentation**
Each applicant must provide a letter of support from a minimum of five (5) partner individual, groups and/or agency/organizations that support the purpose, scope and work of the applicant agency. One letter must be submitted from at least three (3) of the entities listed on **ATTACHMENT #3**. Letters of support must specific to the applicant agency and

current for this SFY 2008 application.

Each applicant must also identify and provide a letter of documentation from the Medical Director/Medical Advisor that will be responsible for providing guidance and leadership to the applicant agency regarding the five (5) service components and four (4) administrative components of the RSCP (see **ATTACHMENT #3**). The letter of documentation must be current for this SFY 2008 application and document the relationship between the Medical Director/Medical Advisor and the applicant agency.

■ **Sickle Cell Advisory Committee**

(This section is included for the applicant's information only-no additional narrative response is required on GMIS 2.0)

During the SFY 2008 to SFY 2011 program period, each applicant is required to establish and maintain a functional Sickle Cell Advisory Committee which meets, at a minimum semiannually, and whose membership reflects/represents 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. As the designated advisory group, the purpose of the Committee is to assist and advise the Regional Sickle Cell Project in formal interagency planning, policy development and implementation of a coordinated, comprehensive and multi-disciplinary system of regional sickle cell services and supports.

By October 15, 2007, each funded applicant must submit (via the Internet) the following document:

1. Advisory Committee Membership by Category Form (see **ATTACHMENT #4**). Refer to the Performance Improvement and Evaluation Activities Section of the ODH Standards and Criteria for information on categories of representation for Advisory Committee membership.

Note: The Sickle Cell Advisory Committee (under this Initiative) must be established outside the administrative boards of the applicant agency.

■ **SCSP Reporting Requirements**

(This section is included for the applicant's information only-no additional narrative response is required on GMIS 2.0)

Each funded applicant will be required to submit 1) Quarterly Education Event Forms; 2) an ODH MDS Collection Packet, 3) SFY 2008 Mid-Year and Year-End Program Performance Report and 4) Advisory Committee Membership by Category information in the time frame as specified under the Reporting Requirements section of this RFP.

- F. Attachment(s):** Attachments are documents deemed necessary to the application that are not part of the GMIS 2.0 system. Attachments will be sent via GMIS 2.0. Attachments sent electronically must be transmitted by the application due date. Attachments that are non-Internet compatible must be postmarked or received on or before the application due date. An original and the required number of copies of non-Internet compatible attachments must be mailed to the ODH, Grants Administration, Central Master Files address on or before **April 23, 2007**. All attachments must clearly identify the authorized program name and program number.

- G. Electronic Funds Transfer (EFT) Form:** Print in PDF format and mail to ODH, Grants Administration, Central Master Files address. The completed EFT form **must be** dated and signed, in blue ink, with original signatures. Submit the original and one (1) copy (**Required only if new agency, thereafter only when banking information has changed**).
- H. Internal Revenue Service (IRS) W-9 Form:** Print in PDF format and mail to ODH, Grants Administration, Central Master Files address. The completed IRS W-9 form **must be** dated and signed, in blue ink, with original signatures. Submit the original and one (1) copy (**Required if new agency, thereafter only when tax or agency address information has changed**).
- I. Public Health Impact Statement Summary:** Submit two (2) copies of a one-page program summary regarding the impact to proposed grant activities on the Local Health Districts Improvement Standards (**for competitive cycle only**).
- J. Public Health Impact Response/Statement:** Submit two (2) copies of the response/statement(s) of support from the local health district(s) to your agency's communication regarding the impact of the proposed grant activities on the Local Health District(s) Improvement Standards. If a statement of support from the local health district is not available, indicate that and submit a copy of the program summary your agency forwarded to the local health district(s) (**for competitive cycle only**).
- K. Liability Coverage:** Liability coverage is required for all non-profits agencies. Non-profit organizations **must** submit documentation validating current liability coverage. Submit two (2) copies of the Certificate of Insurance Liability (**Non-Profit Organizations only; current liability coverage and thereafter at each renewal period**).
- L. Non-Profit Organization Status:** Non-Profit organizations **must** submit documentation validating current status. Submit two (2) copies of the Internal Revenue Services (IRS) letter approving your non-tax exempt status (**Non-Profit Organizations only; for competitive cycle only**).
- M. Declaration Regarding Material Assistance/Non-Assistance to a Terrorist Organization (DMA) Questionnaire:** The DMA is a Questionnaire that must be completed by all grant applicant agencies to certify that they have not provided "material assistance" to a terrorist organization (Sections 2902.32, 2909.33 and 2909.34 of the Ohio Revised Code). The completed Questionnaire **must be** dated and signed, in blue ink, with the Agency Head's signature. The DMA Questionnaire (in PDF format Adobe Acrobat is required) is located at the Ohio Homeland Security Website:

<http://www.homelandsecurity.ohio.gov/dma/dma.asp>

- Click on "DMA Forms and Materials"
- Go to DMA Forms and click on "DMA for funding and business contracts"
- Print a hard copy of the form once it has been downloaded. The Form must be completed in its entirety and your responses must be truthful to the best of your knowledge (**Required by ALL Non-Governmental Applicant Agencies**).

N. EEO Survey: The Civil Rights Review Questionnaire (EEO) Survey will be part of the Application Section of GMIS 2.0. Subgrantees must complete the questionnaire as part of the application process. This questionnaire is submitted automatically with each application via the Internet.

O. Attachments as Required by Program

(All attachments must clearly identify the authorized program name and grant application number).

The applicant must submit the following to ODH via GMIS 2.0 by the filing due date, **Monday, April 23, 2007:**

- ATTACHMENT #1 – C.V./Resumes and Position Descriptions
- ATTACHMENT #2 – Project Activities Timeline
- ATTACHMENT #3 – Letters of Support and Documentation
- ATTACHMENT #4 – Advisory Committee Membership by Category

II. APPENDICES

- APPENDIX #1 – ODH Sickle Cell Program Standards and Criteria
 - Sub – Appendix #1 – Position Description Template – Project Director
 - Sub - Appendix #2 – Position Description Template – Newborn Screening Coordinator
 - Sub – Appendix #3 – Position Description Template - Regional Outreach Educator
- APPENDIX #2 – Funding Allocation by Region
- APPENDIX #3 – Sickle Cell Target Population Projection – Region I
- APPENDIX #4 – Sickle Cell Target Population Projection – Region II
- APPENDIX #5 – Sickle Cell Target Population Projection – Region III
- APPENDIX #6 – Sickle Cell Target Population Projection – Region IV
- APPENDIX #7 – Sickle Cell Target Population Projection – Region V
- APPENDIX #8 – Sickle Cell Target Population Projection – Region VI
- APPENDIX #9 – Application Review Summary Form
- APPENDIX #10 – RSCP Goals, Expected Results and Performance Indicators

ATTACHMENTS AS REQUIRED BY PROGRAM

SFY 2008 – ATTACHMENT #1

C.V./RESUMES AND POSITION DESCRIPTIONS

Include:

1. Curricula Vitae/Resumes for all project staff listed on the GMIS 2.0 Personnel Page.

Note: References to the curricula vitae/resume information “being on file or submitted with a previous ODH grant application” is not acceptable.

2. Positions descriptions for all project staff in which a Curricula Vitae/Resumes is submitted. A listing of core staffing and position descriptions templates are provided in the Staffing Composition and Administration and Appendix Section of the ODH Standards and Criteria. All position descriptions must encompass the duties and responsibilities as outlined in the templates (excluding Medical Director/Medical Advisor). *If staff has not been selected for a vacant position, a description of the recruitment strategies for filling the position must be submitted.*

SFY 2008 - ATTACHMENT #2

PROJECT ACTIVITIES TIMELINE FORM

Sickle Cell Project: _____ Project #: _____

Goal: **Write in the specific Goal (A, B, or C) as listed in APPENDIX #10.**

One objective per page; numbered sequentially. Duplicate form as needed.

(1) Specific Objectives	(2) Expected Result	(3) Action Implementation Steps Responsible Party	(4) Performance Indicator	(5) Timeline/ Start/Finish
<p>Write the specific <u>measurable</u> objective for SFY 2008 that addresses the Expected Result and Performance Indicator. All objectives must be numbered sequentially and limited to one per page.</p>	<p>Write in the Expected Result as listed in APPENDIX #10.</p>	<p>Write in the activities (Action Implementation Steps) that will be undertaken by the project to address the specific objective stated in column (1). For each activity listed, the staff person/position responsible for implementation of the activity (Responsible Party) must be delineated. Action Implementation Steps should be numbered sequentially to match the Timeline (Start/Finish) dates.</p>	<p>Write in the Performance Indicator as listed in APPENDIX #10.</p>	<p>Write in the start/finish date for each activity listed in column (3). Unless the anticipated timeline start/finish dates for a specific activity is the entire grant period, timeline dates should be based on actual completion dates. Timeline (Start/Finish) dates should be numbered sequentially to match the Action Implementation Steps.</p>

SFY 2008 – ATTACHMENT #3

LETTERS OF SUPPORT AND DOCUMENTATION

Include:

1. A letter of support from a minimum of five (5) partner individual, groups and/or agency/organizations that support the purpose, scope and work of the applicant agency. One letter must be submitted from at least three (3) of the following entities:
 - A representative from a Blood Service Agency in the region
 - A representative from a Federally Qualifying Health Center (FQHC)
 - A representative from an organization that has a mission or goal of addressing health disparities for underserved populations
 - A representative (genetic counselor) from the Regional Comprehensive Genetics Center
 - A representative from a Ministerial Alliance or Faith-Based Group
 - A representative from a pediatric health care facility in the region that serves children with sickle cell disease (*community-based applicants*)
 - A representative from an adult health care facility in the region that serves adults with sickle cell disease (*community and hospital-based applicants*)
 - A representative from the local March of Dimes Chapter
 - A representative from the volunteer or advocacy community
 - A representative (project director or designee) from a local Help Me Grow Project
 - A parent of children with sickle disease, age newborn to eighteen (18) years of age
 - An adult with sickle cell disease, age 18 or older

The letter of support must be specific to the applicant agency and current for the SFY 2008 grant application.

Note: The letter(s) of support from the Local Health Districts in the region with the largest estimated carrier populations are required as part of the RFP.

2. A letter of documentation from the Medical Director/Medical Advisor that will be responsible for providing guidance and leadership to the applicant agency regarding the five (5) service components and four (4) administrative components of the RSCP.
 - 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 applicants, based on-site.
 - If the medical director/medical advisor is not a board-certified hematologist based on-site, at a minimum, he/she must be a licensed physician with expertise in the management of persons with sickle cell disease.
 - For applicants with an 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 applicant.

Note: There is no monetary compensation for this position of Medical Director/Medical Advisor under this Initiative.

SFY 2008 – ATTACHMENT #4

ADVISORY COMMITTEE MEMBERSHIP BY CATEGORY*

Categories of Representation for Advisory Committee Membership	Name of Person(s)
Representative from a Blood Service Agency	
Representative from a Federally Qualifying Health Center (FQHC)	
Representative from an organization addressing health disparities	
Representative from Genetics (Regional Comprehensive Genetics Center)	
Representative from a Faith-Based Group or Ministerial Alliance	
Representative(s) (nursing director or designee) from Local Health District(s)	
Representative from a pediatric health care facility serving children with sickle cell disease (community-based projects)	
Representative from an adult health care facility serving adults with sickle cell disease (community and hospital-based projects)	
Representative from the local March of Dimes chapter	
Representative from a volunteer community or advocacy group	
A local Help Me Grow Project Director or designee	
10% representation from parents of children with sickle cell disease-age 18 years or younger	
10% representation from adults affected with sickle cell disease-18 years or older	

* For Advisory Committee information, refer to the Standards and Criteria document.

III. APPENDICES

SFY 2008 - APPENDIX #1

OHIO DEPARTMENT OF HEALTH
SICKLE CELL SERVICES PROGRAM
STANDARDS AND CRITERIA

ODH Approval: March 2004
Revised: January 2007

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 cell services;
- 2) To inform, guide and facilitate required and recommended “best” practices related to the provision of sickle cell services in Ohio; and
- 3) To serve as the foundation for quality assurance of Ohio RSCPs.

Priority for grant funding shall be given 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 Regional Sickle Cell Project.

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

Ohio Department of Health
Bureau for Children with Medical Handicaps
Sickle Cell Services Program
246 N. High Street
Columbus, Ohio 43215

Phone: 614.728.6787
Fax: 614.728.3616

TABLE OF CONTENTS

PREFACE 2

SICKLE CELL PROGRAM OVERVIEW

 Background 4

 Purpose of the ODH Sickle Cell Services Program..... 5

 Operational Definition of a Regional Sickle Cell Project..... 5

 Components of a Regional Sickle Cell Project..... 5

SERVICE COMPONENTS

 Procedures of Care 6

 Education Activities 6-7

 Collaboration and Referral Activities 7-8

 Outreach Activities 8

 Performance Improvement and Evaluation Activities 8-11

ADMINISTRATIVE COMPONENTS

 Facility Arrangements and Policies 11

 Staffing Composition and Administration 11-12

 Culturally and Linguistically Appropriate Services 12-13

 Guiding Operational Principles 13

REFERENCES 14

APPENDIX

 Appendix #1 – Project Director Position Description Template

 Appendix #2 – Newborn Screening Coordinator Position Description Template

 Appendix #3 – Regional Outreach Educator Position Description Template

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 sickle cell services are available to all Ohioans with or at-risk for sickle cell disease, sickle cell trait and related hemoglobin disorders.

In 1987, two federal agencies, the National Institutes of Health (NIH) and the Health Resources and Services Administration, 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 governing tests on newborn infants was revised to include screening for hemoglobinopathies. Specific responsibilities of hospitals, primary care physicians and state-funded sickle cell projects were also modified in the Revised Code. By 1990, statewide universal newborn screening for hemoglobinopathies was mandated in Ohio along with Phenylketonuria (PKU), Homocystinuria, Galactosemia and Hypothyroidism. Ohio currently mandates testing of all newborns for thirty-two (32) 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. As a public health program, the primary goals are to:

- A. Promote the early identification of children and adults with sickle cell disease and related hemoglobin disorders and facilitate their integration into systems of service and care (which includes treatment interventions) that are accessible, continuous, comprehensive, family centered, coordinated and culturally sensitive.
- B. Increase the awareness, knowledge and skill level of Ohio’s health care professionals and providers about the special health care needs and services related to sickle cell disease and other hemoglobin disorders through the promoted use of education, training and outreach.
- C. Expand public and community awareness and access to information on sickle cell disorders and related programs/services with special emphasis on meeting the needs and culture of unserved and/or under-served at-risk population groups.

PURPOSE OF THE ODH SICKLE CELL SERVICES PROGRAM

In partnership with the Regional Sickle Cell Projects (RSCPs), the ODH Sickle Cell Services Program works to ensure and enhance the availability and accessibility of quality, comprehensive services for newborns, children and adults identified with or at-risk for sickle cell disease, sickle cell trait and related hemoglobin disorders in Ohio. Comprehensive services for the purpose of this document may include, but is not limited to:

- Tracking and follow up of abnormal hemoglobin results, including newborn and non-newborn test results;
- Genetic, psychosocial and hemoglobinopathy counseling;
- Hemoglobinopathy education and resource materials, training, outreach and awareness activities; and
- Care coordination and/or referral to specialized medical teams and resources for diagnostic, preventive, transition and evaluative hemoglobin disease management.

OPERATIONAL DEFINITION OF A REGIONAL SICKLE CELL PROJECT

A RSCP will operate as an identifiable, functional unit or program within a tertiary care or community-based facility. It will be organized for and capable of ensuring the provision of **regional** comprehensive sickle cell services to newborns, children and adults with or at-risk for sickle cell disease, sickle cell trait and related hemoglobin disorders.

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) service and four (4) administrative components:

Service Components

- Procedures of Care
- Education Activities
- Collaboration and Referral 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

SERVICE COMPONENTS

I. **Procedures of Care** for a Regional Sickle Cell Project (RSCP) *shall* include:

- A. Documentation forms and/or databases to record information related to the provision of comprehensive services (e.g., diagnostic/confirmatory testing, genetic, psychosocial and hemoglobinopathy counseling, education and applicable treatment interventions) for newborns, children and adults identified with or at-risk for a hemoglobinopathy.
- B. A complete procedure manual detailing the “follow-up” procedures for any positive or potentially positive hemoglobin result from the point of notification to the RSCP to the point of resolution/disposition. Responsibilities and implementation of follow-up procedures should be assigned to a specific project staff member.
- C. Hemoglobinopathy counseling formats for all hemoglobin variants which are:
 - non-directive and aimed at helping consumers make informed decisions about health related and/or family planning issues that they believe are in their best interest; and
 - communicated accurately, thoroughly and clearly to consumers in a manner that is consistent with their primary language, literacy level, learning style and cultural needs (see Culturally and Linguistically Appropriate Services).
- D. Affiliations with approved Bureau for Children with Medical Handicaps (BCMh) Hematology Service Providers for RSCPs that are not based at an established medical institution.
- E. An established operational manual of protocol and responsibility related to the development, implementation and evaluation of the counseling 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.

II. **Education Activities** of an Ohio Regional Sickle Cell Project *shall* include:

- A. **Consumer/family education** consisting of:
 - 1. Up-to-date information related to all aspects of the consumer’s diagnosis (including complications and management, if applicable) communicated accurately, thoroughly and clearly to the consumer/family in a manner consistent with their:
 - primary language (or other mode of communication);
 - literacy level;
 - learning style; and
 - cultural needs (see Culturally and Linguistically Appropriate Services).
- B. **Community education** and public awareness consisting of:
 - 1. Regional outreach programs that focus on the dissemination of hemoglobinopathy education and information to targeted unserved and/or underserved at-risk 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 service 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 verbiage/logo requirements on all RSCP-designed/produced education materials and literature in accordance with ODH guidelines.

E. A regional resource and referral clearinghouse of professional and consumer hemoglobinopathy education materials that are current and of professional quality and culturally, age, language and literacy appropriate (see Culturally and Linguistically Appropriate Services).

F. An established 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 consumers' knowledge about their disorders and promote self-care and empowerment.

III. **Collaboration and Referral Activities** of an Ohio Regional Sickle Cell Project *shall* include:

- A. Active participation and/or collaboration with community, state and national programs and organizations/leaders to enhance individual/family education about specific disorders and to increase availability of peer support resources (e.g. Regional Comprehensive Genetic Centers, State Sickle Cell Affected Family Groups, March of Dimes Chapters, Sickle Cell Disease Association of America (SCDAA)/Ohio Sickle Cell and Health Association, Alliance of Genetic Support Groups).
- B. A designated telephone number and project brochure that is widely publicized for coordinated information and referral services (see Facility Arrangements and Policies).
- C. 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 (BMCH)** – A health care program (Diagnostic, Treatment and Service Coordination) which links families of children 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 (OCCSN)** – 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.
- D. Access to medical support and sub-specialty services necessary for the diagnosis, prevention, transition, evaluation and management of hemoglobinopathies.

In addition, the RSCP should:

- A. Establish and maintain collaborative agreements with appropriate private, public and voluntary service and health care providers to ensure the full range of services necessary to meet the medical, psychosocial and social service needs of the individual and/or family and ensure continuity of care and follow up.
- B. Maintain a database of newborn screening providers, pediatric and adult sub-specialists and adult and primary care providers in the region.

IV. **Outreach Activities** of an Ohio Regional Sickle Cell Project *should* include:

- A. Satellite Sickle Cell Projects that:
 1. Increase accessibility and availability of sickle cell services to underserved target populations through regularly scheduled clinics and/or educational outreach services which are coordinated by credentialed health care professionals based at the site.
 2. Operate under formal agreement or contract with an RSCP through which funding flows but which is located in a non-RSCP health care facility.

And, or:

- A. Outreach Sickle Cell Clinics that:
 1. Increase the accessibility and availability of sickle cell services to underserved target populations through periodically scheduled clinics and educational outreach services.
 2. Are operated by an RSCP and convened in a community-based or non-RSCP facility located outside of the RSCP’s home county.
 3. Are coordinated locally (usually by an employee of the host facility) and staffed by a visiting credentialed RSCP professional as defined under Administrative Components – Staffing Composition and Administration.
 4. Offer a limited range of sickle cell counseling and educational services under the auspices of an RSCP to which referrals can be made for the full range of sickle cell services as needed.

V. **Performance Improvement and Evaluation Activities** of an Ohio Regional Sickle Cell Project *shall*

include:

Project Level Activities

- A. An active program to monitor and evaluate the quality of patient/client and RSCP services/program. An active program must include:
 - 1. An established and regular internal communication mechanism (e.g., team conferences and/or meetings) to discuss the progress and effectiveness of patient/client services, short-and long-term tracking of the follow-up component and ongoing outcome evaluation of the education and counseling components.
 - 2. A mechanism in place to collect information from service recipients and regional providers on an ongoing basis to evaluate, monitor and modify RSCP services.
- B. A process for identifying and resolving individual patient/client, as well as RSCP staff member complaints and/or problems.
- C. Evaluation tools in place to determine and document the level of patient/client understanding of information subsequent to counseling and/or education services.
- D. Compliance with all state and federal data collection, program evaluation and other reporting requirements.
- E. A functional Sickle Cell Advisory Committee which meets, at a minimum, semi-annually, and whose membership reflects 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. **As the designated advisory group, the purpose of the Sickle Cell Advisory Committee is to assist and advise the RSCP in formal interagency planning, policy development (in accordance with ODH standards), and implementation of a coordinated, comprehensive and multi-disciplinary system of regional sickle cell supports and services.**

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

- 1. Advise and assist the RSCP in development and implementation of policies.
- 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 applications for fiscal and other support.
- 4. Advise and assist the RSCP in the promotion and implementation of regional educational campaigns (including Sickle Cell Sabbath/Sunday and National Health Observance Month activities).
- 5. Advise and assist the RSCP in the development and implementation of the evaluation process.
- 6. Advise and assist the RSCP and the ODH in matters regarding transition of adolescent/young adults from pediatric to adult medical care and other appropriate services and resources.

7. Establish standing and ad-hoc committees, task forces and other groups necessary to operations of the committee.

Membership composition of the Advisory Committee:

1. A representative from a Blood Service agency;
2. A representative from a Federally Qualifying Health Center (FQHC);
3. A representative from a organization that has a mission or goal of addressing health disparities for underserved populations;
4. A representative (genetic counselor) from the Regional Comprehensive Genetics Program;
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;
8. A representative from an adult health care facility (or service agency) in the region serving adults with sickle cell disease;
9. A representative from the local March of Dimes chapter;
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 representation from parents of children with sickle cell disease age 18 years or younger;
13. At least 10 percent representation from adults (age 18 or older) affected with sickle cell disease.

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

ODH Data Collection and Reporting Requirements

- A. Setup, collection and electronic reporting of RSCP newborn screening and education event data to ODH in compliance with RSCP database categories/data fields and definitions.
- B. Monitoring and reporting of performance indicators as defined by ODH to measure regional/statewide program results and impact.
- C. Participation in a project self evaluation and monitoring site visit process as requested by ODH.
- D. Maintenance of computer hardware and software as specified by ODH to allow linkage and data entry in designated information systems.

- E. Participation in research and evaluation activities as recommended by the director of health and, ODH Advisory Councils (e.g., Newborn Screening, Ohio Connections for Children with Special Needs).

In addition, the RSCP *should*:

- A. Provide opportunities (e.g., parent group, teen group) for parents/families to meet and interact with other families who are or have been served by the RSCP or who share similar experiences and/or concerns.

ADMINISTRATIVE COMPONENT

I. **Facility Arrangements and Policies** for an Ohio Regional Sickle Cell Project *shall* include:

- A. Identification with an ODH-defined multi-county sickle cell services 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 agency assurances and other documentation as required by ODH.
- E. Adequate and appropriately equipped 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/extension through which all services can be accessed and for contacting the RSCP staff members during regular working hours.
- G. A secure fax machine in compliance of Health Insurance Portability and Accountability Act (HIPAA) guidelines.
- H. Permission for access and review of facility records (including those of project contractors, if applicable) and compliance with the Ohio Public Records Law ORC 19.43.

II. **Staffing Composition and Administration** of an Ohio Regional Sickle Cell Project *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 the organization, implementation and administration of a RSCP which provides and/or coordinates newborn screening follow-up, regional outreach education and hemoglobin-counseling services (see **APPENDIX #1**). The person in this position will also be expected to maintain close contact with the ODH Sickle Cell Program Coordinator and grants management officers. Depending on the funding resources, this responsibility may be combined with other team member functions.

2. **Newborn Screening Coordinator** – This person is responsible for the planning, coordination and implementation of newborn hemoglobin screening follow-up and hemoglobin-counseling services (see **APPENDIX #2**). This is a 100% grant-funded position.
3. **Regional Outreach Educator** – This position is responsible for the overall planning, coordination, implementation and evaluation of public and professional hemoglobinopathy education services (see **APPENDIX #3**). Depending on the funding resources, this position may be combined with other team member functions.
4. **Medical Director/Medical Advisor** – This person is responsible for providing guidance and leadership to the team regarding newborn screening follow-up, disease management, research and other activities related to patient care.
 - 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 expertise in the management of persons with sickle cell disease.
 - For projects with an 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.

In addition, In addition, an extended multi-disciplinary team comprised of the following areas of expertise *must* be readily available and accessible as needed for referral and/or consultation:

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 and massage therapy)
- B. Certified approval documenting satisfactory completion of an approved Hemoglobinopathy Training Program within one year of employment.
 - 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 skills with respect to sickle disease and related hemoglobin disorders through documented attendance at conferences, seminars, workshops and/or in-service education programs.
 - E. Current resumes or CVs on file with ODH with Sickle Cell Program Coordinator.
 - F. Maintenance of written contracts/agreements for all core professional services not directly provided by project personnel, including identification of services to be rendered (including, when appropriate, hours, personnel involved, payment and billing procedures).
 - G. Attendance at all requested and/or required ODH meetings and sickle cell related work groups to include, but not limited to:

- Sickle Cell Project Directors/Coordinators Meeting(s)
- Newborn Screening Coordinators Meeting(s)
- Regional Outreach Educators Meeting(s)

III. **Culturally and Linguistically Appropriate Services** of an Ohio Regional Sickle Cell Project *shall* include:

- A. Access to bilingual staff and interpretation services (at no cost) for clients with limited English proficiency (LEP).
- B. Oral and written notices, including translated signage at key points of contact, to inform clients, in their primary language, of their right to receive interpreter services free of charge.
- C. Signage and commonly used printed patient/consumer educational information and other materials, translated and made available for members of the predominant language groups in service areas (see – Education Activities).
- D. Ongoing education and training for administrative, clinical and support staff in culturally and linguistically competent service delivery.
- E. A strategy to recruit, retain and promote qualified, “diverse” and culturally competent administrative, clinical and support staff that are trained and qualified to address the needs of the racial and ethnic communities being served. **Diverse staff is defined as being representative of the diverse demographic population of the service area.** Staff refers to not only personnel employed by the project but also subcontracted and affiliated personnel.

In addition, the RSCP *should*:

- A. Promote and support the attitudes, behaviors, knowledge and skills necessary for staff to work respectfully and effectively with patients/consumers and each other in a culturally diverse work environment.

IV. Policy, Procedure and Practices of an Ohio Regional Sickle Cell Project shall be developed based on the following **Guiding Operational Principles**:

- A. RSCP services are available, accessible, family-centered and culturally 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 or ability to pay.
- C. Individuals and their families requiring and/or receiving sickle cell services shall have the freedom to utilize the RSCP of their choice and actively participate in decision-making regarding their own health care.
- D. Individual/family privacy and confidentiality is maintained and practiced by RSCP staff, interns and volunteers as outlined by HIPAA guidelines.

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*. Produced for the Office of Minority Health, Public Health Service, U.S. Department of Health and Human Services, 2000.
8. *Ohio Regional Comprehensive Genetic Centers Standard and Criteria*. Ohio Department of Health, Columbus, Ohio, revised 2004.

Sub – Appendix #1

Ohio Department of Health
Bureau for Children with Medical Handicaps
SICKLE CELL SERVICES PROGRAM

POSITION DESCRIPTION TEMPLATE

POSITION TITLE: Project Director

SUMMARY OF RESPONSIBILITY:

Responsible for the organization, implementation and administration of a Regional Sickle Cell Project (RSCP) which provides and/or coordinates newborn screening hemoglobin follow-up, regional outreach education and hemoglobin-counseling services 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 internal operations and components of the RSCP in accordance and compliance with ODH policies and required and recommended “best” practice Standards and Criteria.
2. Supervise and evaluate RSCP staff and conduct performance evaluations. Make recommendations regarding recruitment, hiring and termination of personnel.
3. Administrate and monitor ODH grant funds and other revenues to ensure adherence to expenditure guidelines in the implementation of program activities.
4. Aid in planning and delivery of NBS hemoglobin follow-up, educational programming, outreach and hemoglobin-counseling services as arranged by RSCP staff.
5. Maintain records system and data/statistics on RSCP components for ODH data collection, program evaluation and other reporting requirements.
6. Prepare, write and submit RSCP grant applications, reports and other documents as required by ODH and/or other external funding resources.
7. Participate as a member of ODH sponsored meetings and other relevant committees.
8. Keep ODH State Program Coordinator apprised of activities in the fiscal, education, outreach, hemoglobin-counseling, and newborn screening components of the Project.

POSITION DESCRIPTION TEMPLATE

Project Director

Page 2

B. Regional Outreach

1. Recruit and select members for the RSCP Advisory Committee and other ad-hoc interest groups. Conduct 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, the public and individuals identified with or at-risk for sickle cell disease, sickle cell trait and related hemoglobin disorders.
3. Participate in outreach strategies to increase patient referrals, compliance and access to comprehensive sickle cell services in conjunction with Hematology-Oncology Centers 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 competent 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.

POSITION DESCRIPTION TEMPLATE

Project Director

Page 3

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.

Certification:

1. Certified approval documenting satisfactory completion of a Hemoglobinopathy Training Program required within one year of employment.

Additional Requirements:

1. Ability to provide own transportation.
2. Ability to travel and work flexible hours, including some evenings and weekends.
3. Ability to work closely with diverse populations (various racial/ethnic, socioeconomic and educational backgrounds) and professionals from other disciplines.
4. Ability to develop collaborative relationships with Regional Hematology-Oncology Centers and work as part of an integrated team.

Sub – Appendix #2

Ohio Department of Health
Bureau for Children with Medical Handicaps
SICKLE CELL SERVICES PROGRAM

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POSITION DESCRIPTION TEMPLATE

POSITION TITLE: Newborn Screening Coordinator

REPORT TO: Project Director

SUMMARY OF RESPONSIBILITY:

Responsible for the planning, coordination and implementation of newborn hemoglobin screening follow-up and hemoglobin-counseling 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 newborn screening (NBS) follow-up, hemoglobin-counseling, regional outreach, professional development, administration and research.

PRINCIPAL DUTIES AND RESPONSIBILITIES:

A. Newborn Screening Follow-up

1. Track all newborns identified via NBS with an abnormal hemoglobin trait result to assure confirmation of results and hemoglobin-counseling services.
2. Track all newborns identified via NBS with an abnormal hemoglobin disease result to assure care coordination and referral to specialized medical teams and resources for diagnostic, preventive, and evaluative hemoglobin disease management.

B. Hemoglobin-Counseling

1. Provide on and off site hemoglobin-counseling services to parents of newborns and non-newborn individuals identified with an abnormal hemoglobin result.
2. Coordinate and facilitate reciprocal referrals for hemoglobin-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 hemoglobin-counseling services.
5. Coordinate and/or co-facilitate education sessions and/or activities for parent/affected family group audiences.

POSITION DESCRIPTION TEMPLATE

Newborn Screening Coordinator

Page 2

C. Regional Outreach

1. Participate as a member of the RSCP Advisory Committee and other regional ad-hoc interest groups.
2. Act as a liaison and resource consultant regarding hemoglobinopathies, newborn screening and hemoglobin-counseling services to regional agencies and organizations, health and allied health professionals/providers, the public and individuals identified with or at-risk for sickle cell disease, sickle cell trait and related hemoglobin disorders.
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, newborn screening, hemoglobin-counseling and culturally and linguistically competent 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 hemoglobin-counseling services 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 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 B.A. /B.S. minimum, M.A. /M.S. preferred in a field of study commensurate with duties and responsibilities of the Position.

POSITION DESCRIPTION TEMPLATE
Newborn Screening Coordinator
Page 3

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. Training or experience in counseling techniques essential.
3. Demonstrated proficiency in oral and written communication skills.
4. Capable of functioning independently/self motivated.

Certification:

1. Certification documenting satisfactory completion of a Hemoglobinopathy Training Program required within one year of employment.

Additional Requirements:

1. Ability to provide own transportation.
2. Ability to travel and work flexible hours, including some evenings and weekends.
3. Ability to work closely with diverse populations (various racial/ethnic, socioeconomic and educational backgrounds) and professionals from other disciplines.
4. Ability to develop collaborative relationships with Regional Hematology-Oncology Centers and work as part of an integrated team.

Sub – Appendix #3

Ohio Department of Health
Bureau for Children with Medical Handicaps
SICKLE CELL SERVICES PROGRAM

POSITION DESCRIPTION TEMPLATE

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 consumers, health care providers and 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. Administer the School Intervention Program for pediatric/adolescent patients in conjunction with Regional Hematology-Oncology Centers.
4. Collaborate with Ohio Regional Sickle Cell Projects (RSCP), 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/affect 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.

POSITION DESCRIPTION TEMPLATE

Regional Outreach Educator

Page 2

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 RSCP 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, the public and individuals identified with or at-risk for sickle cell disease, sickle cell trait and related hemoglobin disorders.
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 competent 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.

POSITION DESCRIPTION TEMPLATE

Regional Outreach Educator

Page 3

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 various communications media (e.g. power point).
6. Capable of functioning independently/self motivated.

Certification:

1. Certification documenting satisfactory completion of a Hemoglobinopathy Training Program required within one year of employment.
2. Health Education Specialist Certification highly desirable.

Additional Requirements:

1. Ability to provide own transportation.
2. Ability to travel and work flexible hours, including some evenings and weekends.
3. Ability to work closely with diverse populations (various racial/ethnic, socioeconomic and educational backgrounds) and professionals from other disciplines.
4. Ability to develop collaborative relationships with Regional Hematology-Oncology Centers and work as part of an integrated team.

SFY 2008 - APPENDIX #2

**FUNDING ALLOCATION BY REGION
(Based on Total Target Population)**

REGION	POPULATION 2005 (1)	TOTAL TARGET POPULATION (2)	% OF TOTAL TARGET POPULATION	% OF TOTAL FUNDING AVAILABLE (3)
I	1,702,515	21,041	16.53%	\$117,363
II	1,557,782	15,255	11.98%	\$85,058
III	1,022,158	9,505	7.47%	\$53,037
IV	2,780,265	26,745	21.01%	\$149,171
V	2,126,318	35,335	27.75%	\$197,025
VI	2,275,004	19,434	15.26%	\$108,346
TOTAL	11,464,042	127,314	100.00%	\$710,000

(1) Based on Population 2005: US Census Data Estimates (National Center for Health Statistics)

(2) Estimated cases of Sickle Cell Disease (HbSS, HbSC and HbS/β Thalassemia) and estimated carrier (HbAS) for all races (White, Black, Asian/Pacific Islander, American Indian, Hispanic).

(3) Based on \$710,000 available funding under the Direct Service Initiative.

SFY 2008 - APPENDIX #3

SICKLE CELL TARGET POPULATION PROJECTIONS
(Listed by estimated number of carriers)

REGION I (8 counties)	(2) POPULATION 2005	(3) ESTIMATED CASES OF SC DISEASE (HbSS, HbSC, HbS/β Thal)	(4) ESTIMATED CARRIERS (HbAS)	TOTAL TARGET POPULATION
Hamilton*	806,652	600	15,716	16,316
Butler	350,412	76	2,483	2,558
Warren	196,622	23	917	939
Clermont	190,589	11	649	660
Clinton	42,570	4	182	186
Highland	42,818	3	156	159
Brown	44,398	2	141	143
Adams	28,454	1	77	78
REGION I	1,702,515	720	20,321	21,041

Note: Prevalence estimates are rounded to nearest whole number.

(1) ***Bold** indicates current county of Regional Sickle Cell Project

(2) Based on Population 2005: US Census Data Estimates (National Center for Health Statistics)

(3) SC Disease Prevalence - per 100,000 for all races (White, Black, Asian/Pacific Islander, American Indian, Hispanic)

(4) Carrier (HbAS) Prevalence - per 100, 000 for all races (White, Black, Asian/Pacific Islander, American Indian, Hispanic)

SFY 2008 - APPENDIX #4

SICKLE CELL TARGET POPULATION PROJECTIONS

(Listed by estimated number of carriers)

REGION II (17 counties)	(2) POPULATION 2005	(3) ESTIMATED CASES OF SC DISEASE (HbSS, HbSC, HbS/β Thal)	(4) ESTIMATED CARRIERS (HbAS)	TOTAL TARGET POPULATION
Montgomery*	547,435	343	9,151	9,493
Clark	142,376	42	1,272	1,314
Allen	106,234	40	1,153	1,193
Greene	151,996	33	1,074	1,107
Miami	101,619	9	414	423
Hancock	73,503	5	266	271
Shelby	48,736	4	192	196
Logan	46,580	4	185	189
Champaign	39,698	4	176	180
Darke	52,983	2	153	155
Auglaize	47,242	2	134	136
Preble	42,527	1	120	122
Mercer	41,202	1	109	110
Hardin	32,032	2	102	103
Putnam	34,928	1	96	97

SFY 2008 - APPENDIX #4

SICKLE CELL TARGET POPULATION PROJECTIONS

(Listed by estimated number of carriers)

REGION II (17 counties)	(2) POPULATION 2005	(3) ESTIMATED CASES OF SC DISEASE (HbSS, HbSC, HbS/β Thal)	(4) ESTIMATED CARRIERS (HbAS)	TOTAL TARGET POPULATION
Van Wert	29,154	2	96	97
Paulding	19,537	1	66	67
REGION II	1,557,782	496	14,759	15,255

Note: Prevalence estimates are rounded to nearest whole number.

(1) * **Bold** indicates current county of Regional Sickle Cell Project

(2) Based on Population 2005: US Census Data Estimates (National Center for Health Statistics)

(3) SC Disease Prevalence - per 100,000 for all races (White, Black, Asian/Pacific Islander, American Indian, Hispanic)

(4) Carrier (HbAS) Prevalence - per 100, 000 for all races (White, Black, Asian/Pacific Islander, American Indian, Hispanic)

SFY 2008 - APPENDIX #5

SICKLE CELL TARGET POPULATION PROJECTIONS

(Listed by estimated number of carriers)

REGION III (11 counties)	POPULATION 2005	ESTIMATED CASES OF SC DISEASE (HbSS, HbSC, HbS/β Thal)	ESTIMATED CARRIERS (HbAS)	TOTAL TARGET POPULATION
Lucas*	448,229	245	6,702	6,947
Erie	78,665	22	680	702
Wood	123,929	9	455	464
Sandusky	61,676	7	301	309
Seneca	57,483	5	233	238
Huron	60,385	3	209	212
Defiance	39,112	3	150	153
Ottawa	41,583	2	129	131
Fulton	42,955	2	128	129
Williams	38,688	2	122	124

SFY 2008 - APPENDIX #5

SICKLE CELL TARGET POPULATION PROJECTIONS
(Listed by estimated number of carriers)

REGION III (11 counties)	POPULATION 2005	ESTIMATED CASES OF SC DISEASE (HbSS, HbSC, HbS/β Thal)	ESTIMATED CARRIERS (HbAS)	TOTAL TARGET POPULATION
Henry	29,453	1	94	96
REGION III	1,022,158	301	9,203	9,504

Note: Prevalence estimates are rounded to nearest whole number.

(1) * **Bold** indicates current county of Regional Sickle Cell Project

(2) Based on Population 2005: US Census Data Estimates (National Center for Health Statistics)

(3) SC Disease Prevalence - per 100,000 for all races (White, Black, Asian/Pacific Islander, American Indian, Hispanic)

(4) Carrier (HbAS) Prevalence - per 100,000 for all races (White, Black, Asian/Pacific Islander, American Indian, Hispanic)

SFY 2008 - APPENDIX #6

SICKLE CELL TARGET POPULATION PROJECTIONS
(Listed by estimated number of carriers)

REGION IV (33 counties)	(2) POPULATION 2005	(3) ESTIMATED CASES OF SC DISEASE (HbSS, HbSC, HbS/β Thal)	(4) ESTIMATED CARRIERS (HbAS)	TOTAL TARGET POPULATION
Franklin*	1,090,771	661	17,702	18,363
Fairfield	138,423	27	919	947
Delaware	150,268	20	755	775
Licking	154,806	16	673	689
Ross	75,197	16	523	539
Muskingum	85,579	13	487	501
Jefferson	70,599	14	463	477
Marion	65,932	13	443	456
Belmont	69,228	10	374	384
Scioto	76,561	8	329	336
Pickaway	52,989	9	318	327
Madison	41,295	9	293	302
Athens	62,062	6	257	263
Lawrence	63,112	5	256	262
Union	45,751	5	212	217

SFY 2008 - APPENDIX #6

SICKLE CELL TARGET POPULATION PROJECTIONS
 (Listed by estimated number of carriers)

REGION IV (33 counties)	(2) POPULATION 2005	(3) ESTIMATED CASES OF SC DISEASE (HbSS, HbSC, HbS/β Thal)	(4) ESTIMATED CARRIERS (HbAS)	TOTAL TARGET POPULATION
Washington	62,210	3	202	206
Knox	58,398	3	187	190
Guernsey	41,123	3	158	162
Gallia	31,362	3	142	145
Coshocton	36,945	2	126	129
Fayette	28,199	3	118	121
Jackson	33,526	1	103	104
Noble	14,156	3	102	106
Morrow	34,322	1	97	98
Perry	35,246	1	97	98
Hocking	29,009	1	93	95
Pike	28,146	2	91	93
Morgan	14,958	2	81	83
Meigs	23,232	1	74	75
Harrison	15,920	1	66	67

SFY 2008 - APPENDIX #6

SICKLE CELL TARGET POPULATION PROJECTIONS

(Listed by estimated number of carriers)

REGION IV (33 counties)	(2) POPULATION 2005	(3) ESTIMATED CASES OF SC DISEASE (HbSS, HbSC, HbS/β Thal)	(4) ESTIMATED CARRIERS (HbAS)	TOTAL TARGET POPULATION
Wyandot	22,813	1	62	63
Monroe	14,698	0	39	39
Vinton	13,429	0	36	37
REGION IV	2,780,265	865	25,880	26,745

Note: Prevalence estimates are rounded to nearest whole number.

(1) * **Bold** indicates current county of Regional Sickle Cell Project

(2) Based on Population 2005: US Census Data Estimates (National Center for Health Statistics)

(3) SC Disease Prevalence - per 100,000 for all races (White, Black, Asian/Pacific Islander, American Indian, Hispanic)

(4) Carrier (HbAS) Prevalence - per 100, 000 for all races (White, Black, Asian/Pacific Islander, American Indian, Hispanic)

SFY 2008 - APPENDIX #7

SICKLE CELL TARGET POPULATION PROJECTIONS

(Listed by estimated number of carriers)

REGION V (5 counties)	POPULATION 2005	ESTIMATED CASES OF SC DISEASE (HbSS, HbSC, HbS/β Thal)	ESTIMATED CARRIERS (HbAS)	TOTAL TARGET POPULATION
Cuyahoga*	1,335,317	1,145	29,645	30,790
Lorain	296,307	80	2,521	2,601
Lake	232,466	23	1,022	1,045
Medina	167,010	9	551	560
Geauga	95,218	6	333	339
REGION V	2,126,318	1,263	34,071	35,335

Note: Prevalence estimates are rounded to nearest whole number.

(1) * **Bold** indicates current county of Regional Sickle Cell Project

(2) Based on Population 2005: US Census Data Estimates (National Center for Health Statistics)

(3) SC Disease Prevalence - per 100,000 for all races (White, Black, Asian/Pacific Islander, American Indian, Hispanic)

(4) Carrier (HbAS) Prevalence - per 100, 000 for all races (White, Black, Asian/Pacific Islander, American Indian, Hispanic)

SFY 2008 - APPENDIX #8

SICKLE CELL TARGET POPULATION PROJECTIONS

(Listed by estimated number of carriers)

REGION VI (14 counties)	(2) POPULATION 2005	(3) ESTIMATED CASES OF SC DISEASE (HbSS, HbSC, HbS/β Thal)	(4) ESTIMATED CARRIERS (HbAS)	TOTAL TARGET POPULATION
Summit*	546,604	236	6,638	6,874
Mahoning	254,274	121	3,382	3,503
Stark	380,608	95	2,994	3,089
Trumbull	219,296	58	1,794	1,852
Richland	127,949	39	1,170	1,209
Portage	155,631	21	792	812
Ashtabula	103,221	12	506	518
Columbiana	110,928	10	463	473
Wayne	113,697	8	414	422
Tuscarawas	91,944	4	289	294
Ashland	54,123	3	172	174
Crawford	45,774	2	137	139

SFY 2008 - APPENDIX #8

SICKLE CELL TARGET POPULATION PROJECTIONS

(Listed by estimated number of carriers)

REGION VI (14 counties)	(2) POPULATION 2005	(3) ESTIMATED CASES OF SC DISEASE (HbSS, HbSC, HbS/β Thal)	(4) ESTIMATED CARRIERS (HbAS)	TOTAL TARGET POPULATION
Holmes	41,567	1	115	116
Carroll	29,388	1	85	86
REGION VI	2,275,004	611	18,951	19,562

Note: Prevalence estimates are rounded to nearest whole number.

(1) * **Bold** indicates current county of Regional Sickle Cell Project

(2) Based on Population 2005: US Census Data Estimates (National Center for Health Statistics)

(3) SC Disease Prevalence - per 100,000 for all races (White, Black, Asian/Pacific Islander, American Indian, Hispanic)

(4) Carrier (HbAS) Prevalence - per 100, 000 for all races (White, Black, Asian/Pacific Islander, American Indian, Hispanic)

APPLICATION SUMMARY REVIEW FORM

Applicant Agency _____

Reviewer _____ Date of Review _____

Funding Amount requested by Applicant\$ _____

SCORING

<u>Section</u>	<u>Maximum Score</u>	<u>Reviewer Score</u>
Executive Summary	5	_____
Description of Applicant Agency	15	_____
Statement of Problem/Need	10	_____
Methodology	30	_____
Additional Requirements (Letters of Support and Documentation)	15	_____
Budget Narrative/Justification	10	_____
Position Descriptions/ Biographical Sketches	5	_____
Properly Completed Subgrantee Fiscal Application	<u>10</u>	_____
	MAXIMUM SCORE 100	SCORE _____
Bonus Points (No Programmatic Special Conditions)	5	TOTAL SCORE _____

RECOMMENDATIONS/CONDITIONS
(Select One)

- Approval (with funding) of proposal as submitted (no conditions)
- Approval (with funding) of proposal with conditions
- Disapproval of proposal with reasons

Reviewer's Signature _____

RSCP GOALS, EXPECTED RESULTS AND PERFORMANCE INDICATORS

<p>GOAL A. Promote the early identification of children and adults with sickle cell disease and related hemoglobin disorders and facilitate their integration into systems of service and care (which include treatment interventions) that are accessible, continuous, comprehensive, family-centered, coordinated and culturally sensitive.</p>	
<p>EXPECTED RESULTS</p>	<p>PERFORMANCE INDICATORS</p>
<p>A-1. All infants identified in Ohio's Newborn Screening (NBS) Program with an abnormal hemoglobin result will receive follow-up services (e.g. confirmatory testing, hemoglobin-counseling, disease education, resource referrals, and applicable treatment management) through a Regional Sickle Cell Project (RSCP) or non-RSCP provider.</p>	<p>A-1 (1). The number of resident newborns identified via NBS with an abnormal hemoglobin disease result (e.g. FS, FSA, FSC, FSE) that receive a confirmatory test by two (2) months of age.</p> <p>A-1 (2). The number of resident newborns with a <u>confirmed</u> hemoglobin disease result that are under appropriate treatment management by a board certified pediatric hematologist or BCMH provider.</p> <p>A-1 (3). The number of the resident newborns with a <u>confirmed</u> hemoglobin disease result whose families receive (or have documentation of) hemoglobin-counseling and/or education services from a RSCP staff member or non-RSCP provider.</p> <p>A-1 (4). The number of resident newborns with a <u>confirmed</u> hemoglobin disease result (whose families receive services through a RSCP) that have a case disposition reported back to the ODH in accordance with programmatic timelines and procedures.</p> <p>A-1 (5). The number of the resident newborns identified via NBS with a hemoglobin disease that are determined to be "lost to follow-up" and are referred to a local health district for public health nurse follow-up.</p> <p>A-1 (6). The number of children with a <u>confirmed</u> hemoglobin disease result, age 0-3, referred by a RSCP staff member to a coordinating site for Help Me Grow (HMG) program services.</p> <p>A-1 (7). The number of resident newborns with an abnormal NBS hemoglobin trait result that receive appropriate confirmatory testing in accordance with programmatic timelines and procedures.</p> <p>A-1 (8). The number of resident newborns with a <u>confirmed</u> hemoglobin trait result whose families receive hemoglobin-counseling services from a RSCP staff member or non-RSCP provider.</p>
	<p>A-1 (9). The number of resident newborns with</p>

	<p>a <u>confirmed hemoglobin trait</u> result (whose families receive services through a RSCP) that have a case disposition reported back to the ODH Lab in accordance with programmatic timelines and procedures.</p> <p>A-1 (10). The number of resident newborns with a <u>presumptive hemoglobin trait</u> result that are reported by a RSCP (via case disposition) as lost to follow-up.</p>
<p>A-2. The health and development of children and adults with or at-risk for sickle cell disease and related hemoglobin disorders will be improved.</p>	<p>A-2 (1). The number of non-resident infants (infants born outside of Ohio) and /or non-newborns (individuals of all ages born outside of the reporting period) that receive confirmatory testing for a hemoglobin disease.</p> <p>A-2 (2). The number of non-resident infants and/or non-newborns with a <u>confirmed hemoglobin disease</u> who receive (or whose family receives) hemoglobin-counseling services from a RSCP staff member.</p> <p>A-2 (3). The number of non-resident infants and/or non-newborns that receive confirmatory testing for a hemoglobin trait.</p> <p>A-2 (4). The number of non-resident infants and/or non-newborns with a <u>confirmed hemoglobin trait</u> who receive (or whose family receives) hemoglobin-counseling services from a RSCP staff member.</p> <p>A-2 (5). The number of non-resident and/or non-newborns who receive confirmatory testing and/or hemoglobin-counseling services at a funded project satellite site (<i>refer to Standards and Criteria for definitions under Outreach Activities</i>).</p> <p>A-2 (6). The number of non-resident and/or non-newborns who receive confirmatory testing and/or hemoglobin-counseling services at a project outreach clinic site (<i>refer to Standards and Criteria for definitions under Outreach Activities</i>).</p>
<p>A-3. RSCP projects and services are culturally competent, culturally sensitive and reflect the concerns and priorities of all recipient individuals and the organizations that serve them.</p>	<p>A-3 (1). The number of RSCP Sickle Cell Advisory Committee meetings held during the SFY 2008 reporting period.</p> <p>A-3 (2). The number of RSCP Sickle Cell Advisory Committee members that represent/reflect the recommended categories of membership.</p>
	<p>A-3 (3). The number of professional development and/or in-service trainings attended by sickle cell project core team staff (<i>refer to Standards and Criteria for definitions</i>)</p>

	<p><i>under Staffing Composition and Administration</i>), student interns and/or volunteers (if applicable) related to the provision of culturally competent services.</p>
<p>Goal B. Increase the awareness, knowledge and skill level of Ohio’s health care professionals’ and providers’ about the special health care needs related to sickle cell disease and other hemoglobin disorders through the promoted use of education, training and outreach.</p>	
<p>B-1. Service providers are skilled and knowledgeable in recognizing and providing appropriate care to children, individuals and families with or at-risk for hemoglobinopathies and knowledgeable about (sickle cell) services and referral resources available to them.</p>	<p>B-1 (1). The number of new providers that service newborns that receive information on newborn screening and RSCP services. B-1 (2). The number of hemoglobinopathy lectures, courses, trainings and/or individualized instruction provided to <u>external</u> (off site from the project location/facility) service providers by RSCP staff. B-1 (3). The number of hemoglobinopathy lectures, courses, trainings and/or individualized instruction provided to <u>internal</u> (on site from the project location/facility) service providers by RSCP staff. B-1 (4). The number of <u>external</u> and/or <u>internal</u> service providers who attend sickle cell related education events given by RSCP staff.</p>
<p>Goal C: Expand public and community awareness and access to information on sickle cell disorders and related programs/services with special emphasis on meeting the <u>needs</u> and <u>culture</u> of unserved and/or underserved at-risk population groups.</p>	
<p>C-1. Identified at-risk population groups are aware of hemoglobinopathy issues and RSCP location(s) and services.</p>	<p>C-1 (1). The number of sickle cell related awareness activities (e.g. health fairs, radio/TV spots) in which RSCP staff participated and was targeted to unserved and/or under-served at-risk population groups (<i>Identify unserved and/or under-served group</i>). C-1 (2). The number of hemoglobinopathy <u>talks/presentations</u> provided by RSCP staff and targeted to unserved and/or under-served at-risk population groups. C-1 (3). The number of individuals from targeted unserved and/or under-served at-risk population groups who attend talks/presentations given by RSCP project staff.</p>
<p>C-2. Health Promotion Activities will include “social marketing-health communication” strategies that are targeted to specific segments of the priority populations.</p>	<p>C-2 (1). The number of social marketing-health communication strategies that are targeted to a specific segment of the priority population and is planned and implemented by the RSCP during a National Health Observance month (e.g. January-Birth Defects Month; April-Minority Health Month; September-Sickle Cell Awareness Month). C-2 (2). The number of faith-based</p>

	institutions/groups that participate in Sickle Cell Sabbath activities planned and implemented by the RSCP during September-Sickle Cell Anemia Awareness Month.
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