**A** **HOUSE RESOLUTION**

TO CONGRATULATE THE LOUVENIA D. BARKSDALE SICKLE CELL ANEMIA FOUNDATION AND THE GREENVILLE SICKLE CELL DISEASE COMMUNITY ADVISORY BOARD FOR THEIR TIRELESS WORK, AND TO RECOGNIZE SEPTEMBER AS “SICKLE CELL AWARENESS MONTH” IN SOUTH CAROLINA IN ORDER TO HELP SPREAD AWARENESS OF THE DISEASE, THE NEED FOR INCREASED RESEARCH, AND TO SUPPORT INDIVIDUALS LIVING WITH SICKLE CELL ANEMIA.

Whereas, sickle cell disease, is a group of chronic, progressive, life‑threatening, inherited blood disorders that affects more then one hundred thousand Americans and an estimated one hundred million persons worldwide; and

Whereas, sickle cell disease leads to a blockade of the critical flow of blood and oxygen to vital areas of the body. This results in severe complications such as chronic, severe, and unpredictable pain, anemia, infection, swelling of extremities, fatigue, vision problems, lung tissue damage, kidney disease, stroke, and shortened life expectancy; and

Whereas, long known as the “forgotten” illness, sickle cell disease has had a historical lack of clinical care, research, and community advocacy in comparison to other illnesses; and

Whereas, individuals who live with sickle cell disease often experience medical and social complexities and significant health disparities in comparison to their peers. In many ways, sickle cell disease highlights the ways in which social and political inequalities can affect the care and quality of life of those who suffer with a chronic illness; and

Whereas, in the effort to combat sickle cell disease, clinical trials hold incredible promise for the development of much‑needed new treatments, and if possible, a cure. While there are currently only four United States Food and Drug Administration‑approved drugs to treat the disease, there is now a robust development pipeline to advance treatment and care of those affected by sickle cell disease; and

Whereas, the Comprehensive Sickle Cell Disease Program of Prisma Health is the first program in the upstate of South Carolina, and is currently the only program within the state to provide care for both adults and children with sickle cell disease in the same location by the same dedicated team; and

Whereas, over the last thirty years, children who are affected by sickle cell disease have seen drastic improvements in their survival and quality of life through a standardized approach to treatment, disease modification, and preventative care. However, adults with sickle cell disease have often found that it is difficult to access similar services and thus experience a high amount of disease‑related complications; and

Whereas, in an effort to meet the needs of all individuals who live with sickle cell disease, the Comprehensive Sickle Cell Disease Program has developed a lifespan approach which allows for a strong transition from pediatric to adult care; and

Whereas, dedicated to standardized, cutting‑edge care for both children and adults with sickle cell disease, the Comprehensive Sickle Cell Disease Program works to advance the health outcomes and quality of life for each of their patients; and

Whereas, in order to best approach their work, the Comprehensive Sickle Cell Disease Program works closely with key stakeholders, such as community‑based organization, L.D. Barksdale Sickle Cell Disease Foundation; patient‑led advocacy group, Sickle Cell Lights of Hope; the Greenville Branch of the NAACP; Long Branch Baptist Church; The Blood Connection; and the Greenville Black Caucus of Elected Officials; among others; and

Whereas, the members of the South Carolina House of Representatives urge state agencies, medical service providers, health care agencies, research facilities, medical schools, and federal agencies to work toward increasing clinical care, supportive care, and medical education and research for this chronic inherited blood disorder. Now, therefore,

Be it resolved by the House of Representatives:

That the members of the South Carolina House of Representatives, by this resolution, congratulate the Louvenia D. Barksdale Sickle Cell Anemia Foundation and the Greenville Sickle Cell Disease Community Advisory Board for their tireless work, and recognize September as “Sickle Cell Awareness Month” in South Carolina in order to help spread awareness of the disease, the need for increased research, and to support individuals living with sickle cell anemia.

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