



COMMONWEALTH of VIRGINIA

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July 23, 2008

Division of Legislative Automated Systems
910 Capitol Square
General Assembly Building, Suite 660
Richmond, Virginia 23219
Attention: Legislative Documents and Reports Processing

Dear Sir:

Enclosed please find a report entitled "Funding for Community-Based Sickle Cell Disease Programs." This report was prepared pursuant to Item 297(S) of the 2008 Appropriation Act. Should you have any questions concerning the report, please contact Joe Hilbert, Executive Advisor to the Commissioner, at 864-7006.

Sincerely,

A handwritten signature in cursive script, appearing to read "Karen Remley".

Karen Remley
State Health Commissioner

Encs.

Funding for Community-Based Sickle Cell Disease Programs
Item 297 (S) of 2008 Appropriation Act
Executive Summary

Sickle cell disease (SCD) is a serious blood disorder that causes chronic anemia, episodes of extreme pain and damage to major body organs. It is the most common genetic disorder identified in the African American community and affects approximately 3000 Virginians. During the 2007 General Assembly Session, funding for medical management services increased to \$450,000 a year and a yearly allocation of \$100,000 from general funds was approved for service grants to community-based programs that provide education and family-centered support for individuals suffering from SCD. The purpose of this allocation was to assist individuals and families living with SCD to develop the necessary skills and resources to improve their health status, family functioning, and self-sufficiency. Item 297S of the Appropriation Act requires the Virginia Department of Health (VDH) to develop criteria for distributing these funds, including specific goals and outcome measures, and to submit an annual report detailing program outcomes.

Following the issuance of a Request for Proposals by VDH, the following programs were issued contracts:

1. Fredericksburg Area Sickle Cell Association, Fredericksburg;
2. Sickle Cell Association of Hampton Roads, Norfolk; and
3. Organization of Sickle Cell Anemia Resources, Richmond

VDH monitors all contracts through a combination of individual site visits, telephone calls, written communication, review of quarterly progress reports and billing activities.

As of June 30, 2008, the funded programs have only been operational for nine months. VDH is unable to report on measurable outcomes at this time. However all programs have made significant progress in their efforts to fulfill the purpose of the funding. Specifically, there is greater public awareness of SCD and enhanced sickle cell patient functioning and self-sufficiency.

VDH plans to partner with funded programs in an effort to strengthen their umbrella organization, Statewide Sickle Cell Chapters of Virginia, Inc. This will be done through ongoing training and program development activities. VDH recognizes the need to contract with a culturally competent organization or individual with experience in community-based, non-profit minority health related program development.



Background

Sickle cell disease (SCD) is a serious blood disorder that causes chronic anemia, episodes of extreme pain and damage to major body organs. It is the most common genetic disorder identified in the African American community and affects approximately 3000 Virginians.

In 1989, screening for SCD was added to Virginia's newborn screening panel, resulting in the early identification of approximately 75 newborns a year. To meet the medical needs of this growing population, in 1994, a budget amendment was passed to provide \$250,000 annually for the development of regionally located pediatric comprehensive sickle cell clinics. Currently, over 1200 sickle cell patients are being followed in four major medical institutions; The Children's Hospital of the Kings Daughters, Norfolk, Virginia Commonwealth University Health System, Richmond, Inova Fairfax Hospital for Children, Fairfax, and the University of Virginia, Charlottesville.

During the 2007 General Assembly Session, funding for medical management services increased to \$450,000 a year and a yearly allocation of \$100,000 from general funds was approved for service grants to community-based programs that provide education and family-centered support for individuals suffering from SCD. The purpose of this allocation was to assist individuals and families living with SCD to develop the necessary skills and resources to improve their health status, family functioning, and self-sufficiency. Item 297S of the Appropriation Act requires the Virginia Department of Health (VDH) to develop criteria for distributing these funds, including specific goals and outcome measures. VDH is required to submit an annual report detailing program outcomes to the House Appropriations and Senate Finance Committees of the Virginia General Assembly.

Community-based Program Procurement Activities

On June 6, 2007, VDH was granted authority to use competitive negotiations for the procurement of community-based sickle cell services. Following state procurement law, a request for proposals (RFP) was issued on June 25, 2007 to solicit sealed proposals to establish a reimbursement contract through competitive negotiations for the purchase of these services. Program development and monitoring was placed with the Virginia Sickle Cell Awareness Program under the Division of Women's and Infants' Health in the Office of Family Health Services of VDH. The agency anticipated making multiple awards to insure regional participation and collaboration.

Invitations to apply were sent directly to each member of the Statewide Sickle Cell Chapters of Virginia, a network of regionally located community-based sickle cell programs

(Appendix 1) and other community-based sickle cell support groups. This opportunity was also advertised in six regional newspapers and posted on the eVA system.

An optional pre-proposal conference was held at VDH on July 17, 2007 to allow potential Offerors an opportunity to present questions and obtain clarification relative to any facet of the solicitation. Twelve potential applicants attended.

VDH received five proposals, but two proposals from southwest Virginia arrived too late to be eligible for consideration.

Contract Awards

A proposal review panel consisting of internal and external reviewers convened on August 22, 2007 to evaluate and score all eligible proposals. Three regionally located programs were approved with recommendations for changes to the work plans and budgets. Upon receipt of the requested changes, the following programs were issued contracts that allowed for four yearly renewals. (Appendix 3):

1. Fredericksburg Area Sickle Cell Association, Fredericksburg;
2. Sickle Cell Association of Hampton Roads, Norfolk; and
3. Organization of Sickle Cell Anemia Resources, Richmond

The committee agreed that a new RFP should be issued to solicit proposals for community-based services in Southwest Virginia in an effort to ensure equal access from across the state. This RFP was issued on September 15, 2007.

Actions Impacting Community-based Sickle Cell Program Service Delivery

In September 2007, as part of an overall VDH budget reduction strategy, new general funding for community-based sickle cell grants was reduced by 50%, leaving \$50,000 for field allocations. In an effort to ensure that currently funded programs could provide the types of services described in their work plan; the funding set aside for the RFP for southwest Virginia was eliminated, the capacity building efforts for the new contracts were reduced and the contracts were adjusted to reflect this reduction.

Statewide Sickle Cell Chapters of Virginia, Inc. and other constituents addressed concern over these reductions to VDH, individual legislators and the Joint Commission on Health Care. On October 17, 2007, Dr. Michael Royster, Director of Minority Health and Public Policy and Jene Radcliffe-Shipman, Sickle Cell Program Manager presented an overview of current sickle cell services and emerging needs to the Joint Commission on Health Care (JCHC). This presentation outlined the impact that the 50% budget reduction would have on service delivery for all state-funded sickle cell programs.

On November 8, 2007 the JCHC issued a Draft Decision Matrix that outlined recommendations to advance to the 2008 General Assembly, which included reinstating the fifty percent (50%) budget cut to state funded sickle cell programs. The reduced funding was fully restored by the Governor in his 2008-2010 biennial budget.

Program Outcomes

VDH monitors all contracts through a combination of individual site visits, telephone calls, written communication, review of quarterly progress reports and billing activities. As of June 30, 2008, the funded programs have only been operational for nine months. VDH is unable to report on measurable outcomes at this time. However all programs have made significant progress in their efforts to fulfill the purpose of the funding. Specifically, there is greater public awareness of SCD and enhanced sickle cell patient functioning and self-sufficiency. The following bullets represent program accomplishments and highlights. Individual program outcomes can be reviewed in Appendix 4.

- Development of a community-based program (CBP) client needs assessment tool. Collection will be ongoing through December, 2008. Analysis will be used to identify the types of services most consistently “needed” by sickle cell clients.
- Development of a CBP poster and brochure to be used by all programs.
- Development of a Microsoft Access-based client tracking and intervention system that can be used by all programs.
- Development of a public service announcement that can be used by all programs.
- Development of a work skills and mentoring program by the Fredericksburg Area Sickle Cell Program.
- Development of a high-school mentoring program by the Sickle Cell Association of Hampton Roads.

Challenges Identified

- Funded programs with only volunteer staffing found it difficult to manage billing and service provision as outlined in their goals and objectives. VDH assisted programs through the development of standardized report forms and invoices and the provision of ongoing technical support and training.
- Key personnel are necessary to meet the basic goals and objectives of these awards. The Fredericksburg Area Sickle Cell Association and Sickle Cell Association of Hampton Roads recognized this need and hired staff to provide services as outlined in their work plan. VDH has highly recommended that the Organization for Sickle Cell Anemia Resources follow this practice and added additional funds in their renewal application for the purpose.
- While the potential “pool of clients” is large, the actual number of sickle cell patients and families participating in program activities has not met the expectations of the funded programs. Insights from the completed needs assessment tool may assist programs to target their services and increase participation.

Capacity Building Activities Organized by VDH in Partnership with Statewide Sickle Cell Chapters of Virginia, Inc.

A critical goal for this funding was to strengthen the capacity of community-based programs so that they may better serve their community and enhance their resources. VDH collaborated with Mr. George Carter, the Administrator for Statewide Sickle Cell Chapters of Virginia, Inc. in an effort to identify topics of interest and training opportunities that would

benefit all community-based programs. Mr. Carter assisted in identifying topics, appropriate dates and times to hold such activities; VDH maintained responsibility for program content development, speaker selection, notification and contracting for all services. Two activities were planned during this funding year.

- **Strengthening Community Based Programs through Partnerships**

Scheduled date: January 19, 2008, Richmond, Virginia

Program Facilitator: Cynthia Beadle, Office of Minority Health Services at VDH. Ms. Beadle is also President and CEO of B&B Plus, a human resource development company with twenty-two years experience working with minority health programs and faith-based groups.

Program content included topics on community-based program development and implementation, developing effective community partnerships, collaboration, advocacy and policy change, fundraising and income generation.

Participation was open to all community-based sickle cell programs and their board members. The event was advertised through E-mail, direct phone contact and letters. Total participation was estimated to be twenty-five participants. Unfortunately, only six participants representing two programs registered, resulting in the cancelation of this event. VDH will collaborate with Statewide Sickle Cell Chapters of Virginia, Inc. to reschedule this training opportunity.

- **Funding Sickle Cell Services: Preparing Grants That Deliver**

Scheduled date: April 25, 2008, Richmond, Virginia.

Program Facilitator: Joseph Telfair, DrPH, MSW, MPH

Professor, Public Health Research and Practice, Department of Public Health Education School of Health and Human Performance, University of North Carolina at Greensboro. For more than 30 years, Dr. Telfair has devoted his career to research, teaching, and practice in the areas of social epidemiology, community-based and rural health practice, program evaluation, and policy issues concerning women, adolescents and children with chronic conditions. He currently serves as Director of the two HRSA funded national SCD coordination and data centers.

Participation was mandatory for all funded community-based sickle cell programs and Comprehensive Sickle Cell Clinics. It was opened to two members from each of the non-funded sickle cell programs. Twenty-seven participants registered for this eight hour workshop. The attendance rate was 100%. Dr. Telfair has agreed to return upon request to provide continued training in identified areas of concern.

Future Plans

The Virginia Department of Health plans to partner with funded programs in an effort to strengthen their umbrella organization, Statewide Sickle Cell Chapters of Virginia, Inc. This will be done through ongoing training and program development activities. VDH recognizes the need to contract with a culturally competent organization or individual with experience in community-based, non-profit minority health related program development.

During FY09 VDH will:

- Increase funding to community-based sickle cell programs currently under contract

- Issue a RFP for the provision of community-based sickle cell services in southwest Virginia
- Provide ongoing capacity building opportunities to strengthen program infrastructure and reschedule initial training on partnerships and advocacy

For more information on sickle cell services available in the Commonwealth, or answers to specific questions about state-funded community-based sickle cell programs, please contact:

Jene Radcliffe-Shipman, Program Manager
Virginia Sickle Cell Awareness Program
Division of Women's and Infants' Health
Virginia Department of Health
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Richmond, Virginia 23219
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List of Appendices

1. List of Community-based Sickle Cell Programs
2. Map of Virginia with Location of Funded Community-based Sickle Cell Programs
3. Table of Programs and Awards with Staffing Detail
4. Individual Program Outcomes

Appendix 1: Community-based Sickle Cell Programs Notified of RFP

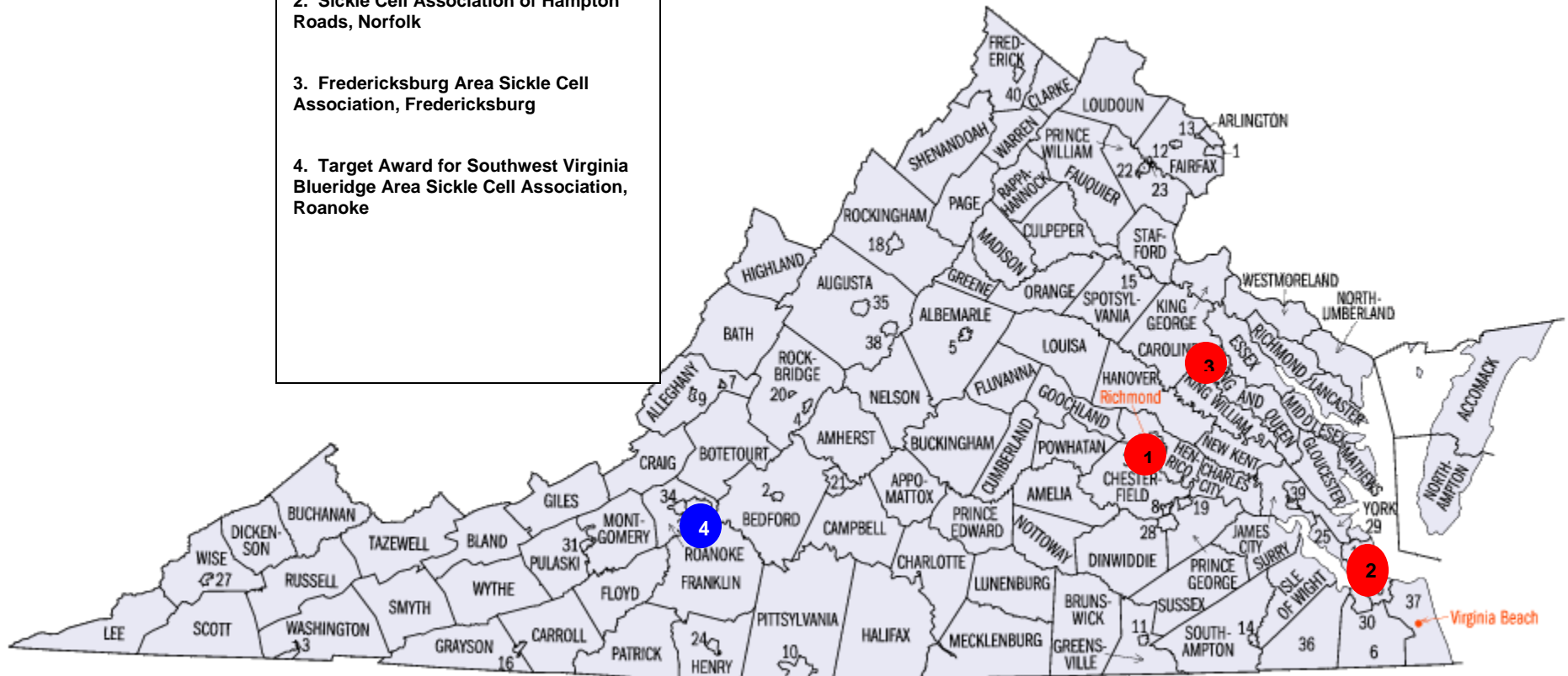
* = Agency Applied for Funding **= Applied and Awarded

Sickle Cell Awareness Association of Central Virginia	P.O. Box 211	Lynchburg	VA	24505
**Fredericksburg Area Sickle Cell Association FASCA	P.O. Box 3275	Fredericksburg	VA	22402-3275
**Sickle Cell Association of Hampton Roads, Inc.	861 Glenrock Road, Suite 120	Norfolk	VA	23502
Halifax-South Boston Sickle Cell Chapter	2199 Virgie Cole Road	South Boston	VA	24592
Blueridge Area Sickle Cell Association	P.O. Box 1211	Rocky Mount	VA	24151
Danville-Pittsylvania County Sickle Cell Association	378 Cumberland Drive	Danville	VA	24541
*Virginian's Associated for the Relief from Sickle Cell Anemia, Inc.	P.O. Box 27655	Richmond	VA	23222-7655
Peninsula Association for Sickle Cell Anemia, Inc.	2021 Cunningham Drive - Suite 102	Hampton	VA	23666
Family and Friends Fighting Sickle Cell Anemia	10461 Gotham Road	Richmond	VA	23235
**OSCAR Organization for Sickle Cell Awareness and Research	3243 Cliff Avenue	Richmond	VA	23222

Appendix 2: Site Location: Funded Community-based Sickle Cell Program Sites

Agency Names

1. Organization of Sickle Cell Anemia Resources, Richmond
2. Sickle Cell Association of Hampton Roads, Norfolk
3. Fredericksburg Area Sickle Cell Association, Fredericksburg
4. Target Award for Southwest Virginia Blue Ridge Area Sickle Cell Association, Roanoke



Appendix 3: Details: Awarded Programs FY-08

Program Name	Staff funded through State contract	Award Amount	Affiliation with Comprehensive Sickle Cell Program	Program Focus
Organization of Sickle Cell Anemia Resources - Richmond	None Volunteer program with no other financial support	\$ 16,000 FY09 (\$20,000)	VCU Health Center	<ul style="list-style-type: none"> • Male Responsibility • Adult Support Groups • Community Education
Sickle Cell Association of Hampton Roads, Norfolk	Yes 50% Social Worker. Program fully staffed with United Way and other grant funds	\$ 16,000 FY09 (\$24,000)	Eastern Virginia Medical School Children's Hospital of the King's Daughters	<ul style="list-style-type: none"> • Tutoring and other school related issues • Medical transition • PSA development for use in all programs • Adult service development
Fredericksburg Area Sickle Cell Association, Fredericksburg	Yes Part-time Program Manager and Service Provider (Volunteer program supported through fundraising activities)	\$ 16,000 FY09 (\$20,000)	None	<ul style="list-style-type: none"> • Program development and community recognition • Career development services and training

Appendix 4: Individual Program Outcomes

Program Name	Number of Clients	FY07 Goal	FY07 Outcome
Organization of Sickle Cell Anemia Resources - Richmond	~125	Educate the community about sickle cell disease (SCD). Focus a program specifically on Male Responsibility regarding awareness of carrier status and genetic inheritance.	12 Community education programs were presented. Number of participants was not documented. Male responsibility was addressed during the education programs however the campaign was not fully developed due to a change in key personnel. A new coordinator for this effort will be identified during FY08.
		Life-Skills: Develop the ability to act responsibly and safely and to live successfully with a chronic disease.	9 monthly support group meetings were held at VCU Health System with an average of 40 sickle cell patients and family members per meeting.
		Decrease the stigmatization of patients with SCD through a campaign to "Accentuate the Positive".	Positive role models addressed each monthly support group. This program will continue next year with a photo and essay campaign to feature successful sickle cell patients.
Sickle Cell Association of Hampton Roads, Norfolk	~250	Assist clients in locating medical transition services.	Partnered with Norfolk Sentara Hospital and Children's Hospital of the King's Daughters in identifying sickle cell clients who needed medical transition services. Part-time social worker attended all adult sickle cell clinics to introduce program services to clients. Held monthly support groups and offered individual counseling services.
		Educate the community about SCD and where to find services through the development of a PSA that can be used by all funded programs and community-based education programs.	Identified 13 media contacts to air the public service announcement. These include local TV, radio, and newspapers in the Tidewater area.
		Life-Skills: Develop the ability to act responsibly and safely and to live successfully with a chronic disease.	Conducted the FOCUS Project (Fundamental Opportunities Creating Useful Skills). Held six sessions at Norfolk State University. Partnered with Hampton Roads Chapter, Top Teens of American, Inc. Twenty-two youth were in attendance.
		Tutoring and other school related issues.	Enrolled three clients with Mentors in the Top Ladies of Distinction, Inc. Contacts have also been made with the national Council of Negro Women for mentoring services.

Program Name	Number of Clients	FY07 Goal	FY07 Outcome
Fredericksburg Area Sickle Cell Association, Fredericksburg (FASCA)	~50	Program development and community recognition.	Hired a part-time program coordinator with experience in mentoring, career development and life-skills training. This person served as a primary contact for all clients and worked collaboratively with the Board of FASCA to create public awareness of SCD and program services in the Fredericksburg area. Created a full color brochure that focused on specific program services. Partnered with local programs and businesses to bring greater awareness to sickle cell issues in the community. Received a cover story in the Fredericksburg paper on their efforts to generate awareness through innovative programs for sickle cell clients and their families.
		Life-Skills: Develop the ability to act responsibly and safely and to live successfully with a chronic diseases.	FASCA developed three programs during the funding period. Employability Skills Training Workshop that focused on job search assistance, interviewing skills and resume preparation. Life Skills Training that focused on building self-esteem and self-advocacy skills, communications and decision-making skills and locating community resources.
		Transportation Assistance	Arranged transportation services for client in need.