

SICK CELLS COVERAGE & THERAPEUTICS SUMMIT

"Access Unlocked"

2026 PROGRAM BOOK

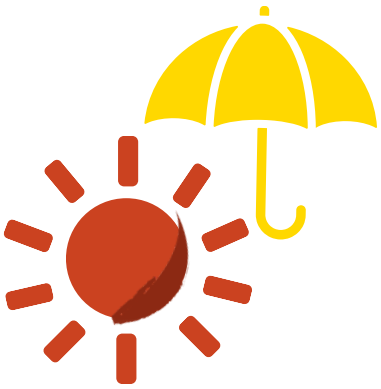


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WHO WE ARE

Sick Cells is a national sickle cell disease (SCD) advocacy nonprofit founded in 2017. Our mission is to elevate the voices of the SCD community and our stories of resilience. By highlighting the challenges this community faces, we will influence decision-makers and drive positive change.

Sick Cells is recognized for its leadership in advocacy, education, and storytelling. Through our Faces of SCD Storytelling Program, Ambassador Program, and signature convenings, including the Annual Policy Forum and Coverage & Therapeutics Summit, we bring lived experiences to the forefront. Our work also includes supporting the bipartisan Sickle Cell Disease Congressional Caucus and advancing policies that improve access to care and treatment.

As a trusted convener and educator, Sick Cells brings together individuals living with SCD, caregivers, healthcare professionals, researchers, policymakers, and industry leaders to share knowledge and collaborate on solutions. We work to ensure that the voices of individuals and families affected by SCD remain central to healthcare policy, therapeutic development, and efforts to advance equitable access to care.

Learn more:

sickcells.org

Follow us:

@sickcells



GET INVOLVED

BECOME AN AMBASSADOR

SHARE YOUR STORY

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SUMMIT OVERVIEW

This year, we're combining our Coverage Summit and Therapeutics Conference into a two-day event: the Sick Cells Coverage & Therapeutics Summit.

The Coverage & Therapeutics Summit brings together the SCD community, healthcare providers, payers, researchers, pharmaceutical manufacturers, advocates, care teams, investors, and policymakers to explore the evolving landscape of treatment, coverage, and access to care.

This year's theme, *Access Unlocked*, reflects our commitment to connecting science, lived experiences, and policy to identify opportunities to improve access, advance innovation, and improve outcomes for people living with SCD.

The summit will be held virtually on November 4-5, 2026.

About Past Events:

2024 Coverage Summit: Our virtual, half-day summit welcomed 150 participants, including payers, state Medicaid directors, providers, and manufacturers for sessions on the CMS Cell and Gene Therapy Access Model, Medicaid access, and state gene therapy strategies.

2025 Therapeutics Conference: Our one-day, hybrid conference in Washington, D.C., welcomed 231 attendees for discussions on clinical trial experiences, emerging therapies, opportunities for trial participation, and the impact of policy and regulation on therapeutic development.

AGENDA

WEDNESDAY, NOVEMBER 4, 2026

10:00 AM - 10:05 AM

Welcome Remarks & Keynote Introduction

Speaker: Jamie Dornfeld

10:05 AM - 10:15 AM

Keynote Address

Speaker: Dr. Ted Love

10:15 AM - 10:35 AM

Current State of SCD Coverage: Medicaid Access

Speaker: Mariah Scott

A 2026 look at Medicaid access and coverage for SCD, including findings from Drug Utilization Review Board engagement and landscape review. The discussion will highlight current treatment coverage, insights from patients and advocates engaged in the process, and ongoing disparities and barriers to care.

10:35 AM - 11:05 AM

Navigating Medicaid Coverage: Drug Utilization Review Boards and Advocacy

Speakers: Deanna Darlington, James Griffin, Cory Lewis, Mariah Scott (Moderator)

This session will take a closer look at the role of Drug Utilization Review Boards in Medicaid coverage decisions and how advocates can engage in the process. Panelists will share lessons from state-level advocacy and opportunities to strengthen community engagement in decisions that affect access to SCD treatments.

11:05 AM - 11:25 AM

Break

11:25 AM - 11:45 AM

Company Presentations

Novo Nordisk; Pfizer

AGENDA

11:45 AM - 12:15 PM

Medicaid in Transition: What Changes Mean for the SCD Community

Speakers: Latoya Thomas, Josh Trent, Melissa Akinlawon (Moderator)

This panel will explore the changing Medicaid landscape and what recent policy changes could mean for people living with SCD. Speakers will discuss Medicaid work requirements, state implementation considerations, and other emerging changes that could affect coverage and access to care.

12:15 PM - 12:45 PM

Lunch

12:45 PM - 1:10 PM

The Cell & Gene Therapy Access Model: From Policy to Implementation

Speakers: Dr. Tayiana Reed, Dr. Michael Coleman, TaLana Hughes, Jamie Dornfeld (Moderator)

A closer look at how states and their partners are putting the CMS Innovation Center's Cell and Gene Therapy Access Model into practice. Panelists will discuss access and affordability, implementation challenges, coordination across Medicaid agencies, healthcare providers, and community partners, and the support needed to help eligible individuals and families navigate these potentially transformative treatments.

1:10 PM - 1:25 PM

The Cell & Gene Therapy Access Model: Early Lessons and What Comes Next

Speaker: Bianca Desai

As states begin implementing the Cell & Gene Therapy Access Model, early experiences are providing important insights into what it takes to expand access to transformative therapies. This session will explore the goals of the CMS model, early lessons and insights emerging from implementation, and opportunities to strengthen access for individuals living with sickle cell disease. The presentation will also highlight what these early efforts may mean for the future of coverage, affordability, and access to cell and gene therapies.

AGENDA

1:25 PM - 1:45 PM

Congressional Remarks
Speakers: Maisie Ruddy, Houston James

Hear directly from legislative offices on current federal priorities, the importance of ongoing collaboration, and future policy initiatives with the bipartisan Sickle Cell Disease Caucus.

1:45 PM - 1:50 PM

Warrior Story
Speaker: Constance Benson

1:50 PM - 2:00 PM

Break

2:00 PM - 2:07 PM

Company Presentation
Terumo Blood & Cell Technologies

2:07 PM - 2:12 PM

Warrior Story
Speaker: Brittani Malcolm

2:20 PM - 2:50 PM

The Cost of Inaction: Investing in SCD Coverage
Speakers: Dr. Tobi Amosun, Dr. George Goshua, Melissa Akinlawon (Moderator)

What happens when we fail to invest in comprehensive SCD care? This conversation will examine the human, healthcare, and economic costs of gaps in coverage and access, including the longer-term impact of delayed or inadequate care. Panelists will explore the value of investing in timely, comprehensive care and what better coverage could mean for patients, payers, and the broader healthcare system.

2:50 PM - 2:55 PM

Day 1 Closing Remarks
Speaker: Ashley Valentine

AGENDA

THURSDAY, NOVEMBER 5, 2026

10:00 AM - 10:05 AM	**Welcome Remarks** **Speaker: Ashley Valentine**
10:05 AM - 10:20 AM	**State of Drug Development in SCD** **Speaker: Dr. Biree Andemiriam** This session will provide an overview of the current therapeutics pipeline, explain what clinical trials are, outline the phases of clinical trials, and address topics such as accelerated approvals, withdrawals, trial purpose, safety, and a preview of ongoing clinical trials.
10:20 AM - 10:55 AM	**Patient Voice in Drug Development: Community Engagement with the FDA** **Speakers: Jamie Sullivan, Dr. Julie Kanter, Terri Booker, Esq.** A look at the role of patient voice in FDA decision-making and drug development, including Sick Cells involvement in the 2014 Sickle Cell Disease Patient-Focused Drug Development (PFDD) meeting and opportunities for the SCD community to engage in the upcoming meeting.
10:55 AM - 11:15 AM	**Break**
11:15 AM - 11:45 AM	**Company Presentation** **Genetix Biotherapeutics; Agios**
11:45 AM - 12:15 PM	**Perspectives from the U.S. Department of Health and Human Services** **Speakers: Cmdr. Matthew Johns, Dr. Donna Whyte-Stewart, Capt. David Wong, MD** A discussion of the evolving policy and regulatory environment for SCD therapeutics and how FDA policies and processes can influence drug development, innovation, patient access, and the future treatment landscape.
12:15 PM - 12:45 PM	**Lunch**

AGENDA

12:45 PM - 12:55 PM	**SCD on Capitol Hill: Congressional SCD Caucus Update** **Speaker: Ryann Hill** The Sickle Cell Disease Caucus is a bipartisan platform dedicated to advancing policies that improve the lives of individuals and families affected by sickle cell disease. The Caucus works to elevate awareness of SCD, support research and innovation, strengthen access to high quality care, and build support for legislation and federal funding that addresses the needs of the sickle cell community. These updates will highlight progress and strategic plans from the SCD Caucus.
12:55 PM - 1:20 PM	**Case for Investing in SCD** **Speakers: Rushmie Nofsinger, Dr Michelle Lee, Mel Hayes (Moderator)** This conversation will bring together clinical and investment perspectives to explore why continued investment in SCD is important, where innovation is still needed, and what investors consider when evaluating opportunities in the space. Panelists will discuss what can help attract greater investment to SCD and how sustained investment can support therapeutic development and improve outcomes for people living with SCD.
1:20 PM - 1:40 PM	**Break**
1:40 PM - 2:10 PM	**Company Presentations** **Vertex Pharmaceuticals, Sanofi**
2:10 PM - 2:45 PM	**Inside a Clinical Trial: The Patient Experience** **Speakers: Wunmi Bakare, Simone Day, Ted Nicolas, Yvonne Carroll, RN, JD (Moderator)** Patients who have participated in clinical trials will share firsthand perspectives on their experiences, from recruitment and enrollment through participation and study completion. The conversation will also explore the support patients may need navigating common barriers that can make participation difficult, and what they wish they had known before participating.
2:45 PM - 1:50 PM	**Video Testimonial** **Speaker: Dr. Dana LeBlanc**
2:50 PM - 2:55 PM	**Day 2 Closing Remarks** **Speaker: Ashley Valentine**

DID YOU KNOW?



MEDICAID WORK REQUIREMENTS

On June 1, 2026, the Centers for Medicare & Medicaid Services (CMS) issued a rule that requires certain Medicaid enrollees to show they are working, volunteering, or participating in other "qualifying activities" for at least 80 hours each month. This rule took effect July 31, 2026 and must be implemented by state Medicaid offices by January 1, 2027. We've prepared an FAQ with information about the rule as well as how the sickle cell disease (SCD) community may be affected:

Who will be impacted by this rule?

The rule applies to non-pregnant adults ages 19–64 who are enrolled in Medicaid under the adult expansion group and are not co-enrolled in Medicare.

How does CMS define a "qualifying activity"?

Those affected can meet the work requirement through any combination of the following activities, as long as the total time spent on these activities adds up to 80 hours each month:

- Employment
- Participation in a work program
- Community service or volunteering
- Enrollment in schooling at least part-time
- Earning at least $580/month

How do I show proof of employment?

If you are a new applicant, you must meet the work requirement for at least one month before applying for Medicaid coverage. If you are a current enrollee, you must show compliance with the requirement at your next renewal. States retain the option to check compliance more frequently if they choose.

SPEAKERS



Keynote Address: Dr. Ted Love

Cardiologist and Former Biotech Executive

Dr. Ted Love is the immediate-past chair of the Board of Directors at the Biotechnology Innovation Organization (BIO). A long-time BIO Board Member, Dr. Love most recently served as president and chief executive officer of Global Blood Therapeutics (GBT) from June 2014 until October 2023, when the Pfizer acquired the company. During his tenure at GBT, he led the company from a pre-clinical start-up, through the accelerated approval and launch of Oxbryta®, and into a global commercial company with an advanced pipeline of innovative therapies focused on sickle cell disease.



Melissa Akinlawon, MA

Senior Director of Community Programs, Sick Cells

Melissa Akinlawon is an award-winning communications strategist focused on equity in public health. With 14+ years shaping prevention, chronic disease, and community campaigns, her past work includes NIH Heart Health Education and CDC's Stop HIV Together, plus social media leadership for a primary care provider serving the senior/Medicare population. She is pursuing a DrPH at George Washington University to transform public health storytelling to influence and amplify healthy lifestyle behaviors.



Dr. Tobi Amosun

Deputy Commissioner for Population Health, Tennessee Department of Health

Tobi Amosun, MD, FAAP, is a respected healthcare leader and a recognized speaker and writer whose work has been featured by local, state, and national organizations. She is a board member of numerous professional organizations, including the Cumberland Pediatric Foundation. She also currently serves as the director-at-large for the Association of Maternal Child Health Programs. She previously served as Assistant Commissioner and the Director of the Division of Family Health and Wellness.



Dr. Biree Andemariam

Professor of Medicine - Division of Hematology/Oncology, University of Connecticut

Biree Andemariam, MD is an internationally recognized clinician and advocate. She is the Founding Director of the New England Sickle Cell Institute and Director of the Connecticut Bleeding Disorders Center. Dr. Andemariam has served as the lead principal investigator for three global sickle cell disease clinical trials. She is the immediate-past Chief Medical Officer of the Sickle Cell Disease Association of America, where she received the Chairman's Award three times for her outstanding service.

SPEAKERS



Wunmi Bakare

Co-Founder & Executive Director, Sickle Cell Prodigy

Wunmi Bakare is the Co-Founder of Sickle Cell Prodigy, a patient-driven nonprofit redefining survivorship for individuals living with sickle cell disease exploring curative-intent therapies. She is recognized as a pioneering advocate in the rare disease community for advancing inclusion, challenging stigma, and elevating patient voice at the intersection of medicine, media, and community.



Terri Booker, Esq.

SCD Warrior & Advocacy Relations Professional

Terri Booker decided it was necessary to become a patient advocate after the medical team during her 2012 hospitalization had no idea about sickle cell. Ms. Booker is an active advocate and has spoken at various conferences and conventions around the United States. She is the founder of Hemoglobin Advocates, where its mission is to help the world see the humanity in those with sickle cell, disabilities, and melanated skin. Terri enjoys cooking, eating, and traveling when she is not serving the Lord and practicing law.



Yvonne Carroll, RN, JD

Director of Hematology Department, St. Jude Children's Research Hospital

Yvonne is a researcher, lawyer, nurse, and patient advocate focused on sickle cell disease, including the establishment of a Newborn Screening program at Aminu Kano Teaching Hospital in Kanu, Nigeria. Yvonne sits on the Governor of TN Genetics Advisory Board and the Steering Council of the Newborn Screening Translational Research Network, American College of Genetics and Genomics; She holds a Bachelor of Nursing Degree from the University of Tennessee and a Law Degree from the University of Cincinnati.



Dr. Michael Coleman

CGT Access Model Project Director, Illinois Department of Healthcare and Family Services

Dr. Michael A. Coleman leads statewide efforts to expand access to innovative gene therapies for Medicaid beneficiaries. He coordinates with federal agencies, healthcare providers, manufacturers, and community partners to achieve meaningful healthcare outcomes for Illinois residents. He holds a Doctorate in Business Administration, with research focused on artificial intelligence, organizational trust, and leadership decision-making.

SPEAKERS



Deanna Darlington

Founder, Links2Equity

Deanna Darlington has more than 25 years of experience in government and external affairs, patient advocacy, policy, and reimbursement consulting, at Amgen Inc. and a number of other Pharmaceutical companies. She specializes in engaging patient advocacy organizations on access and policy issues which includes a focus on health disparities for vulnerable patient populations. Deanna works closely with advocates on key policy issues that support dialogue and engagement to patient access to quality care.



Simone Day

SCD Warrior & Advocate

Simone Day is a Sickle Cell Warrior turned Advocate. She's passionate about addressing barriers to clinical trial participation, elevating patient voices, and ensuring advances in genomic medicine are accessible, inclusive, and impactful.She graduated from Virginia Commonwealth University with a B.S. in Clinical Laboratory Science and currently works as a Regional Account Executive for GeneDx.



Bianca Desai

CGT Access Model Co-Lead, CMMI Division of Drug Innovation

Bianca Desai, MPH is a healthcare policy specialist currently serving as a Co-Lead for the Cell and Gene Therapy (CGT) Access Model at the Centers for Medicare & Medicaid Services (CMS). She holds a Master of Public Health (MPH) in Health Policy from The George Washington University and a Bachelor's degree in Public Policy from the University of North Carolina at Chapel Hill.



Jamie Dornfeld

Chief of Staff and Operations, Sick Cells

Jamie Dornfeld has over 20 years in healthcare and nonprofit operations. A mission-driven leader, she builds systems that work for people with complex medical, behavioral, and social challenges. Jamie brings a deep understanding of integrated care models, multi-site operations, and cross-sector collaboration. A strong voice for health equity, she has led efforts to expand access and strengthen services. Jamie holds an MBA from the University of Chicago Booth School of Business.

SPEAKERS



Dr. George Goshua

Assistant Professor of Medicine (Hematology), Yale School of Medicine

George Goshua, MD, SM, FACP, is a hematologist-oncologist, Assistant Professor of Medicine (Medical Oncology & Hematology) and principal investigator of the first quantitative decision analytic modeling lab in hematology and hematologic oncology in the United States, based at the Yale School of Medicine, Yale Cancer Center, and the Yale Center for Outcomes Research and Evaluation, which anchors a 16-institution Collaborative Research Hub in hematology-oncology health decision science.



James Griffin

SCD Warrior & Advocate

Since 2013, James' advocacy work has focused on eliminating the stigma and biases associated with the disease through speaking engagements at national conferences and universities. James works for Versiti Blood Center of Wisconsin as a Community Health Navigator, where he educates others on the importance of blood donations. He is also a published author. He's best known for his powerful book, Breaking Silence: Living With Sickle Cell Anemia.



Mel Hayes

Rare Disease Innovator and Biotech Executive; Co-Founder, AiRare

Mel H. Hayes is a biotech and AI technology executive with more than 30 years of leadership experience. He is Co-Founder of AiRare by Lumiio, an agentic AI platform designed specifically for rare disease that focuses on transforming the fragmented information generated between traditional healthcare encounters into actionable, longitudinal health insights. Mel earned his MBA in Strategy and Finance from Columbia University and holds undergraduate degrees from Southern Methodist University.



Ryann Hill

Founder/CEO, Indigo Hill Strategies

Ryann Hill, MPH, is a public health advocate and policy strategist. A Chicago native, she advances equitable policies for marginalized communities. She has advised U.S. Senator Tammy Duckworth on expanding care access and strengthening disability rights. Ryann holds a Bachelor of Science in Health Policy from Carnegie Mellon University, a Master of Public Health from The George Washington University, and is an active member of Alpha Kappa Alpha Sorority, Incorporated.

SPEAKERS



TaLana Hughes

Executive Director, Sickle Cell Disease Association of Illinois (SCDAI)

TaLana Hughes has dedicated over 20 years to advancing the mission of the Sickle Cell Disease Association of Illinois (SCDAI). She began her journey as an intern, educator and case manager, and now leads the organization's vision, advocacy, and statewide programs. Her passion is also deeply personal: as a mother of a child born with sickle cell disease who is now thriving post bone marrow transplant, TaLana brings unmatched dedication, empathy, and determination to her work.



Houston James

Legislative Aide, Office of U.S. Representative Rich McCormick (GA-07)

Houston James serves in the office of U.S. Representative Rich McCormick (GA-07). In this role, he manages a diverse legislative portfolio with a primary focus on healthcare, education, immigration, and judiciary policy. His prior experience on Capitol Hill includes working as a Staff Assistant for Representative Jack Bergman and serving as a legislative correspondent.



Cmdr. Matthew Johns

Strategic Partnerships Lead, HHS Office of Minority Health

Commander Matthew Johns is a senior public health official and an officer in the U.S. Public Health Service (USPHS) Commissioned Corps. He currently serves as the Regional Health Administrator (RHA) for HHS Region 9, where he leads federal public health strategies, emergency preparedness, and health equity initiatives across the Western United States and Pacific territories.



Dr. Julie Kanter

President, National Alliance of Sickle Cell Centers (NASCC)

Dr. Julie Kanter is Professor of Medicine and Pediatrics and Clinician Scientist at the University of Alabama at Birmingham School of Medicine. She is the co-director of the Lifespan Comprehensive Sickle Cell Center. Dr. Kanter has two main research focuses: advancing novel therapies through improved understanding of biology and clinical endpoints and using dissemination and implementation science to improve access to care in sickle cell disease.

SPEAKERS



Dr. Michelle Lee

Transplantation and Cellular Therapy, Pediatric Hematology/Oncology, Northwell Health

Dr. Michelle Lee is an attending physician at Cohen Children's Medical Center/Northwell in Queens, New York. There, she educates, empowers, and treats persons who have sickle cell disease with curative cellular therapies. Transferring living cells from a donor, or from a person's own body after the cells have been genetically modified, can cure disease and offer a new chance at a healthier life.



Cory Lewis

SCD Warrior & Advocate

Cory Lewis' work draws on lived experience and a decade of work across patient engagement, health policy, research, education, and rare disease advocacy. It also centers on a simple principle: improving sickle cell outcomes requires not only treating disease, but creating the conditions for people to live well. His nonprofit, RedMoon Project, Inc., advances whole-person wellness, health literacy, and sustainable quality of life for adults living with sickle cell disease.



Ted Nicolas

SCD Warrior & Advocate

Diagnosed with sickle cell disease at birth in Haiti, Ted defied the odds to survive into adulthood through unwavering determination and support. At age 50, his life was transformed by a groundbreaking experimental stem cell transplant through the National Institutes of Health (NIH). Today, fueled by renewed health and Christian faith, Ted co-operates a Maryland-based business with his wife, Marie, serving his community with excellence while cherishing life as a dedicated husband and father.



Rushmie Nofsinger

Biotech Executive and Former Chief Corporate Affairs Officer

Rushmie is a corporate affairs executive and trusted advisor with more than 25 years of experience helping leaders and organizations communicate with clarity and build meaningful, trust-based relationships. She has held senior corporate affairs roles across the biopharmaceutical industry spanning corporate communications, investor relations, patient advocacy, thought leadership, corporate reputation, culture and brand building, and employee engagement.

SPEAKERS



Dr. Tayiana Reed

Pharmacist, District of Columbia Department of Health Care Finance

Dr. Tayiana Reed is a clinical pharmacist with the DC Department of Healthcare Finance (DHCF), where she serves as the clinical lead for the District's participation in the CMS Cell and Gene Therapy Access Model. She brings extensive experience in Medicaid pharmacy policy, pharmaceutical outcomes, and the implementation of innovative therapies, with a focus on improving access to high-quality evidence-based care.



Maisie Ruddy

Legislative Aide, Office of U.S. Representative Glenn Ivey (MD-04)

Maisie Ruddy leads Congressman Glenn Ivey's (MD-04) activities on healthcare, foreign policy, transportation, and energy issues. Her portfolio includes supporting his work as a member of the Appropriations Committee and his leadership as Co-Chair of the Congressional Sickle Cell Disease Caucus. Before joining the Hill, Maisie worked as a contractor for USAID's Office of Gender Equality and Women's Empowerment (GenDev) and the White House Office of Presidential Correspondence.



Mariah Scott

Research Consultant, Sick Cells

Mariah Scott's ambition for sickle cell research is inspired by living with Sickle Cell Disease (SS). Her patient advocacy and drive to share her own story as researcher and a mother were ignited while living with debilitating pain and experiencing racial biases while seeking healthcare. She is pursuing her Ph.D. in Prevention Science at Rutgers University to implement healthcare policies and measure patient-reported outcomes for the pediatric and adult sickle cell community.



Jamie Sullivan

SVP of Policy & Advocacy, RARE Foundation

Jamie Sullivan, MPH, leads federal and state policy initiatives to accelerate the development of and access to life-saving treatments for people with rare diseases. With two decades of experience in public health and health policy, Jamie brings deep expertise in legislative strategy, regulatory affairs, and patient engagement. She is a passionate advocate for equitable healthcare and works to ensure that the voices of patients with rare diseases and their families are reflected in policy decisions that impact their lives.

SPEAKERS



Dagmawit Teka

Community Programs Manager, Sick Cells

Dagmawit Teka is a Community Programs Manager at Sick Cells with a deep passion for health equity, maternal and child health, and the advancement of underserved communities. Her work reflects a strong foundation in grant writing, health policy, and reproductive health, and is guided by a commitment to justice and community-centered impact. She holds a Master of Public Health (MPH) degree from The George Washington University, where she specialized in maternal and child health.



Latoya Thomas

Head of Public Policy & Government Affairs - US, Terumo Blood and Cell Technologies

Latoya Thomas is a nationally recognized health policy leader with over 15 years of experience driving regulatory and legislative strategy at the intersection of technology and patient care. As the US Head of Public Policy and Government Affairs at Terumo Blood and Cell Technologies, she leads strategic government relations to advance innovation in blood management, cell therapies, and medical devices.



Josh Trent

CEO, Leavitt Partners

Josh Trent is CEO of Leavitt Partners, a premier bipartisan health policy and government affairs firm in Washington, D.C. Josh previously served as Chief Health Counsel the Committee on Energy and Commerce of the U.S. House of Representatives where he worked for two Chairmen and played a key part in developing the Medicaid, Medicare, and CHIP policies included in multiple bipartisan laws. He's also acted as a health policy advisor for a U.S. Senator and served in the Administration of President George W. Bush.



Ashley Valentine

Co-Founder/CEO, Sick Cells

Ashley, Co-Founder and CEO of Sick Cells, turned her family's experience with SCD into a life of advocacy. With a Master's in Research Methods, she worked in research and policy, helping secure CMS support to reduce ER disparities. Since 2017, she has led Sick Cells, including successfully leading the SCD community in its first-ever ICER review, building coalitions to advocate for federal legislation to be signed into law, testifying at the FDA about the importance of drug development, and more.

SPEAKERS



Dr. Donna Whyte-Stewart

Senior Physician, Division of Nonmalignant Hematology, FDA Center for Drug Evaluation and Research (CDER)

Donna Whyte-Stewart, MD, ScM is a pediatric hematologist and Senior Physician in the Division of Nonmalignant Hematology in the Office of New Drugs at the U.S. Food and Drug Administration (FDA). At FDA, she is a part of the following: American Society of Hematology Research Collaborative's Program on Sickle Cell Disease, HHS (Human Health Services) Sickle Cell Disease Federal Interagency Working Group, and Kidney Health Initiative's (KHI) Sickle Cell Disease Project.

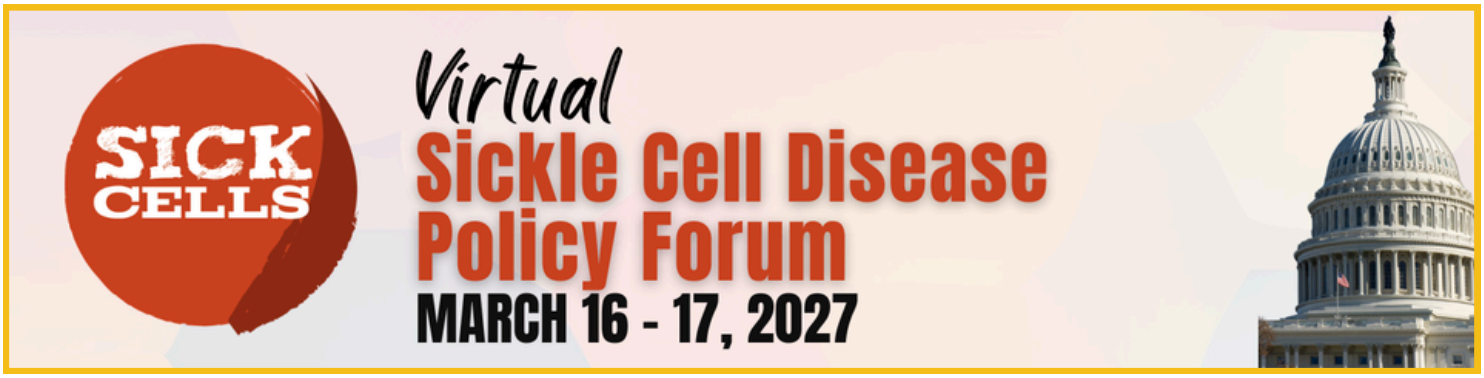


Capt. David Wong, MD

Senior Advisor for Sickle Cell Disease, HHS Office for Human Research Protections and Office of the Assistant Secretary

CAPT David Wong, MD, is Senior Advisor to the Director at the HHS Office for Human Research Protections (OHRP) in the Office of the Assistant Secretary for Health (OASH). OHRP provides leadership in the protection of the rights, welfare, and well-being of human subjects involved in research conducted or supported by HHS. OHRP oversees approximately 12,000 institutions (domestic and international) and 5,000 institutional review boards (IRBs).

We'd like to see more of you! Save the date for our 2027 Policy Forum!



WHAT'S NEXT IN SCD: COMPANY PRESENTATIONS



Drewry Carter

Agios

Drewry Carter, PharmD, is a member of the Global Medical Affairs team at Agios, where she serves as a Medical Science Liaison. In this role, she collaborates with healthcare professionals and the broader medical community to advance scientific education and research in sickle cell disease. Her previous experience as an inpatient pediatric pharmacist gave her firsthand insight into the significant impact sickle cell disease can have on patients and families, inspiring her commitment to helping drive meaningful change for the sickle cell community.



Ravi Singh

Genetix Biotherapeutics

Ravi Singh serves as Vice President of Market Access, Advocacy, & Policy at Genetix Biotherapeutics, where he has held roles of increasing responsibility since joining the company, then known as bluebird bio, in 2018. Ravi has participated in health policy and industry discussions focused on access to innovative therapies, including issues related to the value and reimbursement of treatments for serious diseases such as sickle cell disease.



LaTasha Lee

Sanofi

LaTasha Lee is a PhD-trained neuroscientist and epidemiologist with nearly two decades advancing patient-centered policy and advocacy. She leads global public affairs strategy for Sanofi's rare neuromuscular and sickle cell disease portfolios. Previously she led US patient advocacy for one of the first gene therapies approved for SCD, served as VP of Social and Clinical Research at the National Minority Quality Forum, and led the Sickle Cell Disease Coalition initiative at the American Society of Hematology. She is an Adjunct Professor at George Washington University School of Medicine and a Florida native based in Washington, DC.



Shantá Robertson

Vertex Pharmaceuticals

Shantá Robertson, M.A., has been a sickle cell disease (SCD) community advocate for over 20 years. In 2006, she co-founded and served as Executive Director of the Maryland Sickle Cell Disease Association, Inc. (MSCDA). Professionally, Shantá has worked in the healthcare industry for over 30 years. In July of 2023, Shantá joined Vertex Pharmaceuticals as a Patient Educator.

WHAT'S NEXT IN SCD: COMPANY PRESENTATIONS



Ene Omakwu

Novo Norodisk

Dr. Ene Omakwu, PharmD, BCPS, is a licensed pharmacist and Medical Science Liaison at Novo Nordisk specializing in sickle cell disease and thalassemia. In her current role, she partners with hematologists, pharmacists, nurses, and other healthcare professionals to support scientific exchange and advance evidence-based care for individuals living with sickle cell disease.



Barima Opong-Owusu

Pfizer

Barima Opong-Owusu, PharmD, BCPS is a Field Medical Director for Pfizer and a clinically trained pharmacist. He's been in the Sickle Cell space since his days at Global Blood Therapeutis, prior to the Pfizer acquisition. He has navigated the initial withdrawal and listened to the community post voluntary withdrawal up to now. He is committed to improving care and outcomes in sickle cell disease. He partners with clinicians and advocacy organizations and health systems to translate medical insights into meaningful, patient - centered impact with a strong commitment to education and health equity.



Lianne McLean

Terumo Blood & Cell Technologies

Lianne McLean, RN, BN, MN is a Medical Education Leader at Terumo Blood and Cell Technologies.

MEET THE SCD COMMUNITY VOICES



Constance D. Benson
SCD Warrior

A sickle cell advocate and bone marrow transplant recipient. Constance became the first person cured of SCD via the Stride-HCT & Bone Marrow Transplant Study in 2012.



Brittani Malcolm
SCD Warrior

A sickle cell warrior and advocate, who works in the construction and cosmetology industries. Brittani shares how coverage and recent policy updates have impacted her SCD journey.



Dr. Dana LeBlanc
Clinician

Dr. LeBlanc currently serves as the Director of the Pediatric Sickle Cell Program, as well as Medical Director, of the Vascular Anomalies Center at Manning Family Children's Hospital in New Orleans, LA. She is also an Associate Professor of Pediatrics in the Division of Hematology/Oncology at Lousiana State University Health Sciences Center.

ACCESS UNLOCKED: MARIAH'S STORY



Sick Cells sat down with Mariah Jacqueline Scott, MS, MPH, a sickle cell warrior and Sick Cells Research Consultant, to discuss her personal experiences navigating barriers to care and how those experiences have shaped her advocacy and research. Mariah is currently pursuing her Ph.D. in Prevention Science at Rutgers University, where her work focuses on improving care and outcomes for people living with sickle cell disease.

What does access to sickle cell treatments mean to you?

Access is not just receiving treatments It's unlocking quality of life. How can I unlock being the best mom I could for my daughter, Autumn? Or how can I unlock doing the things that I love again, despite having sickle cell and having less coverage and access? And I think that's very important, not just for our community, but also for a lot of payers, researchers, and any other decision-makers, because they have to understand that in order to get access to these therapeutics, it means more than just paying for a drug. It means that we're paying for the best life that we can have.

What treatments have helped unlock a better quality of life for you?

One of the disease modifiers that I'm on is Adakveo. I've been on it since it came out in 2019 and it's been a game changer for me, knock on wood. But I've had challenges getting access to it.

I live in New Brunswick at the center of New Jersey and I go to school in Camden, which is about an hour and five minutes southwest from me. I have a hematologist down in Camden and they have an infusion center. So I tried to get Adakveo when I'm down there so it's a one-stop deal. But unfortunately, my insurance doesn't cover it because that location is billed as a hospital and not as an outpatient clinic. So now I have to make monthly appointments back in North Jersey and travel across the whole state to get the treatment I need.

Have you encountered other challenges accessing the care you need?

Right now, I'm in a legal battle with my health insurance because they won't cover the back surgery that I need. Even though it's fairly common and a procedure that is done often in cancer cases and elderly patients: they're just going in and putting cement to stabilize the bone. But they're not covering it because they don't see it as medically necessary.

In my research, when I was looking at why they don't see it as medically necessary, insurance companies do a lot of systematic reviews: they base coverage on a few conditions like cancer, osteoporosis, old age—but nothing with sickle cell. So now I have to find lawyers and actually have a court case to get coverage on that back surgery.

In the meantime, it's really impeding my quality of life. It's painful enough to wake me up at night. Picking Autumn up and playing, it hurts. My husband took the week off to help me with the surgery, but the insurance company denied coverage and canceled the surgery the day before, and he wasn't able to reschedule his time off—which meant we had to cancel our honeymoon, since he didn't have enough days left for the year.

As a researcher and Ph.D. student, how have your personal experiences navigating health care shaped your understanding of the challenges others face?

I still have a hard time navigating insurance! But I just finished up one of my research projects where there were focus groups with warriors from 13 to 26. We also did a focus group with caregivers. There were a lot of comments like, "I don't know what a copay is, I don't know what a deductible is. If I have a problem with my Medicaid that helps me with transportation, where is that hotline number?"

Maybe that should ring a bell and ring some type of alarm for Medicaid. If someone's 18 or just turned 18, let's send an email or call them and say, "Hey, would you like to see this webinar, a link we have about copays and deductibles?"



Mariah and her daughter

(Continued)

There are also lots of information gaps about drug and treatment options from providers. For example, a lot of warriors and caregivers heard about gene therapies, of course, from the news and social media, but a lot of them did not hear about Adakveo. A lot of them did not hear about Endari or the clinical trials where patients could take both hydroxyurea and Adakveo/Endari.

Some of those gaps are related to pricing. I've heard a couple of providers saying, "Well, I don't suggest Adakveo because of the price." Well, can you at least explain it to the patient to see if they even want to try it? There's programs out there to help pay for that.

We need to continue educating what pricing means in everything that we do (as insurers, clinicians, advocates, and warriors) and making it as forward-looking as possible. For example, with my back surgery: my insurance will pay me to get a full liter of hydration and three doses of Dilaudid. That's a lot cheaper than paying for anesthesia and the cement in the short-term, but long-term it's not — it'll be $2,000 every two weeks to manage the pain instead of the one-time cost of a surgery.

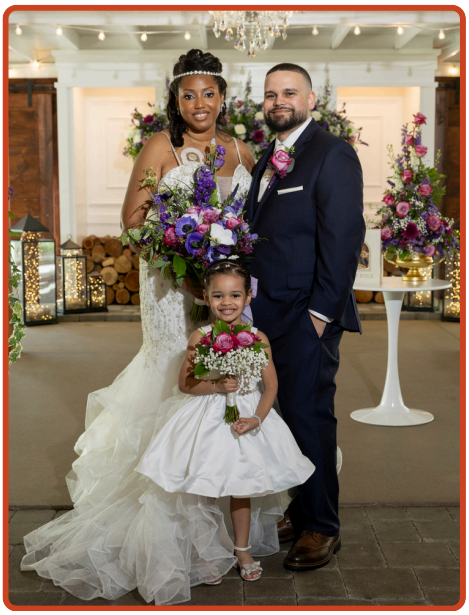


Mariah and her family

Your research focuses on strengthening resources for the SCD community. Can you tell us more about the interventions you're developing?

I'm focused on warriors' transition from pediatric care to adult care for sickle cell disease. My own experience with that transition included a crisis when I was a teenager. A doctor treating me didn't know you couldn't give prednisone to people with sickle cell because it can cause crises. When I woke up from the crisis the steroid caused, I was in the ER because I passed out from pain. I was seen as an adult and assigned an adult provider, a hematologist who said, "Hi, I'm Dr. So-and-so."

And then that was it—my transition from pediatric to adult care. My new provider had one phone call with my pediatric doctor and I never looked back.



Mariah and her family

That was in 2010. Now we're in 2026, we're still seeing teens having a high rate of mortality and a bad quality of life during this transition. Think back to what your perspective is like when you're a teenager: I want to do everything. I think I'm Superman, but I also don't want to talk about my sickle cell. I'm embarrassed. I really just want to help make programs and implement more research and programs for teens during this time. In my Prevention Science program, we learned how to do just that.

I'm designing an intervention that addresses a big community piece that's missing from teenagers' transition [from pediatric to adult care]. A lot of that transition happens in hospitals or clinics. Here's your pediatric provider, here's your adult provider, and that's it.

Right now, there aren't many spaces for girls living with sickle cell to connect with others that look like them, like a girls' night out where they can talk about school, college, reproductive health, or even dating.

That same community-centered piece is also missing for caregivers. It's not just the warrior transitioning. The whole family is transitioning. They need space to ask questions like, "What does that look like for my child going to college?"

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A clinical trial has four phases:

Phase 1:

Determines whether a medical approach (e.g., drug, diagnostic test, device) is safe, identifies side effects, and establishes appropriate dosing.

Phase 2:

Examines whether the medical approach works and continues monitoring for side effects to help design larger Phase III trial.

Phase 3:

Confirms whether the medical approach works, compares it to existing treatments, and continues safety monitoring.

Phase 4:

Occurs after a treatment or medical approach is approved for use and monitors long-term effectiveness, side effects, and real-world outcomes.

Find a clinical trial: search clinicaltrials.gov or reach to your local sickle cell community-based organization (CBO) for guidance on trials currently recruiting in your local area.



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Visit our booth to:

- **Connect with** the Patient Educators and other members of your community
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We are honored to join Sick Cells in its mission to improve the quality of life and care for people living with sickle cell disease by elevating, educating, and empowering the SCD community, and look forward to seeing you at the Coverage & Therapeutics Conference, November 4-5, at the Hyatt Regency Bethesda.

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Our name has changed, but our mission remains the same–**transforming lives through curative therapies** for people with sickle cell disease.

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"I never asked for this. I never wished for pain, or sickness, or fear. But maybe I was chosen for a reason, chosen to bear the weight of sickle cell—not as a punishment, but as an opportunity. Maybe my story will make an impact on someone's life."
—Markus, sickle cell warrior

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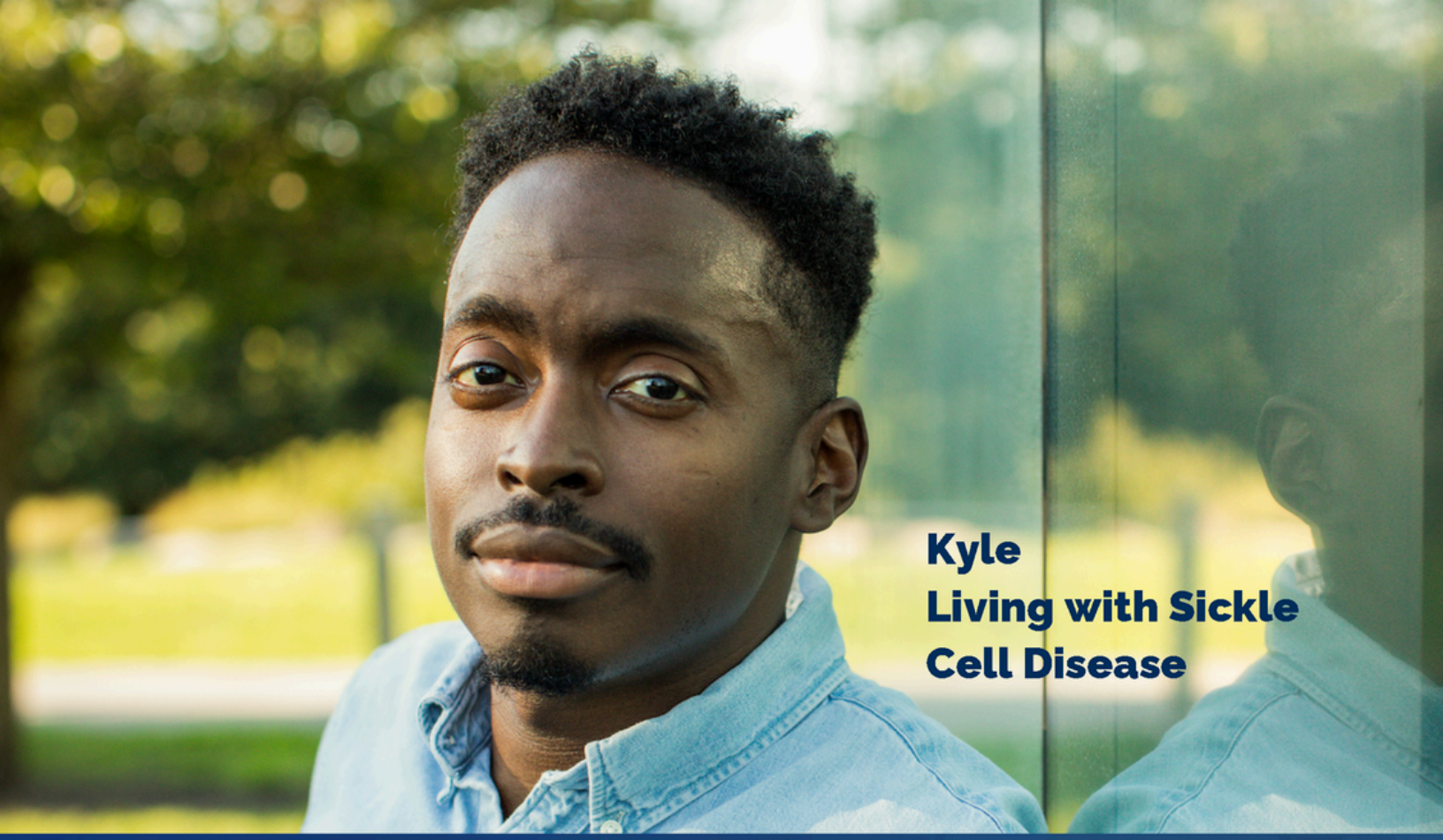
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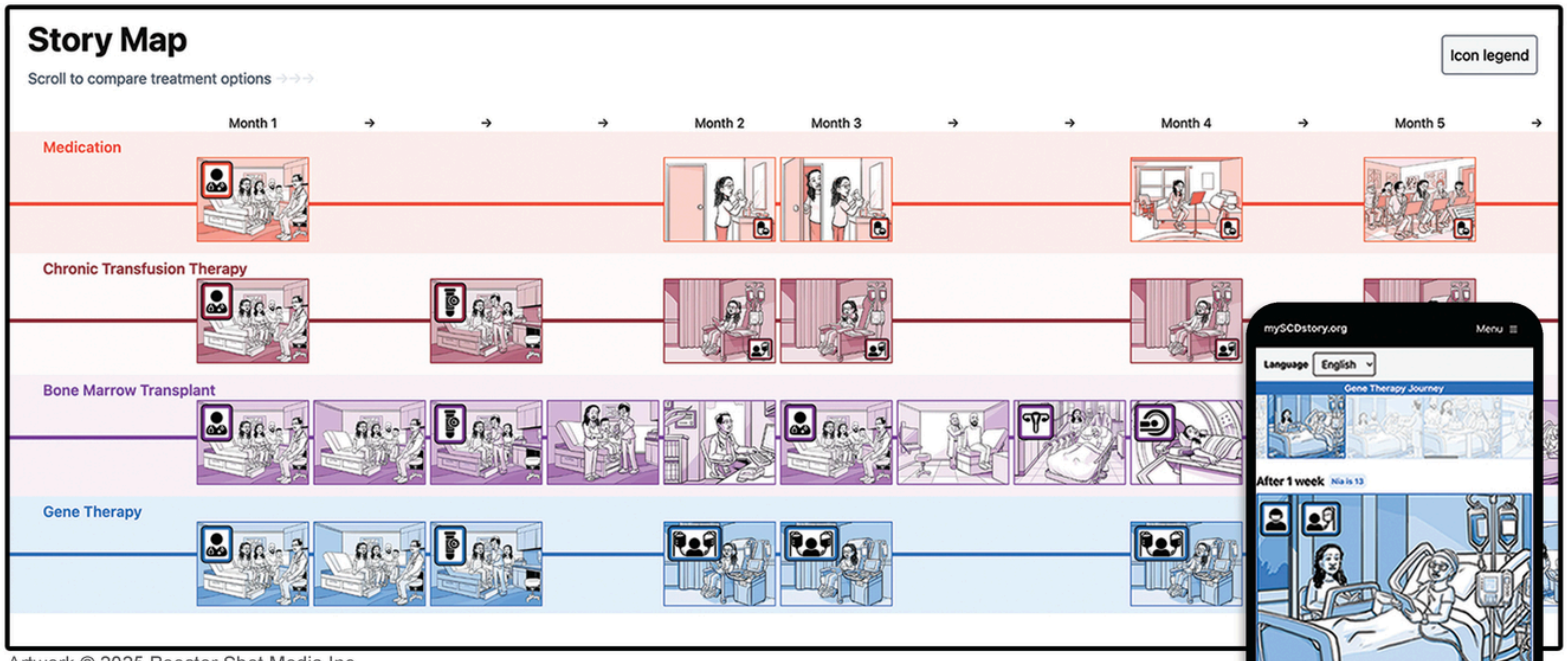
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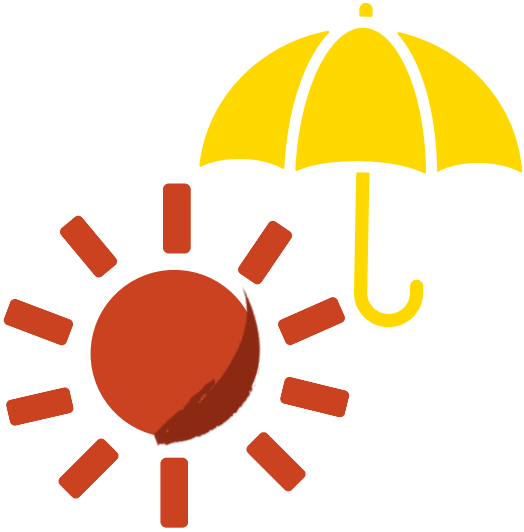
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