TESTIMONY

JOINT HEARING OF THE FINANCE AND HEALTH COMMITTEE

I am the parent of a son that was born with sickle cell disease. My son, Shakir Lateef Cannon died on December 5, 2017 due to acute complications attributed to sickle cell disease. He was only 34 years old. He was a devoted husband and loving father of a 5 year-old daughter. He was employed in Information Technology at the State Department of Health in Albany, NY.

Shakir's passion was advocating for sickle cell disease and his personal motto was "any day without pain is a good day". His personal motto is inscribed on his headstone. His advocating took him to Washington, DC where he attended the White House Precision Medicine Initiative Summit in 2016.

My son went beyond merely accepting his condition. He worked tirelessly to increase awareness, needed research and treatment of sickle cell disease. I also have a son and three grand children who have sickle cell trait.

I have been advocating to improve care for sickle cell patients for over 30 years. My advocacy began with the birth of my youngest son Shakir. Shakir was diagnosed with sickle cell disease at birth through new born screening.

Shakir was followed by a regular pediatrician until he had a stroke at age three. After he had the stroke, he was followed by a hematologist. Transfusion therapy was the only treatment as there was a high risk of having another stroke. My son received transfusions every three weeks from age 3 to 34.

Being a parent of a child with a chronic illness such as sickle cell disease is very challenging. My husband and I were our son's primary care givers. I worked midnight to 8am to be able care for our son during the day and my husband worked 3pm-11pm to provide care for him at night. Many parents of children with sickle cell disease are unable to be gainfully employed due to their child's frequent hospitalizations. As parents, my husband and I was aware of our son's needs and medications. We were trained to care for his port-a-cath and how to give him his medication. We gave him nightly infusions of Desferal via a port-a-cath to reduce iron overload, which if not treated could be fatal.

My son received coordinated care for his sickle cell disease from age 3 until age 21 when he transitioned from pediatric to adult care. Most adult patients are not in care with a hematologist or a primary doctor. Care is very inconsistent. Many of the adult patients are seen in the emergency room when they are in pain crisis. As an adult, my son experienced frequent changes to his hematologist and no longer received the comprehensive care that he received in pediatrics.

Sickle Cell Disease is a complex disease with worsening complications and organ damage, including lungs, heart and kidneys, as patients age. The life expectancy for sickle cell disease patients is decreasing. The median life expectancy for men is 38 years and women 42 years. Sickle cell disease requires specialized care to achieve the best possible outcomes for patients. Sickle cell is the most costly disease per patient to NYS Medicaid. However, Federal, State and

private funding for sickle cell disease is severely lacking. In 2018, sickle cell funding in the NYS budget was cut from $250,000 to $170,000.

There is currently a sickle cell bill that has to be re-introduced in the NYS Legislature that would establish eight demonstration programs throughout NYS and one coordinator center to improve the care of sickle cell disease patients and educate about sickle cell trait.

I urge you to support the bill and to increase the amount allocated in the next budget to $5,000,000 to fully fund the bill.

The passing of this bill will positively impact the lives of individuals living with sickle cell disease in New York State, the lives of my three grandchildren who have the sickle cell trait, and the lives of future generations who will inherit the sickle cell gene.

Thank you for your consideration,

Cheryl A. Cannon
Parent