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

June 30, 2010

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. However no follow-up centers for the delivery of comprehensive care were identified. Beginning in 1994, in order to decrease morbidity and mortality among children, Virginia began to provide statewide comprehensive sickle cell services. 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 can not address the multiple social and psychological and education needs of individuals living with a chronic disease such as Sickle Cell Disease. Consequently, community-based services are a key component of support for sickle cell clients and their families. A volunteer network of regionally located community-based sickle cell organizations provides a variety of services across the Commonwealth.

During the 2007 General Assembly Session, $100,000 was appropriated to the Virginia Department of Health 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 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.

Subsequent state budget actions reduced the appropriation for this program to $50,000 in FY08. Starting in FY09, annual appropriations were as follows:

- FY09 - $95,000
- FY10 - $81,000
- FY11 - $90,000
- FY12 - $90,000

Item 288Q of the 2010 Appropriation Act requires that VDH develop criteria for distributing these funds, including specific goals and outcome measures and submit an annual report to the House Appropriations and Senate Finance Committees of the Virginia General Assembly detailing program outcomes.

Table 1 provides a summary of the community-based education and outreach activities performed by Virginia’s comprehensive sickle cell centers during FY10.

Table 1 - Community-based Education and Support Activities Performed by Comprehensive Sickle Cell Centers in FY10

Centers	Number of Clients Served*	Activities	Outcomes
University of Virginia	303	Community outreach to residents in low income housing (Westhaven Day). A "Challenge Course" was used to improve the confidence and partnerships with friends, families and staff. A message about sickle cell was displayed on SunTrust Bank marquee for Sickle Cell Awareness month. A panel of students and patients living with sickle cell disease was used to explain comprehensive sickle cell health care during the annual "Cell of Society" conference sponsored UVA Office of African-American Affairs, School of Medicine, and Office of Diversity. Health screenings and exhibits were offered during the annual Gospel Health Day, with participants from African-American churches in southern Albemarle County and Buckingham County, along with Southern Albemarle Family Practice and the UVA Cancer Center. Sickle cell disease literature was displayed at the Orange County health fair. An educational session on the transition of adolescent children to adult care was presented during the Annual Sickle Cell Family Education day.	One clinic is held per month, serving about 15-20 patients per month. Three pediatric patients transitioned to adult care, 10 additional patients are ready for transition to adult care.

Table 1 - Community-based Education and Support Activities Performed by Comprehensive Sickle Cell Centers in FY10

Centers	Number of Clients Served*	Activities	Outcomes
Inova Health System	22	No activities completed in collaboration with community businesses and foundations from July 2009 to March 2010 in order to minimize exposure to H1N1 per direction of Inova Fairfax Hospital administration. Staff had planned a Sickle Cell Picnic/Awareness event for October 2009. An End of School Year Ceremony & Parent Appreciation Celebration was held.	12 clinics are held per month, serving about 120 patients per month. Five pediatric patients transitioned to adult care.
Children's Hospital of the King's Daughters	89	An educational session on Managing Sickle Cell pain was provided to increase awareness of current pain management options and treatments for sickle cell patients. To increase the confidence and self-esteem of Sickle Cell patients, a partnership with a professional photographer and make-up artist was developed to provide professional family portraits of sickle cell patients. Ice skating was used to make learning about Sickle Cell a fun activity and to improve communication between patients, staff and families.	12 clinics are held per month, serving about 96 patients per month. 12 pediatric patients transitioned to adult care.

Table 1 - Community-based Education and Support Activities Performed by Comprehensive Sickle Cell Centers in FY10

Centers	Number of Clients Served*	Activities	Outcomes
Virginia Commonwealth University Medical Center	275	*The Sickle Cell Matters Newsletter* was developed and distributed to sickle cell patients, families and interested parties. The second annual Sickle Cell Walk was held in partnership with the Virginia Baptist Convention. Educational materials were provided. Sickle Cell information was displayed in the main lobby of Virginia Commonwealth University Health System. Portraits were displayed of sickle cell patients and educational information regarding sickle cell disease. Joint community meetings were held with the Sickle Cell Association of Richmond (OSCAR). Educational materials were provided. A Transition Christmas Party was organized with the Sickle Cell Association of Richmond to allow patients and families the opportunity to learn about making the transition from pediatric care to adult care. Information was provided concerning 1) the patient's ability to participate in a medical treatment plan, 2) methods of asking questions of healthcare providers, 3) healthcare benefits, 4) the decision to attend a vocational school or college, and 5) financial support. A concert was held in collaboration with Virginia Commonwealth University Health System Arts Department, in partnership with OSCAR.	Eight clinics are held per month, serving approximately 85 patients per month. Six pediatric patients transitioned to adult care.

Note: *As of March 31, 2010

Pediatric Comprehensive Sickle Cell Centers Funding - FY10

The Centers provide timely and appropriate treatment of acute illness which is critical, because life-threatening complications develop rapidly. It is essential that every child with SCD receive comprehensive care that is coordinated through a medical home with appropriate expertise. Table 2 summarizes state funding provided by VDH to comprehensive sickle cell centers in FY10.

Table 2 - Comprehensive Sickle Center State Funding Allocations for FY10

Center	FY10 Allocation
Children's Hospital of the King's Daughters	$ 110,000
INOVA	$124,080
University of Virginia	$45,160
Virginia Commonwealth University	$116,160
Total	$395,400

During FY10 the comprehensive centers were required to pilot a plan to transition patients from pediatric to adult care. VDH provided the Centers with the *Parent and Adolescent Transition Tools and Transition Notebook* to be used by the staff with their patients and families. The Centers were directed to have a transition coordinator designated to help facilitate this process. Two Centers hired social workers, but the other two Centers could not due to funding and hiring constraints. However, all Centers initiated the transition program.

Subsequently, in FY11 VDH will require each Center to have a transition plan using the revised materials from the FY10 experiences. A national expert on sickle cell transition programs at VCU has assisted VDH to revise the transition plan and tools and will partner with VDH to collect and analyze the statewide data. The comprehensive centers will provide quarterly reports on the status of the program performance measures and progress on the identified targets in their work plan.

Community-based Organizations Funding Status FY09

The Governor's October 2008 Budget Reduction plan contained a $5,000 GF reduction in FY09 for grants to community-based programs that provide patient assistance, education, and family-centered support for individuals suffering from sickle cell disease (Program 492 – Item 297S). The Governor's Budget Reduction plan also contained a $100K GF reduction to the comprehensive sickle cell services program (Program 430 - Item 295F). Regrettably, due to a misinterpretation of the language contained in the budget reduction plan, VDH staff mistakenly believed that the Governor's intent was to eliminate the entire $100K GF for the community-based program grants and reduce the comprehensive sickle cell services program by only $5,000.

Because of this erroneous interpretation, VDH cancelled the three community-based sickle cell grants/contracts in December 2008. This involved the cancellation of contracts with the following organizations:

- Fredericksburg Area Sickle Cell Association,
- Sickle Cell Association, Inc., and
- Sickle Cell Association of Richmond.

VDH regrets this error. VDH has implemented a series of corrective actions to ensure that all provisions of the Appropriation Act are clearly communicated to program managers at all levels of the agency. In addition, as an interim step pending completion of a new Request for Proposals for funding for FY11, VDH approved $4,000 in funding for FY10 for each of the three community-based organizations listed above. Appendix A contains further information concerning FY09 funding for community-based sickle cell programs.

Appendix A

Program Funding Status

In June 2009, the error in cancelling the community-based sickle cell grants was identified. On July 1, 2009, the VDH Deputy Commissioner for Public Health Programs notified the Secretary of Health and Human Resources and the Department of Planning and Budget of the misinterpretation of the Governor’s October Reduction Plan strategies and the subsequent cancellation of the grants by program staff**.** The Deputy Commissioner further advised the Secretary that VDH would immediately reinstate the grants at the approved reduced amount and implement the $100K reduction to the Comprehensive Sickle Cell Services Program in FY10.

However, due to the requirements of public procurement, VDH was unable to reinstate the grants for FY10. The grant funds were awarded as contracts under a competitive process; and once the contracts were cancelled, they could not be reinstated without initiating a new competitive Request for Proposals (RFP).

In order to comply with procurement laws and ensure that these funds were expeditiously made available to the community for service delivery in FY10, the funds were allocated to the comprehensive sickle cell centers (Inova Health System, Children’s Hospital of the Kings Daughters, Virginia Commonwealth University and the University of Virginia) through existing contracts**.** VDH knew that the comprehensive sickle cell centers were beginning community outreach activities of their own. This was a result of VDH’s prior insistence that the comprehensive sickle cell centers include community outreach within their scope of work. The centers have 1) established programs serving a large number of children with sickle cell disease; 2) an infrastructure that supports community-based education; and 3) partnerships with lay and professional stakeholders.

Community Based Sickle Cell Organizations

Following the cancellation of the contracts with the three community-based organizations, and the subsequent realization that VDH had misinterpreted the budget reduction plan, VDH received, and responded to, several requests for information and documentation from these organizations. In April 2010, VDH staff met personally with representatives of these organizations.

During the meeting, VDH explained to the organization’s representatives the error that initiated the cancellation of the contracts, and FY09 funding was no longer available as these dollars had since reverted to the general fund. They were further advised that the FY10 funding had been allocated to the comprehensive sickle cell centers to deliver community based services under their existing contracts. Given the uncertainty of the FY10 budget situation, the program staff believed this strategy was a more prudent approach as this action eliminated the need for a new RFP in FY10 and expeditiously put these funds in the community to deliver services. VDH explained that for FY11 and beyond, a new RFP was being developed for the community-based program grant funding, and each of their organizations will have the opportunity to submit a proposal for funding. VDH further advised the representatives that it would thoroughly explore

VDH's legal options to award some portion of funds for the remainder of FY10 but could not commit to any particular remedy at that time.

VDH management subsequently consulted with the VDH Office of Purchasing and General Services and the Attorney General's Office concerning options under the state procurement rules. It was determined that because the contracts were cancelled, there is no legal basis for "reinstating" them and to do so would violate state procurement rules. As an interim step, pending the completion of an Request for Proposals (RFP) for funding for FY11, VDH has approved funding of $4,000 for the remainder of FY10 for each of the three community based organizations that were previously funded by VDH (Sickle Cell Association of Hampton Roads, Organization for Sickle Cell Anemia Resources, and the Fredericksburg Area Sickle Cell Association) The award will be used to assist 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. The specific intent is to fund one community event for each of the community-based organizations. The three organizations have proposed the following activities to be completed by the end of FY10.

- Fredericksburg Area Sickle Cell Association:
  Observance of World Sickle Cell Awareness Day on June 19, 2010 in order to provide resources to sickle cell clients and their families, increase their skills and their knowledge regarding additional resources and agencies, provide linkages to job training, resume building, disability benefits and health care providers, and provide sessions on self-esteem building, stress reduction and coping skills.
- Sickle Cell Association, Inc.:
  Implementation of a module of the Fundamental Opportunities Creating Useful Skills (FOCUS), by June 29, 2010, to help teens with sickle cell disease develop work ethics and skills that will foster self-sufficiency.
- Sickle Cell Association of Richmond (formerly Organization of Sickle Cell Anemia Resources):
  Convene a "Re-invent, Re-energize and Enhance the Future" meeting by June 24, 2010. This meeting will be used to provide an overview of the organization, including staff roles and the assistance they provide. It will also provide an opportunity for their adult clients to share information concerning their progress in order to serve as source of encouragement for other clients concerning how to maintain good health and become self-sufficient.

VDH is completing work on a new RFP will establish the parameters by which any community-based organization can competitively seek funding in FY11.