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**TESTIMONY IN SUPPORT OF
HB 1170/SB 883 Sickle Cell Testing at Community Health Fairs**

Health Fairs are the best possible outreach program of those who may be have or be affected by Sickle Cell Disease. Sickle Cell Testing is not allowed in non-lab venues in Maryland. Health Fair represent the best possible method to get SC information out to those people carrying the SC Trait gene. The possible carriers need to know their blood history. Such knowledge imparts the gravity of the situation if one gene in each parent creates the Sickle Cell disease.

Currently Maryland does Infant screening for the Sickle Cell Trait but there is no protocol for follow up counseling should the results indicate the SCT. The State of Maryland needs a genetic Counseling program for parents and their children once the disease is detected. Today, once providers receive results from the lab after birth, the results are communicated to the parents and no explanation or counseling is provided.

Most Moms at health fairs prior to pandemic did not remember child results from infant screening early on. Most Teens asked at health fairs prior to pandemic did not know blood history. These two facts are strong indicators that no explanation or counseling was provided at time of testing.

Our granddaughters screened positive for SC/Thalassemia trait from their mom (our daughter with SC/Thalassemia Disease). These young women are witnesses to their mother's painful episodes with the disease and DO NOT want to bring another Sickle Cell Warrior into the world. Knowledge and counseling is clearly an important part of this decision-making process. Informed reproductive decisions are critical.

Those with the SCT have catastrophic health conditions. In fact, clinical trials have reported the following debilitating and painful conditions:

Renal Medullary Carcinoma (rare kidney cancer)

Hematuria (blood in urine)

Complications with trauma to the eyes

Spleen tissue death at high altitudes

False positives on A1C Type 2 Diabetes tests.

It is estimated that 4000-5000 people annually test positive for the SCT gene in Maryland. Statistics further show that an estimated 5,000 Marylanders have SCD and over 150,000 Marylanders have the SCT. The full story of SCT must be communicated to those carrying the gene.

KNOWLEDGE IS POWER

I URGE YOU TO ENTER A FAVORABLE REPORT FOR HB 1170. The bill is also cross filed as SB883.