HB1176 Public Health – Sickle Cell Disease Registry – Establishment

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Support

I am Dr. Sophie Lanzkron, I am a practicing hematologist at the Johns Hopkins School of Medicine where I am the Director of the Sickle Cell Center for Adults. The views expressed here are my own and do not necessarily reflect the policies or positions of Johns Hopkins University/Johns Hopkins Health System. I treat adults with sickle cell disease (SCD), which is characterized by episodes of excruciating pain, known as vaso-occlusive crises and I support HB1176. Over time, adults with SCD suffer from organ damage that leads to significant morbidity and mortality. Average life expectancy for those with sickle cell disease still remains 25-30 years less than the general population.

People with SCD have been historically underserved by the medical establishment. Sickle cell disease is complex medically and many of the people with the disease are also impacted by social determinants of health that multiply the daily struggle with the disease. Due to disabilities caused by the disease, only 40% of people with SCD are employed and 50% report incomes of less than $20,000 a year. Fifty percent of people with SCD are insured through Medicaid and it is estimated that the costs of acute care alone is $1.5 million/100 patients/yr.

I care for about 550 adults with the disease and as the only comprehensive sickle cell program in the state I see new patients, often with very complicated, poorly managed disease. Their disease is poorly managed because they have not had access to high-quality sickle cell expert care. Poor outcomes that are preventable happen to people living with SCD in Maryland because there is a lack of access to high quality care and poor provider knowledge about the disease. **Maryland has been identified as one of the states with an inadequate number of comprehensive clinics for the number of people estimated to be living with SCD in the state.**

SB 859/HB 1176 is a good first step toward improving care for people with SCD in the state and could facilitate improved outcomes for this underserved population. There is currently no accurate count of the number of people with SCD living in Maryland. As a result, we do not have comprehensive data on patient outcomes or where patients receive care. The development of a SCD registry and surveillance system would be beneficial in several ways:

1. With an effective registry and surveillance program healthcare providers can understand how people interact with the healthcare system and can help identify people with SCD who may be receiving the majority of their care in the emergency department and are unaffiliated with high quality sickle expert care.
2. An effective registry and surveillance program would provide needed information that will allow researchers and public health professionals to know where to target activities and programs;
3. Most importantly, the bill will result in focused efforts to provide expert care to this vulnerable, underserved population which will lead to improvement in health care

outcomes, including better access to new treatments or cures. Improved access to care has also been demonstrated to decrease costs of care.

In summary SB 859/HB 1176 creates the first key step that could result in a true change in how care is provided to people with SCD in Maryland. Identifying where the need is for establishing additional high-quality comprehensive sickle programs will offer the foundation to build infrastructure that improves outcomes; and with improved outcomes there will be better quality of life for those who live with this disease. I urge a favorable report on SB 859/HB 1176.