

Sickle Cell Task Force Members

Member	Position/Category	Term Expiration
Titilope Fasipe, M.D., Ph.D. (Chair)	Representative of a health-related institution	August 31, 2023
Marqué Reed-Shackelford (Vice-Chair)	Member of the public who has sickle cell disease or is a parent of a person with sickle cell disease or trait	August 31, 2023
Melissa Frei-Jones, M.D., M.S.C.I.	Physician specializing in hematology	August 31, 2022
Priscilla Hill-Ardoin	Member of the public who has sickle cell disease or is the parent of a person with sickle cell disease or trait	August 31, 2023
Dawn Johnson, M.D.	Member from a community-based organization with experience addressing the needs of individuals with sickle cell disease	August 31, 2024
Alecia Nero, M.D., M.S.C.S.	Physician specializing in hematology	August 31, 2022
Alysian Thomas, J.D.	Member from a community-based organization with experience addressing the needs of individuals with sickle cell disease	August 31, 2022

Member Composition

The task force is composed of the following members appointed by Health and Human Services (HHS) executive commissioner:

- two members from community-based organizations with experience addressing the needs of individuals with sickle cell disease;
- two physicians specializing in hematology;
- two members of the public, each of whom either has sickle cell disease or is a parent of a person with sickle cell disease or trait; and
- one representative of a health-related institution.

Appointment Terms

Members are appointed to serve two-year terms. Initial terms were staggered to ensure the continuity of the Task Force. Members with an initial term of 2 years served through August 31, 2021. Members with an initial term of 3 years will serve until August 31, 2022. If a vacancy occurs, a person is appointed to serve the unexpired portion of that term. Regardless of the term limit, a member serves until his or her replacement has been appointed. Individuals may apply to be reappointed to serve a second term. A member may serve these terms consecutively.

Biographies

Titilope Fasipe, M.D., Ph.D. – Harris County

Membership Position – Representative of a health-related institution

Term expires August 31, 2023

Chair Term expires August 31, 2023

Dr. Titilope Fasipe has the unique perspective of relating to and understanding the need for education, community awareness, support, and medical care as she is a physician as well as an individual with sickle cell disease. Dr. Fasipe has a Bachelor of Science in biology with a minor in chemistry from the University of Texas at Arlington. She obtained her doctorate in cell biology and her medical degree from the University of Texas Medical Branch (UTMB), Galveston, Texas. In July 2016, she joined the faculty at Baylor College of Medicine as Assistant Professor of Pediatrics in Hematology/Oncology and has continued her research on sickle cell disease. She also provides care to sickle cell patients at the Texas Children's Hematology Center. Dr. Fasipe has multiple professional memberships including: American Society of Hematology; American Society of Pediatric Hematology/Oncology; Fellow, American Academy of Pediatrics. She also is a board member of Supporting our Sicklers (SOS) Parent and Guardian Support Group and a member of Sickle Cell Disease Network-Houston. Dr. Fasipe was a member of the Sickle Cell Advisory Committee from 2016 to 2018 and joined the DSHS Newborn Screening Advisory Committee in September 2018 as one of two members in positions representing the sickle cell community. She currently serves as co-chair for the Sickle Cell Subcommittee of the Newborn Screening Advisory Committee. In 2022, Dr. Fasipe was appointed to a second term on the Sickle Cell Task Force.

Marqué Reed-Shackelford – Harris County

Membership Position – Member of the public who has sickle cell disease or is a parent of a person with sickle cell disease or trait

Term expires August 31, 2023

Vice-Chair Term expires August 31, 2023

Marqué Reed-Shackelford is the parent of two sons with sickle cell disease, giving her an understanding not only of the medical aspects of the disease, but of the daily challenges faced when living with sickle cell disease. Ms. Reed-Shackelford, recognizing the need for resources in her community, co-founded a support group for parents called "Supporting Our Sicklers (S.O.S.) Parent & Guardian Support Group" in 2014 and is the Board President. Under her leadership, the non-profit has received 501(c)(3) status with the objectives to support, educate, and advocate, with programs such as Parent Support "TeleTalks," financial support for families, and "Survivor Relief Kits." Ms. Reed-Shackelford also works in healthcare as a Systems Analyst within the Harris Health System and has had previous professional experience as an instructor and training developer. She has also had volunteer experience as a "navigator" for other parents and guardians of children with sickle cell at the Texas Children's Hematology Center. Ms. Reed-Shackelford was appointed a member of the Sickle Cell Advisory Committee in April 2018 and served until its abolishment in August 2018. In 2022, Ms. Reed-Shackelford was appointed to serve a second term on the Task Force.

Melissa Frei-Jones, M.D., M.S.C.I. – Bexar County

Membership Position – Physician specializing in hematology

Term Expires August 31, 2022

Dr. Melissa Frei-Jones is board-certified in pediatrics, as well as pediatric hematology and oncology. She is an Associate Professor of Pediatrics with the University of Texas School of Medicine. Dr. Frei-Jones is also the Medical Director of the South Texas Sickle Cell and Thalassemia Center where she cares for children and young adults with sickle cell disease. She has over 10 years of experience including serving seven years as Medical Director of the Pediatric program in San Antonio. Her other professional experience related to sickle cell disease includes: medical director of Camp Cell-A-Bration, program director of Pediatric Hematology/Oncology Fellowship program, and participant with the regional Mountain States Sickle Cell Consortium. Dr. Frei-Jones has professional memberships in: American Society of Hematology; American Society of Pediatric Hematology/Oncology (ASPHO), Hemoglobinopathy Special Interest Group; ASPHO representative to the American Board of Pediatrics Foundation for the development of a Sickle Cell Disease Learning Network Initiative; Medical Director and physician

representative/ board member of the Sickle Cell Disease Association of Austin – Marc Thomas Chapter. She was an active member of the Sickle Cell Advisory Committee from 2016 to 2018. Dr. Frei-Jones was appointed to the Newborn Screening Advisory Committee in September 2018 and serves as co-chair of the Sickle Cell Subcommittee of the Newborn Screening Advisory Committee.

Priscilla Hill-Ardoin – Bexar County

Membership Position – Member of the public who has sickle cell disease or is a parent of a person with sickle cell disease or trait

Term expires August 31, 2023

Having raised a son with sickle cell disease and another son with sickle cell trait, Ms. Priscilla Hill-Ardoin is intimately familiar with the physical and mental impact of the disease on the person and their family. In honor of her son, Ms. Hill-Ardoin founded the Aaron Ardoin Foundation for Sickle Cell Research and Education after he died from sickle cell disease. The Foundation has granted over \$0.5 million to non-profit organizations to fund sickle cell-related projects such as the development of teaching/learning aids and an emergency fund to assist families in crisis.

Ms. Hill-Ardoin has also served as a parent representative on the Vanderbilt-Meharry-Matthew Walker Center for Excellence in Sickle Cell Disease in Nashville Tennessee. She was appointed to the task force in 2022.

Dawn Johnson, M.D. – Dallas County

Membership Position – Member from a community-based organization with experience addressing the needs of individuals with sickle cell disease

Term expires August 31, 2024

Dr. Dawn Johnson is Medical Director of the Children’s Health Primary Care Clinic, where she treats patients with sickle cell disease and trains pediatric residents. Dr. Johnson is passionate about making medical care better for the vulnerable population of patients with sickle cell disease.

She has served on the North Texas Sickle Cell Community Advisory Board and national sickle cell disease committees, such as the American Society of Hematology Sickle Cell Disease Committee. She would like to be a voice for patients with sickle cell disease, as she is not only a pediatrician, she is also a person living with sickle cell disease. Dr. Johnson was appointed to the task force in 2022.

Alecia Nero, M.D., M.S.C.S. – Dallas County

Membership Position – Physician specializing in hematology

Term expires August 31, 2022

Dr. Alecia Nero is board-certified in internal medicine and pediatrics and in the subspecialty of hematology and has a Master of Science in Clinical Sciences. Dr. Nero has been an Associate Professor of Internal Medicine/Hematology-Oncology at UT Southwestern Medical Center, Parkland Memorial Hospital, and Children's Health/Children's Medical Center in Dallas since 2011. She has been the Director of the Sickle Cell Transition Program at UT Southwestern Medical Center since 2012. She previously served as Medical Director of the Sickle Cell Day Treatment Program and was a member of their Clinical Transformation Task Force and President's Council on Diversity and Inclusion-Health Equity Action Team. Dr. Nero cares for both adults and children with sickle cell disease, giving her a unique perspective on treatment throughout a patient's lifespan, including the difficult transition from pediatric to adult care. She has also worked on promoting awareness of sickle cell to support her patients and families outside of the clinic and has frequently spoken on topics related to sickle cell disease at conferences and in the media. Dr. Nero has served on the Hemoglobinopathies Interest Group on the Mountain States Genetics Regional Collaborative (MSGRC) and the Hemoglobinopathies Uniform Medical Language Ontology Project with the National Heart, Lung, and Blood Institute (NHLBI)/ National Institutes of Health (NIH) - Health Resources and Services Administration (HRSA). Dr. Nero's professional memberships include the American Society of Hematology, Dallas County Medical Society, Texas Medical Society, Sickle Cell Adult Provider Network, American College of Physicians, American Medical Association, and National Medical Association. Dr. Nero's experience as a physician in the Dallas area broadens the geographical perspective of medical professionals on the task force to the North Texas region.

Alysian Thomas, J.D. – Travis County

Membership Position – Member from a community-based organization with experience addressing the needs of individuals with sickle cell disease

Term expires August 31, 2022

Alysian Thomas has been the Chief Operating Officer and Attorney for the Sickle Cell Association of Texas Marc Thomas Foundation since 2013. The Sickle Cell Association of Texas Marc Thomas Foundation, founded in 1997 by her father, Marc Thomas, focuses on serving families affected by sickle cell trait and disease and has provided education and sickle cell awareness throughout Texas. Under her leadership, the organization has expanded its reach to serve families in 52 counties, including 17 in rural areas, and has secured over \$2.5 million in grant funding. Ms. Thomas has both a professional and personal connection to issues related sickle cell disease and sickle cell trait. Not only was she impacted by the death of her father at the age of 46 due to sickle cell disease complications, she has sickle cell trait herself, and is the mother of two sons with sickle cell trait. Ms. Thomas, as a

certified hemoglobinopathy educator, was previously a client service specialist and health educator, giving her a background in how to effectively educate families affected by sickle cell trait and sickle cell disease. She has provided case management, education, support group meetings, and referral services to behavioral and mental health services to clients across Texas. As a licensed attorney, she has also provided legal advice to families. Ms. Thomas is highly recommended by leadership from the Sickle Cell Disease Association of America (SCDAA) and leaders in City of Austin public health and state government. Ms. Thomas was also a member of the Sickle Cell Advisory Committee from 2016-2018, and her experience will be helpful in making further contributions to the Sickle Cell Task Force.