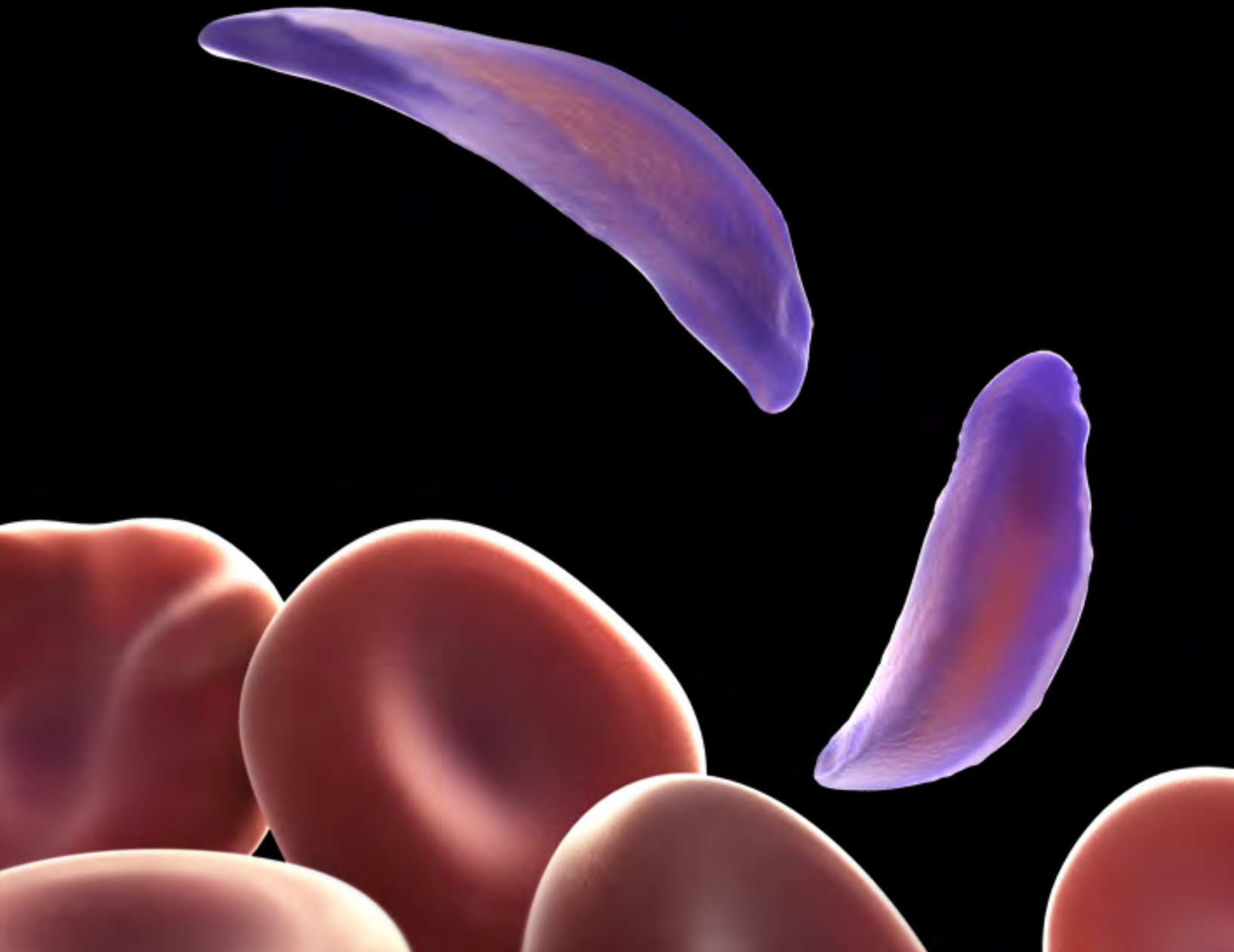
Transforming Sickle Cell Disease Care Through Transplantation and Other Options

Wednesday September 23, 2020

12:00-1:30 ET • Free Webex Event



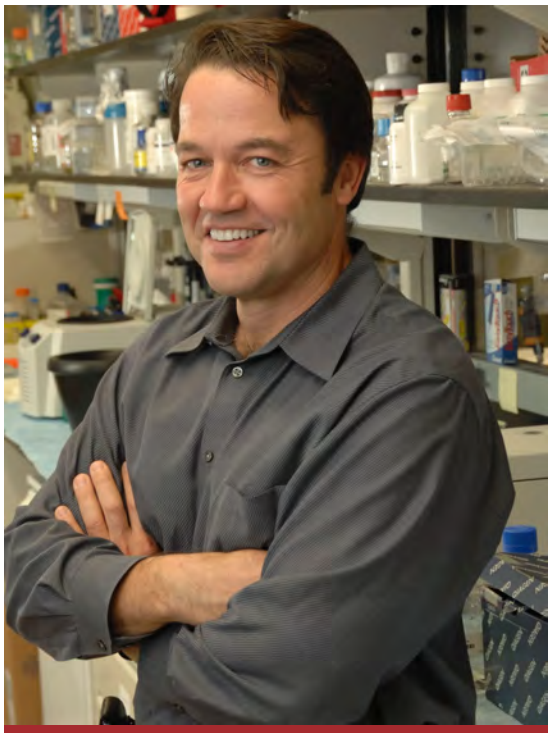
Agenda

12:00 pm	Introduction	Jennifer Gillette, *nbmtLINK*
12:10 pm	Discussion	Dr. John Tisdale
12:30 pm	Discussion	Dr. Courtney Fitzhugh
12:50 pm	Patient speaker	Clevetta Drew
1:05 pm	Questions	Jennifer Gillette, *nbmtLINK*
1:30 pm	Adjourn	

NIH National Heart, Lung, and Blood Institute

nbmtLINK National Bone Marrow Transplant Link

Speaker Biography



Dr. John Tisdale

John Tisdale received his medical degree from the Medical University of South Carolina in Charleston after obtaining his B.A. in Chemistry from the College of Charleston. He completed an internal medicine and chief residency at Vanderbilt University Medical Center in Nashville and then trained in hematology in the Hematology Branch, National Heart, Lung and Blood Institute (NHLBI), where he served as a postdoctoral fellow. He joined the Molecular and Clinical Hematology Branch of NHLBI in 1998 and is now the Chief of the Cellular and Molecular Therapeutics Branch. In 2011 the College of Charleston recognized Dr. Tisdale with the Alumni of the Year Award and the Pre-Medical Society's Outstanding Service Award in Medicine. He was recently elected to the American Society for Clinical Investigation and is a member of the American Society of Hematology. Dr. Tisdale's research and clinical work center on sickle cell disease. His group focuses on developing curative strategies for sickle cell disease through transplantation of allogeneic or genetically modified autologous bone marrow stem cells.

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Speaker Biography

Dr. Courtney Fitzhugh

Courtney Fitzhugh received her B.S. magna cum laude from the University of California, Los Angeles in 1996, and her M.D. from the University of California, San Francisco in 2001. During medical school, Dr. Fitzhugh participated in the NIH Clinical Research Training Program, where she studied with Dr. John Tisdale at the NHLBI. After receiving her M.D., Dr. Fitzhugh completed a joint residency in internal medicine and pediatrics at Duke University Medical Center, and in 2005 she did a combined adult hematology and pediatric hematology-oncology fellowship at the NIH and Johns Hopkins Hospital. Dr. Fitzhugh returned to the NHLBI in 2007 and was appointed as Assistant Clinical Investigator in 2012 and Clinical Tenure Track Investigator in 2016. She is a member of the American Society of Hematology.

Patient Speaker

Clevetta Drew

Clevetta Drew, is a 40 year old sickle cell patient who participated in a gene therapy clinical trial in October 2019 at NIH.

I was diagnosed at 18 months old with sickle cell anemia, and was lucky not to have any crises during childhood.

My pain crises began at age 19 and progressed in adulthood, which caused an interest in transplant due to frequent pain crises and blood transfusions. I began participating in various clinical trials at NIH in 2011 for pulmonary hypertension, high blood pressure, and hydroxyurea, which was continued outpatient to help manage the sickle cell.

Due to an injury and increased crises, I eventually suffered from job loss resulting in a huge ripple effect on life and health. In October 2019, I volunteered for a new gene therapy clinical trial at NIH, drastically changing my life for the better.

I'm proud to say I have returned to work after just 6 months, delivering packages with high physical demands, fully operating on much less sleep than before and I'm now able to withstand extreme temperatures. I'm managing household chores and social activities, and have successfully stopped all pain medication just 3 months after my transplant. I'm not experiencing pain crises, urgent care or hospital visits, or having to undergo weekly management of the disease with IV fluids. Also, I have been able to successfully stop all other medications, including blood thinners, GI meds, and antidepressants.

I realized that while life and challenges are still occurring I'm now able to handle them, without pain. The biggest change though, is the mental toughness I've gained from pushing past old habits and triggers that were developed from years of managing a disease that brought on pain, distress, and many other ailments that deteriorate the body over time. Gene therapy was a rebirth and it changed my life in less than a year. I am thankful for the opportunity to live life as close to "normal" as possible.