

DECEMBER 10
12PM-4PM EST
VIRTUAL EVENT



SICKCELLS.ORG

**2024
COVERAGE
FOR SCD
SUMMIT**



CONTENTS



WHO WE ARE

03

WHAT IS THE COVERAGE
FOR SCD SUMMIT?

04

AGENDA

05

SPEAKERS

07

SPONSORS

11

SUPPORT SICK CELLS

11

WHO WE ARE



Sick Cells is a national sickle cell disease (SCD) advocacy nonprofit founded February 28, 2017. Sick Cells' mission is to elevate the voices of the SCD community and their stories of resilience.

In highlighting the grave disparities this community faces, we hope to influence decision-makers and propel change.

Find us at Sickcells.org or:



WHAT IS THE COVERAGE FOR SCD SUMMIT?

The annual Coverage for SCD Summit provides a **collaborative forum** to discuss the changing landscape of healthcare coverage for sickle cell disease (SCD). This meeting brings together the SCD community members, payers, providers, pharmaceutical manufacturers, patient groups, researchers, care teams, and policymakers to discuss ways to tackle the complexities of coverage and access to SCD treatments and care.

THIS YEAR'S SESSIONS:

Innovative Access Models for Sickle Cell Disease:

Learn about the CMS Cell and Gene Therapy Access Model and how it aims to expand access to cutting-edge treatments for Sickle Cell Disease (SCD), ensuring equitable care delivery.

Medicaid Access and Coverage Insights:

Hear from healthcare experts and state Medicaid directors about the current landscape of Medicaid coverage for SCD, key challenges, and actionable policy recommendations to improve access and reduce disparities.

Patient Experiences and Community Engagement:

Gain valuable insights from patients who have accessed new therapies for SCD, along with discussions on how community-based organizations (CBOs) are addressing critical healthcare coverage gaps for underserved populations.

AGENDA



12:00 PM – 12:05 PM

Welcome

12:10 PM – 12:40 PM

Keynote

Speaker: Aurelia Chaudhury

12:45 PM – 01:15 PM

SCD Landscape Over the Years: Reflections of Progress, Treatment Access, and Future Hope

Speakers: Pat L Corley, Tristan Lee

In this session, we will hear a community perspective about how the landscape for SCD has changed since the 2014 FDA Patient Focused Drug Development meeting. Community members will speak on topics such as the monumental shifts in awareness about SCD, an increase in community advocacy surrounding access and care, an uptick in federal engagement and funding, and a lush pipeline for drug.

01:20 PM – 01:50 PM

Leading the Way: Payers Discuss Sickle Cell Coverage Initiatives Panel

Speakers: Jennifer Strohecker, Emily Tsiao

In this session, we hear from Premera Blue Cross and Utah State Medicaid as they share their strategies and initiatives to improve access to care for individuals with sickle cell disease, highlighting current efforts to expand coverage and address disparities in treatment.

01:50 PM – 02:00 PM

Break 1

02:00 PM – 02:20 PM

The CMS Cell and Gene Therapy Access Model: Transforming Sickle Cell Disease Treatment

Speaker: Elizabeth Hassett

This session will provide an in-depth overview of the CMS Innovation Center's Cell and Gene Therapy Model, highlighting how it aims to enhance access to cutting-edge treatments for sickle cell disease, while addressing challenges related to affordability, implementation, and equitable care delivery.

02:25 PM – 02:35 PM

Breaking Barriers: My Experience with Accessing New Sickle Cell Therapies

Speaker: Jimi Olaghere

In this session, we will hear from a person who is a gene therapy recipient. They will share their personal journey of accessing treatment and highlight the challenges, successes, and the transformative impact of these innovative treatments on their health and life.

02:40 PM – 03:00 PM

Building Knowledge Through the Community: The Consolidated Learning System for Sickle Cell Gene Therapy

Speaker: Nikki Braccio

This session will explore the community learning system within the CMS Innovation Center's cell and gene therapy model, highlighting how collaborative networks and shared knowledge are driving the successful implementation and expansion of gene therapies for sickle cell disease.

03:00 PM – 03:10 PM

Break 2

03:10 PM – 03:40 PM

Navigating Coverage Gaps: The Critical Role of CBOs in Sickle Cell Healthcare Panel

Speakers: Ginger Davis, Linda Thomas Wade, and Tabatha McGee

This session will explore the critical role of community-based organizations (CBOs) in navigating the complex landscape of coverage gaps in sickle cell disease healthcare. Attendees will gain insights into how CBOs are addressing disparities in access to care, advocating for patients, and driving innovation in local and national healthcare systems. The discussion will highlight successful strategies used by CBOs to bridge gaps in insurance coverage and enhance patient outcomes through community-centered solutions.

03:45 PM – 03:55 PM

Closing



SPEAKERS

Aurelia Chaudhury (Centers for Medicare & Medicaid Services) – Keynote

Aurelia Chaudhury is a Model Co-Lead for the Cell and Gene Therapy Access Model at the CMS Innovation Center. Aurelia graduated from Rice University with a degree in Economics in 2009. She worked in healthcare consulting and for the Massachusetts Medicaid program prior to attending Yale Law School, from which she graduated in 2016. Aurelia spent several years in litigation, clerking for two federal judges and later working for a plaintiffs' side antitrust firm. Aurelia joined CMMI in 2021. Prior to taking on her current role, she served as the Model Lead of the Value-Based Insurance Design Model.

Pat L Corley, RN – Panelist

In 1979 Pat became the Nurse Coordinator for one of ten newly found National Institutes of Health Sickle Cell Centers. She was Nurse Coordinator at LAC+USC for the Sickle Cell Disease Comprehensive Center for over three decades. Her many projects have included the "Unveil Sickle Cell" campaign, sitting on the NIH Focus Groups committee, the International Association of Sickle Cell Nurses and Professional Associates committee, and the Children's Hospital of Los Angeles Group committee. Today, Pat is the recipient of the Elliott Vichinsky Health Care Provider Award, she lectures at numerous institutions, and partners with Cayenne Wellness Center and Axis Advocacy to improve the plight of persons living with sickle cell disease.

Tristan Lee- Panelist

Tristan Lee was diagnosed at the age of 6 month's old w/ Sickle Cell Disease in 1983. Due to not much being known about SCD the Dr. who diagnosed me told my Mom, and grandmother that I wouldn't live past 20. However, being a family of faith they trusted in the lord understanding that God has the final say. Today Tristan is a professional model, actor, and I have a fashion line for SCD called DiVo Stars. I am a professional patient advocate for the SCDA and Sick Cells. He has had the opportunity of being NORD's Rare Disease Day Hero in 2020, presenting on the inaugural HHS Sickle Cell Summit during September of 2024, and representing the SCD community locally, nationally, and internationally. Spreading Sickle Cell Disease Awareness is a passion for Tristan just as much as fashion and acting.

Jimi Olaghere – Speaker

Jimi Olaghere is a gene therapy recipient who has developed a keen interest in the advancements of cell and gene therapies, since his transformative participation in the groundbreaking clinical trial. He is passionate about the positive impact these therapies can have on patients in need and has become a staunch advocate for increased accessibility of gene therapies for SCD patients worldwide.

SPEAKERS CONTINUED

Emily Tsiao (Premera Blue Cross) – Panelist



Emily Tsiao, PharmD, BCPS, is the Medical Policies Clinical Pharmacist at Premera Blue Cross, where she leads drug clinical policy development across the medical and pharmacy benefit for over 2 million members. She has experience overseeing drug utilization management strategy, drug pipeline surveillance, and clinical programs.

Dr. Tsiao earned her Doctor of Pharmacy degree from Auburn University and completed a postgraduate managed care pharmacy residency with Premera Blue Cross. She is also a Board Certified Pharmacotherapy Specialist (BCPS). Dr. Tsiao has been an active Academy of Managed Care Pharmacy (AMCP) member since 2015. She previously served as President of the Northwest AMCP Affiliate and was awarded the 2024 JMCP Award for Excellence. She currently serves as a Clinical Affiliate Faculty member at the University of Washington School of Pharmacy and is a preceptor and mentor to pharmacy students and residents.

Jennifer Strohecker (Utah Department of Health and Human Services) – Panelist



Dr. Jennifer Strohecker, PharmD, serves as the Integrated Healthcare Division and Medicaid director at the Utah Department of Health and Human Services. She has direct oversight of the state Medicaid and Children’s Health Insurance Program (CHIP), Office of Substance Use and Mental Health, and the Utah State Hospital. This purview includes more than 1,500 employees and an annual budget of more than \$5 billion. For more than 20 years, Dr. Strohecker has been a practicing pharmacist in a variety of settings, including the senior pharmacy director with a Medicare and Medicaid managed care plan and as full-time adjunct professor with a college of pharmacy. Dr. Strohecker has a bachelor’s degree in pharmacy from the Philadelphia College of Pharmacy and Science and Doctor of Pharmacy from the University of Florida. Additionally, Dr. Strohecker participates in semi-annual medical mission trips to the Camotan Clinic in Camotan, Guatemala, which provides free medical and dental care.

Nikki Braccio (Center for Medicare and Medicaid Services Innovation Center) – Speaker



Nicole “Nikki” Braccio, PharmD, serves as the learning system lead for the Cell and Gene Therapy (CGT) Access Model at the Center for Medicare and Medicaid Services Innovation Center (CMMI). In this role, Nikki designs and implements learning communities to support model participants and partners with improving equitable access to cell and gene therapies for people living with sickle cell disease. Prior to joining CMS, Nikki served as the policy director for National Patient Advocate Foundation and prior to that, advised life science clients with coverage and access policies at Avalere Health. Nikki began her career as a pharmacist in the community setting – practicing in New York and New Jersey. She earned her Doctor of Pharmacy degree from Rutgers University.

SPEAKERS CONTINUED



Elizabeth Hassett - Speaker

Elizabeth Hassett is an Associate at Leavitt Partners, based in Washington, D.C., and through her work, an Advisor to the Sickle Cell Disease Partnership. At Leavitt Partners, Elizabeth supports clients and multistakeholder alliances by managing projects and providing strategy on health policy issue areas related to rare diseases, access to treatments, drug development and pricing, and pharmaceutical supply chain management.

Before joining Leavitt Partners, Elizabeth was a Law Clerk at the Centers for Medicare and Medicaid Services in the Provider Reimbursement Review Board, where she focused on Medicare Part A reimbursement regulation and appeals. She additionally served as a Law Clerk at the Maryland Office of the Attorney General for the Maryland Department of Health. Elizabeth received both her MPH in Health Policy and Bachelor of Arts in Political Science from the University of Pittsburgh. She is currently completing her law degree at the University of Maryland, where she is specializing in health law and policy.



Linda Thomas Wade (Marc Thomas Foundation) - Panelist

Linda Thomas Wade is the CEO and President of the Sickle Cell Association of Texas Marc Thomas Foundation (SCAMTF). SCAMTF was founded in 1997 by the late, great Pastor Marc Thomas, a sickle cell warrior, and his wife Linda. Pastor Marc lived with severe sickle cell disease (SCD) which took his life too soon at the age of 46. Pastor Marc never stopped believing families living with SCD needed a strong voice to raise awareness of the disease and the suffering it causes. Pastor Marc's wife, Linda and their daughter, Alysian have dedicated themselves to continuing his legacy and mission. The SCAMTF serves more than 1,000 individuals and families across the State of Texas living with SCD and provides education and awareness activities about SCD and sickle cell trait. The association has three physical locations in Austin, Houston and San Antonio and additionally serves families in the Dallas area and beyond.



Tabatha McGee (Sickle Cell Foundation of Georgia) - Panelist

Tabatha McGee is an innovator, a leader, and a woman whose strong faith has carried her through trials and triumphs. As the Executive Director of the Sickle Cell Foundation of Georgia, Inc., and Founder of Sickle Cell Sanctuary Wellness Center – the first and only holistic center in the nation for sickle cell patients – Tabatha is tireless in her mission to ensure the highest quality of life and hope for sickle cell warriors and others with life-threatening blood disorders. After graduating from high school, Tabatha opted to join the U.S. Army, where she excelled as one of the few women paratroopers in the 82nd Airborne Division at Fort Benning. Following her service, Tabatha found her niche in the technology field. The year 2015 brought Tabatha back to Atlanta where she became a caregiver for her mother, a role that tested her strength and resilience. She battled back from both a heart attack and a stroke to now have vibrant health.

SPEAKERS CONTINUED

Ginger Davis (Sickle Cell Thalassemia Patients Network) - Panelist



Teresa Ginger Davis has been a life-long health and education advocate, and spokesperson for sickle cell disease. She has more than 25-years of experience in the health industry. Through Sickle Cell Thalassemia Patients Network (SCTPN), Ms. Davis applied her biology and naturopathic health science education towards working with twenty New York City hospitals on HRSA grants to deliver care coordination and transitions services for pediatric hematology clients and their families, also care coordination and referral to needed services for adults lost to care after transitioning from pediatrics. On June 29, 2024, Ginger was bestowed an Honorary Doctorate of Humanities by the Anointed by God Ministries and Seminary for lifelong advocacy for education, health, youth mentorship, and community service. Ginger is now leading SCTPN as its newly elected president.

Ashley Valentine (Sick Cells) - Speaker



Ashley Valentine, Co-Founder and President of Sick Cells, is a recognized leader in the sickle cell community. With a professional background as a policy research analyst for federal clients, including Medicaid, Medicare, and the CDC, Ashley's passionate advocacy is deeply rooted in her personal connection to sickle cell disease, driven by her brother Marqus. Together, they have achieved significant milestones, such as leading the SCD community in its first-ever ICER review, forming impactful coalitions to advocate for federal legislation, testifying at the FDA to emphasize the significance of drug development, and more.

Kelly Hawthorne (Sick Cells) - Moderator



Kelly is the Director of Community Programs for Sick Cells. She brings notable international experience in community-building, patient engagement, health awareness campaigns and dynamic storytelling. In her role at Sick Cells, Kelly works directly with our large and vibrant group of Sick Cells Ambassadors, centering the voices and needs of our community in everything we do.

Kelly has been dedicated to working in rare disease communities, across the US and Australia, for 10+ years. From testicular cancer to sickle cell disease, Kelly has overseen initiatives that bolstered peer navigation, patient advocacy in government and lived experience storytelling series. She is purposeful in her sharp focus on inclusion, championing stories left untold and communities often dismissed.

Arielle Krahenbuhl (Sick Cells) - Moderator



Arielle S. Krahenbuhl is the Community Programs Coordinator at Sick Cells. She is a social innovator and health advocate who has combined her diverse background in health care administration and community organizing to lead nonprofit and advocacy campaigns throughout her career. She recently completed her Master of Science in Biotechnology with a concentration in Health Science at Johns Hopkins University.

SPONSERS

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SUPPORT SICK CELLS

With your gift, Sick Cells will be able to continue to do programming like the 2024 Coverage Summit and we will continue to elevate the voices of the SCD Community. All funds received will go towards accomplishing our mission.

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YOU**