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

June 30, 2011

Background

The Code of Virginia places responsibility for sickle cell screening and treatment with the Commissioner of Health. Virginia began screening all newborns for sickle cell disease in July of 1989. At inception of the program, centers for comprehensive follow-up care were unavailable. In 1994, Virginia began to provide statewide comprehensive sickle cell services to decrease morbidity and mortality among children. The provision of comprehensive care is a time-intensive endeavor that includes ongoing patient and family education, periodic comprehensive evaluations and other disease-specific health maintenance services, psychosocial care, genetic counseling, and transition services. However, research demonstrates that the medical management model alone cannot address the multiple social, psychological, and educational needs of individuals living with chronic illnesses such as sickle cell disease.

Community-based programs provide formal and informal resources to support the development of coping strategies and networks of support for families impacted by sickle cell disease — addressing unmet social, psychosocial, and educational needs. A network of community-based sickle cell disease organizations provides a variety of support services across the Commonwealth.

During the 2010 General Assembly session, $90,000 was appropriated to the Virginia Department of Health (VDH) for FY2011 and FY2012 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 intent of the funding is 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 288Q of the 2010 Appropriation Act requires VDH to develop criteria for distributing these funds with specific goals and outcome measures. VDH is also required to submit an annual report to the House Appropriations and Senate Finance Committees of the Virginia General Assembly detailing program outcomes.

Community-Based Organizations Funding Status FY11

VDH issued a Request for Proposals (RFP) for community-based Sickle Cell Support Services on July 16, 2010. The RFP was issued via Virginia's web-based purchasing system, Virginia Business Opportunities (VBO), where registered vendors received notice that the solicitation was open. In addition, 14 potential providers (e.g., community-based organizations and medical facilities) statewide received individual notification of the RFP. The response date and time for the RFP was August 16, 2010, at 3:00pm. The RFP solicited non-clinical activities that provide assistance, education, and family-centered support for individuals with sickle cell disease.

VDH received three proposals in response to the RFP from the following organizations:

- Sickle Cell Association of Richmond – OSCAR
- Children's Hospital of the King's Daughters
- Fredericksburg Area Sickle Cell Association, Inc

The three aforementioned organizations were awarded funding to begin community-based services on October 1, 2010. Table 1 summarizes state funding provided by VDH to those community-based programs in FY11. Table 2 provides a summary of the community-based education and outreach activities performed as of March 31, 2011. Contractors will continue to conduct activities until the end of the fiscal year (June 30, 2011). Upcoming events include two transition conferences that will be hosted by the Children's Hospital of The Kings Daughters and Sickle Cell Association of Richmond-OSCAR. A majority of the activities provided focus on mental and social well-being. These stress-reducing activities have a positive effect on physical well-being.

Table 1. Community-Based Sickle Cell Programs State Funding Allocations for FY11

Community-Based Program	FY11 Allocation
Children's Hospital of The King's Daughters	$ 35,000
Sickle Cell Association of Richmond-OSCAR	$30,000
Fredericksburg Area Sickle Cell Association, Inc	$25,000
Total	$90,000

Table 2. Community-Based Education and Outreach Activities Performed as of March 31, 2011

Community-Based Program	Number of Clients Served	Activities	Outcomes
Children's Hospital of The King's Daughters	500	Conducted monthly sickle cell support group sessions titled "I Can Cope" for youth aged 13-18.	An average of 13 individuals attended each support group session where they were provided ongoing medical education about sickle cell and possible complications. Attendees also learned the following: • Coping strategies, • Educational accommodations, and • Career/job maintenance strategies.
		Hosted a sickle cell education forum to provide information on community resources.	Twenty-three (23) attendees gained insight on the availability of community resources to assist with managing sickle cell disease and promote self-sufficiency. Community participants included the Sickle Cell Association, Patient Advocate Foundation, Medicaid, as well as a Psychiatrist.
		Convened a Transition Open House to introduce the Sickle Cell Transition Intervention Program to patients' aged 16-21 and the medical and social community.	Forty-five (45) attendees were introduced to the Sickle Cell Transition Intervention Program. Families and patients were able to: • Meet medical and psychosocial support professionals involved in the transition process; • Learn the process for transitioning from pediatric to adult care; and • Meet other families with the similar circumstances.

Community-Based Program	Number of Clients Served	Activities	Outcomes
		Distributed a quarterly newsletter, *The Sickle Cell Connection*, to communicate information about the disease and upcoming events.	The newsletter was sent to approximately 500 patients with the following information: • Home pain management • Transition from pediatric to adult care • Teen support groups • Sickle cell disease maintenance in inclement weather
Fredericksburg Area Sickle Cell Association	43	Hosted *Heart to Heart Family Centered Support Groups*.	An average of 30 individuals attended support group sessions and gained knowledge on emergency room protocol for sickle cell patients at Mary Washington Hospital to ensure appropriate level of care; and availability of resources within the organization.
		Job skills training to increase self-sufficiency.	Two individuals received Group Facilitator and Education Specialist job skills training.
		Partnered with Mary Washington Hospital to assess the needs of sickle cell patients and families.	Mary Washington Hospital staff developed a protocol for sickle cell patients who visit the Emergency Department and referred two individuals to FASCA for sickle cell support
Sickle Cell Association of Richmond-OSCAR	300	Monthly support group meetings to educate clients on overcoming health and psychological issues.	An average of 30 individuals attended each support group meeting and gained knowledge on the following: • Stress management • Heart disease • Pain management • Transition from pediatric to adult care
		Distributed a *Sickle Cell Data Sheet* to assist in emergency room treatment.	20 clients utilize the tool to effectively communicate their health history with medical professionals.

Community-Based Program	Number of Clients Served	Activities	Outcomes
		One-on-one home visits were conducted to assist with parenting and domestic issues, legal concerns, employment, and advocacy.	12 clients received assistance with one or more of the following: employment, obtaining disability benefits, vocational rehabilitation, education accommodations and referrals, housing, transportation, advocacy and legal assistance, and domestic and parenting issues.
		Conducted telephone calls to clients to assess needs and provide ongoing support.	575 telephone calls to clients were conducted within a five month period to provide support and assess needs.

Future Plans

Item 288Q of the 2011 Appropriation Act directed VDH to allocate its $90,000 appropriation for community-based sickle cell programs to the Statewide Sickle Cell Chapters of Virginia (SSCCV). The funding is to be used for grants to community-based programs that provide patient assistance, education, and family-centered support for individuals suffering from sickle cell disease. The SSCCV will develop criteria for distributing these funds including specific goals and outcome measures. Due to this change, the contracts with the three FY2011 contractors are being terminated.