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DETROIT'S SICKLE CELL EXPERT, WANDA SHURNEY, M.D., LAUDS FDA APPROVAL OF ADAKVEO

First targeted treatment sparks excitement and hope among doctors and those living with the debilitating condition

DETROIT, MI. (November 20, 2019) – Friday, the FDA gave its approval for Adakveo (crizanlizumab-tmca), the first targeted therapy to treat pain in patients with sickle cell disease (SCD). "This medication is a potential game changer in the quest for better treatment for patients with sickle cell disease (SCD)," said Wanda Whitten-Shurney, M.D., CEO and Medical Director of the Sickle Cell Disease Association of America - Michigan Chapter (SCDAAMI). "We are excited that after 109 years, individuals with SCD can finally say there is a medication developed specifically for them. For 20 years our patients had only one disease modifying medication, hydroxyurea.

"Unfortunately, because it is a drug used to treat cancer, many physicians are hesitant to prescribe it and many patients are afraid to take it – leaving supportive care such as blood transfusions, antibiotics for infections, and potent narcotics for essential pain relief as their only options," said Dr. Shurney.

First recognized by the medical community in the United States in 1910, SCD is a genetic condition inherited from two parents who carry the gene for sickle cell trait. The hallmark of the disease is episodes of unpredictable and often excruciating pain due to crescent- (sickle) shaped red blood cells that block the flow of blood, and therefore the delivery of oxygen, to vital organs. These red blood cells are also fragile and break down early causing anemia and fatigue. The newly-approved Adakveo targets the episodes of pain frequently referred to as a pain crisis.

"We hear story after story from patients in genuine need of significant pain treatment being denied the compassionate and competent care they desperately need and deserve because many in the medical community are unsure, uncomfortable, or unaware of how to best treat sickle cell patients," said Dr. Shurney. "Patients in crisis are often questioned about the validity of their symptoms and assumed to be 'drug seeking'." This problem is exacerbated by the current opioid crisis.

In addition to her role at the SCDAAMI – fondly known as the Sickle Cell Center throughout the community – Dr. Shurney has been a familiar face to many families whose children have been patients at the Comprehensive Sickle Cell Clinic at Children's Hospital of Michigan during her 30-year career providing out-patient care with an emphasis on education and coping strategies. She has worked relentlessly to help kids and their families manage the chronic ailment while enjoying healthier, more active lives. Many of her patients are now adults – something unheard of 30 or 40 years ago.

(cont.)

"Thanks to advances like the administration of penicillin to give children with SCD a fighting chance against infection, we're now seeing many patients living a closer to normal lifespan, but they are still faced with significant challenges," said Dr. Shurney. "This illness can disrupt every aspect of the family's life. Children miss school, parents and adults miss work which can result in termination of employment and the resultant financial strain on the family. Frequent trips to the doctor and repeated hospitalization are an additional burden. Many individuals have some level of pain every single day. After 109 years, it is past time to improve life and offer hope to this patient population."

Though numbers are thought to be higher, an estimated 100,000 individuals in the U.S. currently live with some form of the debilitating and life-threatening disease. Comparatively, there are about 30,000 people with cystic fibrosis and 20,000 people (predominantly men) with hemophilia.[1] Yet, despite three to five times as many people living with SCD, the disease remains widely unknown, misunderstood, and poorly resourced.

"This in the face of the fact that SCD primarily affects people of color - mostly African Americans and Latinos, but also East Indians, Greeks, Italians, individuals from the Middle East, and other people from malaria-afflicted parts of the world," said Dr. Shurney. The disease is an evolutionary response to malaria: Those with sickle cell trait are less likely to get malaria. But nature's protective mechanism brought about its own unbearable consequences.

"Thanks to the Orphan Drug Act, there are numerous promising clinical trials underway. We are also encouraged by the National Institutes of Health's Cure Sickle Cell Initiative striving for a genetic cure in the next five to 10 years," said Dr. Shurney. "The FDA's approval of Adakveo is a big step in the right direction. Our next challenge is to make sure the medication is accessible to the patients who so desperately need it. Individuals with sickle cell disease are living longer, but we are also focused on improving their quality of life."

[1] *Cystic fibrosis and hemophilia statistics courtesy of the Centers for Disease Control at www.cdc.gov*

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Our Mission

To maximize the quality of life of individuals living with sickle cell disease.
To enable individuals with sickle cell trait to make informed decisions with respect to family planning.
To provide education and testing for the general public.

Founded in 1971 by Charles F. Whitten, M.D., the Sickle Cell Disease Association of America – Michigan Chapter, provides education, assistance, and advocacy for individuals living with and families affected by sickle cell disease. Other services include counseling, support groups, referrals for financial assistance and medical care. SCDAAMI connects students and job seekers with school, college and employment assistance; sends children to summer camp each year, and works to raise public awareness. The agency also serves as the coordinating center for the newborn sickle cell screening program for the Michigan Department of Health and Human Services. Appointments are available and walk-ins are welcome for blood tests to diagnose sickle cell trait and other sickle cell conditions at 18516 James Couzens Fwy, Detroit, MI 48235.
SCDAAMI's services are available throughout Michigan and span lifetime needs.
For more information, visit www.scdaami.org or call 313-864-4406 for more information.