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MEMORANDUM

DATE: January 27, 2011

TO: All Members of the House of Representatives

Representative Kenyatta Johnson FROM:

SUBJECT: Co-sponsorship: Evaluating Pennsylvania's Sickle Cell Disease Program

In the near future, I will introduce legislation directing the Legislative Budget and Finance Committee (LBFC) to conduct an in-depth review of Pennsylvania's sickle cell disease program.

The Centers for Disease Control and Prevention estimate that 70,000 to 100,000 Americans suffer from this disease. In fact, it occurs in approximately 1 out of every 500 African American births while 1 in 12 African Americans carry the sickle cell trait. Comprehensive treatment is vital to those afflicted with this disease. Therefore, a delivery system that is accessible, responsive, and adequate is key to their health and survival.

The Sickle Cell Disease program, administered by the Pennsylvania Department of Health (DOH), currently provides grants to major medical institutions and community based organizations for the purpose of providing comprehensive treatment and psychosocial services to those afflicted with this disease. However, funding for this program has decreased from slightly over \$2 million in 2007 to approximately \$1.7 million in 2010.

My legislation would direct the LBFC to study the accessibility and effectiveness of this program, as well as determine what additional programs and services may be required to meet the needs of persons afflicted with sickle cell disease. In the 2009/2010 session, I introduced a similar measure (HR 285), which directed the Department of Health to conduct this study.

If you wish to join me in the effort by adding your name as a co-sponsor, please contact Deborah Brady at drbrady@pahouse.net.