COMMONWEALTH of VIRGINIA

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August 3, 2009

Mr. Jay Landis, Director
Division of Legislative Automated Systems
General Assembly Building, Suite 660
Richmond, VA 23219

Dear Mr. Landis:

Enclosed please find a report from the Virginia Department of Health titled, "Report to the House Appropriations and Senate Finance Committees of the Virginia General Assembly on Community-based Sickle Cell Programs." This report is submitted pursuant to Item 297(S) of the 2009 Appropriation Act. Please contact my Executive Advisor, Joe Hilbert, at 864-7006 or joe.hilbert@vdh.virginia.gov should you have any questions.

Sincerely,

Karen Remley, M.D., M.B.A., F.A.A.P.

Enc.

Report to the House Appropriations and Senate Finance Committees of the Virginia General Assembly on Community-based Sickle Cell Programs

June 30, 2009

Background

During the 2007 General Assembly Session, $100,000.00 was allocated to Virginia Department of Health (VDH) to provide service grants to community-based programs for education and family-centered support for individuals, and families, with a diagnosis of sickle cell disease. The service grants expectation was to support local community activities that would enable individuals and families living with sickle cell disease to develop the necessary skills and resources to improve their health status, family functioning, and self-sufficiency.

Item 297(S) of the Appropriation Act requires that VDH develop criteria for distributing these funds, including specific goals and outcome measures and submit an annual report detailing program outcomes to the House Appropriations and Senate Finance Committees of the Virginia General Assembly.

Program Administration Narrative

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

- Contracts with three community-based programs were renewed on July 1, 2008 and continued until December, 2008.
- General goals and objectives established in the previous year were continued by most programs. Adjustments to the work plans reflected awareness that many of the services offered by the programs were not being utilized by clients. Programs were encouraged to partner with other organizations targeting similar populations to enhance their educational outreach capabilities.
- The Organization for Sickle Cell Anemia Resources (OSCAR) sent an e-mail to VDH stating that it did not have the capacity to fulfill its contract to provide community-based services and did not wish to renew the contract. That request was later rescinded when OSCAR merged with another Richmond based program. A renewal application was submitted, and approved, under the name Sickle Cell Association of Richmond. VDH received two complaints (phone and e-mail) from a parent indicating that OSCAR was not holding open meetings and not responding to calls and requests for information. These concerns were addressed with both the parent and the program leadership. Open meeting were initiated in October and November.

The following activities were conducted by VDH to enhance community-based program development. (See Attachment 1 for Table of Program Activities)

- Pursued opportunities to fund sites in the Lynchburg, Roanoke, and Charlottesville areas through active solicitation with established Statewide Sickle Cell Chapters. The Sickle Cell Association of Central Virginia (Lynchburg) stated it did not have the capacity to provide services and did not wish to apply. Carilion Medical Center

in Roanoke was requested to consider submitting a proposal, but did not submit a proposal.

- In collaboration with contractors, a set of posters and educational bookmarks that could be used across the Commonwealth to advertise community-based sickle cell program services was developed and disseminated.
- A nationally recognized sickle cell awareness media campaign was distributed to all Sickle Cell Chapters for use in their communities.
- Assisted in the overall coordination and evaluation of a Statewide Sickle Cell Chapters Conference, held in Richmond in September 2008. The conference attracted 101 participants from across the Commonwealth and was given an overall rating of excellent-very good by 49 participants completing the evaluation form.
- 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 conducted an in-depth training on writing successful grant applications in September, 2008. Participation was mandatory for all funded community-based sickle cell programs.
- Completed an analysis of the Community-based Program (CBP) Client Needs Assessment Tool. December, 2008. (See Attachment 2 for a copy of that report)

Lessons Learned from the Needs Assessment Tool

- Only 4 percent of the sickle cell clients responding to the Client Needs Assessment Tool viewed community-based support as a mechanism to cope.
- Insights from the completed needs Assessment Tool the most important supportive services or activities used by sickle cell clients to cope with sickle cell disease are family, friends, and faith.
- The majority of respondents reported talking to, or receiving educational materials from, their healthcare provider as the best way of understanding sickle cell disease and its complications.
- Key personnel are necessary to meet the basic goals and objectives of these awards.
- 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.

Current Community-based Sickle Cell Program Service Delivery

The VDH budget reduction plan for FY 2009, approved in October 2008, provided the opportunity to address the challenges identified throughout the process of implementing Community-based Sickle Cell Programs. The budget reduction eliminated contracts with community groups for community education, public service announcements, and support groups. Contractors were notified by phone on November 17, 2008 and the contracts were terminated on December 17, 2008. VDH-funded sickle cell medical services were retained.

Community-based Sickle Cell Programs continue to be active in areas of the state. The Fredericksburg Area Sickle Cell Association continues to provide services to clients.

The paid coordinator is providing services as a volunteer with the agency. There are hopes to list the agency with the United Way in that area as a means to garner more funds and agency awareness. Fund raising activities continue to provide funding necessary to provide supportive and direct services to clients while enabling services and social activities have been scaled back. The Sickle Cell Association of Hampton Roads has obtained funding from a variety of sources, including United Way. The social work position funded through general funds is being supported 100% by the agency. All client services continue to be provided. The agency is collaborating with Children's Hospital of the King's Daughters, Norfolk Sentara Hospital, and Bon Secours to enhance medical transition for adult clients. This organization continues to apply for public and private grants to meet their agency and goals and objectives. The Sickle Cell Association of Richmond continues to participate in community awareness activities and in is receipt of donations from local fund raising activities. Supportive services are provided through collaboration with the Adult Sickle Cell Program at VCU hospital.

Sickle Cell Centers are required to incorporate community focused programs into the annual workplans and provide quarterly reports on progress of implementing the workplan. The Centers are established with community partners and have an infrastructure that supports community education and support. As the Centers continue to enhance a medical model of care, based on holistic and continuing care, the sickle cell client is gaining education and support in healthcare decision making, advocacy and other expressed needs.

Attachment 1

Community-based Sickle Cell Program Activities and Outcomes – FY 2009

Program Name Number of clients served	Number of Clients Serving	Budget	Staffing	Program Focus	Outcomes
Sickle Cell Association of Richmond	Not reported ~ 125 based on FY-08 data	$20,000	One part time position approved. (Not hired) Volunteer: no staff dedicated to program delivery Funds used in conjunction with this contract: Not available	1. Male Responsibility 2. Accentuate the Positive Campaign (Self-esteem) 3. Adult Support Groups 4. Community Education	1. Male Responsibility was not addressed 2. Accentuate the Positive was not addressed this funding year (Note: 40% of program activities were assigned to the position that was not hired) 3. Three meetings held through MCV Hospital Adult Program 4. Successful State Conference with 101 participants and positive evaluation. No report submitted: information is from site visit
Sickle Cell Association of Hampton Roads, Norfolk	158	$24,000	50% Social Worker. Program fully staffed with United Way and other grant funds. Funds used in conjunction with this contract: Approximately $250,000 in agency funds.	1. Tutoring and other school related issues 2. Medical transition 3. Adult service development 4. Community Education	1. Held workshop at Hampton University 2. Social worker attending adult clinic weekly to introduce program and services 3. Held Family Forum: October 2008 4. 21 Programs provided in conjunction with United Way Goals and Objectives
Fredericksburg Area Sickle Cell Association, Fredericksburg	17	$20,000	25% Program Manager and Service Provider (Volunteer program supported through fundraising activities) Funds used in conjunction with this contract: Not available	1. Program development and community recognition 2. Career development services and training	1. Three education programs with local and regional advertisements 2. Published agency brochure and developed community liaisons. Hosted dinners and published client poetry 3. Recognized formal skills training presentations were not needed based on differing needs of client population. Changed to personal counseling and training efforts based on identified needs of each client.

Attachment 2

Summary of Community-based Program Patient Service Needs Assessment

Introduction

Sickle cell disease (SCD) is one of the most common genetic disorders in the United States primarily affecting African-Americans. It is estimated that more than 4,000 Virginians are living with sickle cell disease.

In 2008, the Virginia Department of Health (VDH) in corporation with community-based sickle cell programs conducted a survey to assess the local service needs of individuals living with SCD. The survey measured availability and access to community services and prioritized critical needs of individuals living with SCD. (Appendix 1)

Methodology

The survey was designed by the Virginia's SCD program administrator in collaboration with the administrator of Statewide Sickle Cell Chapters of Virginia, Inc. and reviewed by the Office of Family Health Service's Research and Evaluation Team. The survey was comprised of three sections (1) general information, (2) medical services, and (3) a medical and supportive services checklist. A letter of introduction and explanation regarding the purpose of the survey accompanied the packet. No incentives were offered other than the importance to identify client needs so that appropriate services could be developed on a community level. Individual names were not collected, however if respondents were interested in the results of this survey, an information reply card could be filled out and left with the local Chapter.

In February of 2007, each of the three funded sites was given 50 surveys to disseminate to their client base. Programs chose to either mail surveys to their active clients with a return post paid and envelope addressed to VDH and/or distribute the surveys as a part of their regularly scheduled support group activities. To help reduce bias and enhance a sense of confidentially, envelopes were provided if clients wished to mail their survey directly to VDH instead of leaving it with the distributor. No clients responded to the general mailing, therefore the timeline for survey data collection was extended for an additional six months to give all programs the opportunity to contact active clients and encourage participation. The data entered was collected at agency sponsored support group activities. A copy of the survey can be found at the end of this report. SAS 9.2 statistical software was used to analyze descriptive statistics.

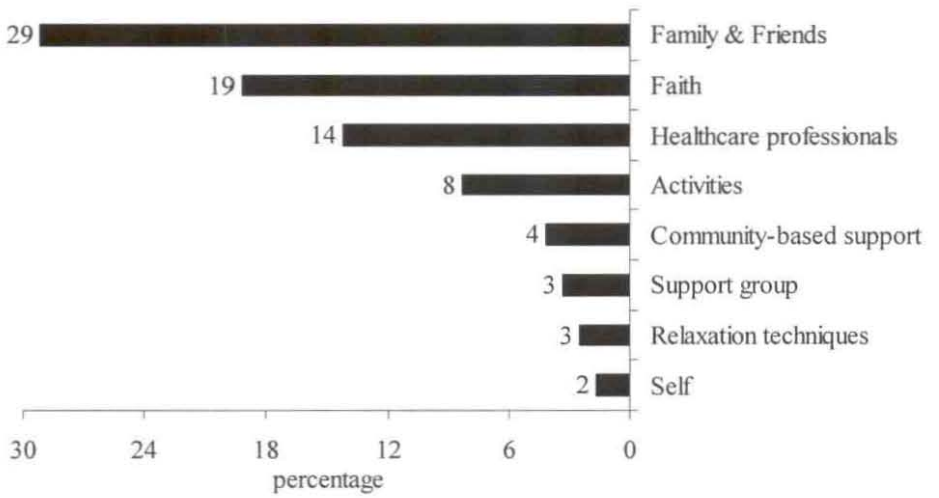
Results

Of the 120 respondents, 82 percent (99) resided in Hampton Roads, 15 percent (18) resided in greater Richmond, and less than 1 percent (2) resided in Fredericksburg. Most respondents were single African American, females between the ages of 21-40 years, with more than a high school education. However 34 percent reported that they did not work or attend school. Only 9 percent of reported that they were uninsured.

General Well-being
Interestingly, 86 percent reported overall health to be fair to very good, even though 73 percent reported having 3 or more pain episodes in the past year and 61 percent were hospitalized for sickle cell related episodes in the past year. Moreover, 35 percent missed 16 to 30 days of work or school due to sickle cell related complications.

Coping
Just over half (54%) of respondents stated that they felt overwhelmed by their disease "some of the time." The most important supportive services or activities used to cope with SCD are shown in Figure 1. Individuals living with SCD typically rely on family, friends, and faith to cope with the disease. Although two-thirds of respondents knew where to find community-based support services, only 4 percent viewed community-based support as a mechanism to cope.

Figure 1. Ways to cope with sickle cell disease.



Sickle Cell Awareness and Education
The majority of respondents reported talking to or receiving educational materials from their healthcare provider as the best way to learn more about SCD and its complications. Just as frequently, talking with one another provided insights and understanding. While 65 percent of clients reported using the internet to gain insights into updated information about SCD, 50 percent indicated that they did not attend workshops or conferences related to SCD.

Access to Care
Adults with SCD see their physician much more often than pediatric patients. Approximately 25 percent saw their doctor monthly while 27 percent indicated they visited their doctor between four and six times a year for routine comprehensive care and evaluation. Fifty-five percent stated that the medical services that they needed were available in their community. A majority of respondents traveled less than 25 miles to be seen by the doctor who treats them for SCD and report that the distance traveled does not keep them from going to the doctor. However, a quarter of respondents have to travel more than 25 miles and 18 percent of respondents said that the distance has kept them for going to the doctor. The primary mode of transportation was driving their own vehicle (64 percent) or riding with a friend or relative (43 percent). A few respondents took a cab (13 percent), rode the bus (8

percent) or had transportation arranged by Social Services or another agency (4 percent). As stated earlier, 91 percent reported having medical insurance (66% public insurance and 25% private insurance).

Services and Basic Needs (See Figure 2)
Individuals living with SCD in Virginia indicated that they needed or wanted help acquiring adult and family support group services, community-based programs, disability services, financial assistance for emergencies and pain management support services. Lower priority was indicated for transportation, unemployment, and vocational rehabilitation and planning services.

Conclusions and Recommendations
It should be noted that this survey is biased both by the sample selection (only clients participating in community-based programs) and the demographics of the participants; 82% residing in the Hampton Roads area. The voices of those clients who choose not to participate in community-based programs are not heard. That being stated, the implications for program planning and development for the adult living with sickle cell disease should focus on several vectors:

- Family, friends, and faith are the primary means of coping for individuals living with sickle cell disease, therefore strengthening these components and offering support through faith-based venues could prove most beneficial.

- Clients indicate that they gain coping skills and greater awareness of their disease through conversations with others who have experienced challenges. Indications for community-based programs include the use of client forums as a primary means of providing supportive services and education.

- Patients see their physician often and rely on them to provide the latest information about treatment and advances. As a means of increasing client participation and involvement, community-based program leaders might consider establishing a liaison with known providers to establish referrals to services and programs offered by the program. Greater visibility and affiliation with providers has the potential for increasing client participation.

- Clients are utilizing the internet, social networking pages and blogs to locate and communicate with one another. This awareness provides new opportunities for programs to increase services and serve this new breed of client who shuns the more formal workshop or conference opportunity.

We would like to thank the staff of the Sickle Cell Association of Hampton-Roads, the Fredericksburg Area Sickle Cell Association, and the Sickle Cell Association of Richmond – OSCAR for coordinating the delivery of this survey. We remain grateful to the individuals who took the time to share their perceptions with us. The provision of quality community-based services requires a partnership to insure we develop the types of services desired in the manner that will meet the needs of this generation of sickle cell clients.

Figure 2. Essential Medical and Support Services

Medical and Supportive Services	%
Support Group - Adult	77
Community-Based Sickle Cell programs	69
Disability Services	68
Financial Assistance - Emergency	64
Pain Management	63
Support Group - Family	63
Dental Health Services	61
Financial Assistance School/College	59
Financial Assistance - Healthcare services	58
Medicaid or Social Security Benefits	57
Accommodations at school/college for students	56
Fuel Assistance	56
Health Insurance/Medicaid	55
Financial Assistance Prescriptions	54
Employment Assistance	53
Nutrition Services	52
Housing Assistance Services	50
Transition Planning - Medical	49
Depression Loneliness	48
Pastoral Support	46
Job Skills Training Services	45
Food and Clothing	45
Counseling having a child with sickle cell disease	43
Legal Services	41
Vocational Rehab and Planning	39
Career Planning Services	35
Unemployment Services	34
Transportation for Medical Appointment	33
Agency/program that can provide info about sickle cell to my employer	33
Child Care Services	29
Transportation for non-medical appointment	28
Mental Health Services	25
Marital Counseling	23
Alcohol Management	12