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Medical College of Wisconsin Receives Funding from Doris Duke Charitable Foundation to Expand Research on Sickle Cell Disease Patients With COVID-19

New York, Aug. 20, 2020 – The Medical College of Wisconsin (MCW) and the Doris Duke Charitable Foundation (DDCF) jointly announce that MCW is receiving a grant of \$100,000 from DDCF to expand a secure, rapid-response surveillance registry, which collects de-identified data on individuals with sickle cell disease (SCD) and COVID-19, and to aggregate and analyze the collected data.

The purpose of this grant is to expand the registry, which is overseen by Dr. Julie Panepinto, a professor of pediatrics and hematology/oncology/bone marrow transplantation at MCW, from solely including U.S. patients with COVID-19 and sickle cell disease to including children and adults in Africa with the same diagnoses, and to support investigations of associations between the two diseases. Research will enable understanding of health outcomes and longer-term impact of COVID-19 infections and treatments on SCD-specific progression and therapies. Prior studies have shown that people with SCD have higher rates of mortality from influenza and are at increased risk from respiratory pathogens, which indicates that this population may be particularly vulnerable to COVID-19.

“In light of this emerging epidemic and the potential for future infectious disease epidemics, it is important to obtain a better understanding of the risk factors and natural history of this viral infection in this medically vulnerable population,” said Dr. Panepinto. “By establishing and supporting the Surveillance Epidemiology of Coronavirus Under Research Exclusion (SECURE)-SCD registry, we hope to learn more about the impact of COVID-19 outbreaks on sickle cell disease patients.”

Sickle cell disease is the most common inherited blood disease, affecting approximately 100,000 patients in the U.S. and millions of people in Africa. Patients with SCD produce abnormal hemoglobin that causes red blood cells to become rigid and deform into a sickle shape, clumping together and blocking flow within blood vessels and resulting in severe pain, among other problems. This disease, which is most prevalent in people of African and Hispanic descent, affects nearly every organ system in the body, and is associated with an early death, with the average global life expectancy estimated to be about 45-55 years old.

“This repository of data provides a critical tool for helping the field better understand the impact of Covid-19 on individuals with sickle cell disease and for equipping health care providers with what they need to best deliver the appropriate treatments and counsel to their patients,” said Dr. Betsy Myers, program director for medical research at the Doris Duke Charitable Foundation. “We are proud to support the Medical College of Wisconsin in the expansion of this registry to include children and adults in Africa, which is home to the largest population of sickle cell disease cases in the world, and we encourage health care providers to contribute to it.”

Working collaboratively, researchers hope to quickly identify the impact of COVID-19 on patients with sickle cell disease and understand the impact of risk factors on health outcomes from the information found in the registry. Researchers know that SCD patients are a population that may be at increased risk of infection. Impact and consequences of novel COVID-19 affecting patients with SCD are emerging from the preliminary data from the registry.

Health care providers are being notified of the registry through professional and patient advocacy networks, and a link to the registry is available on the CDC website. To report a case or view the data, which is being updated on a weekly basis, please visit <https://covidsicklecell.org>.

About the Medical College of Wisconsin

With a history dating back to 1893, The Medical College of Wisconsin is dedicated to leadership and excellence in education, patient care, research and community engagement. More than 1,400 students are enrolled in MCW's medical school and graduate school programs in Milwaukee, Green Bay and Central Wisconsin. MCW's School of Pharmacy opened in 2017. A major national research center, MCW is the largest research institution in the Milwaukee metro area and second largest in Wisconsin. In the last 10 years, faculty received more than \$1.5 billion in external support for research, teaching, training and related purposes. This total includes highly competitive research and training awards from the National Institutes of Health (NIH). Annually, MCW faculty direct or collaborate on more than 3,100 research studies, including clinical trials. Additionally, more than 1,600 physicians provide care in virtually every specialty of medicine for more than 2.8 million patients annually.

About the Doris Duke Charitable Foundation

The mission of the Doris Duke Charitable Foundation is to improve the quality of people's lives through grants supporting the performing arts, environmental conservation, child well-being and medical research, and through preservation of the cultural and environmental legacy of Doris Duke's properties. The foundation's Medical Research Program supports clinical research that advances the translation of biomedical discoveries into new preventions, diagnoses and treatments for human diseases. For more than a decade, the foundation has supported sickle cell disease research through a variety of grant-making mechanisms, including the Sickle Cell Disease/Advancing Cures awards, which were launched in 2017. Doris Duke, who endowed the foundation and for whom it is named, expressed a specific interest in supporting sickle cell disease research in her will, which in part guides the foundation's funding priorities. To learn more, visit www.ddcf.org.