SICKLE CELL DISEASE 115 YEARS LATER SYMPOSIUM

Improving Health Outcomes Through Policy, Research & Collaboration

November 12, 2025 9AM - 5 PM

NYU Medical Science Building
540 1st Avenue Schwartz Hall E,
New York, NY 10016

Co-hosted by NYU GPH Implementing Sustainable Evidence-based Interventions through Engagement (ISEE Lab) and NYU Langone Institute for Excellence in Health Equity (IEHE)

TABLE OF CONTENTS

Scan here to download this booklet onto your mobile device:

COMMEMORATING THE 115TH ANNIVERSARY OF A LANDMARK MOMENT IN MEDICAL HISTORY

In 1910, Dr. James Herrick published the first documented medical description of sickle cell disease (SCD), based on the case of Walter Clement Noel, a first-year dental student from Grenada. Noel was the first patient formally diagnosed with the condition. This landmark observation laid the foundation for over a century of scientific inquiry, clinical care, and advocacy dedicated to understanding and managing this complex genetic disorder.

While significant progress has been made in SCD research, treatment, and patient outcomes, persistent challenges remain—particularly in ensuring equitable access to care, advancing evidence-based interventions, and addressing health disparities.

SCD: 115 Years Later Symposium

The SCD 115 Years Later Symposium will bring together leaders from across sectors to explore innovative, evidence-based solutions for improving the health and quality of life of people living with SCD. The event honors both the scientific contributions of Dr. Herrick and the legacy of Walter Clement Noel, whose case continues to shape the trajectory of SCD research, care, and advocacy.

Understanding the Burden: Sickle Cell Disease and Trait

Approximately 10% of individuals with SCD in the U.S. live in New York State, with the majority residing in the New York City (NYC) metropolitan area. According to NYC Health data, nearly 100 babies were born with SCD in NYC in 2023, with the Bronx and Brooklyn showing the highest incidence, particularly of HbSS, the most severe genotype.

Sickle cell trait (SCT) remains widely prevalent, affecting an estimated 3 million Americans. Nationally, about 1 in 12 people of African descent carry the trait, though it also occurs in Hispanic, South Asian, Southern European, and Middle Eastern populations. Globally, over 100 million individuals have SCT, particularly in malaria-endemic regions where the trait offers a genetic survival advantage.

SYMPOSIUM OBJECTIVES

The SCD Symposium aims to bring together patients, clinicians, researchers, policymakers, advocates, and community leaders to advance dialogue on improving health outcomes for individuals living with SCD. The event seeks to foster collaboration, highlight innovation, and identify actionable policies and strategies to address persistent disparities in SCD care. The objectives and themes are as follows:

1. Promote Evidence-Based Interventions
Highlight the role of policy, healthcare systems, and community-led programs in reducing disparities in SCD care and outcomes.

2. Foster Collaborative Dialogue
Facilitate cross-sector conversations among researchers, clinicians, policymakers, industry leaders, advocates, and affected communities.

3. Raise Awareness and Drive Equity
Highlight the disproportionate burden of SCD in Black and Brown communities and propose data-driven solutions to improve equity and care.

Symposium Themes

- Advances in SCD Research and Therapeutic Innovation
- Healthcare Disparities and Access to Comprehensive Care
- Public Policy and Legislative Efforts in SCD Management
- Community Engagement and Advocacy for SCD Awareness
- Strategies to Improve Regional and National SCD Surveillance

SYMPOSIUM OVERVIEW

8:15 AM – 9:00 AM | **Registration & Breakfast Networking**

9:00 AM – 10:00 AM | **Opening Remarks & Keynote Addresses**

10:00 – 11:00 AM | **Session I – Health Equity in Sickle Cell Disease: Addressing Systemic Disparities with Clinicians, Community, and Government Partners**

Moderator: Naheed Ahmed, PhD, MPH. Assistant Professor, NYU Grossman School of Medicine

11:00 AM – 11:15 AM | **Morning Break, Networking**

11:15 AM – 12:15 PM | **Session II – Policy Solutions for Sickle Cell Disease**

Moderator: Jose Pagan, PhD. Professor and Chair, NYU School of Global Public Health

12:15 PM – 1:30 PM | **Lunch, Networking & Poster Session**

1:30 PM – 2:30 PM | **Session III – Enhancing Care Delivery Across the Lifespan**

Moderator: Torian Easterling, MD. Senior Vice President of Population & Community Health/Chief Strategy & Innovation Officer, One Brooklyn Health

2:30 PM – 2:45 PM | **Afternoon Break & Networking**

2:45 PM – 3:45 PM | **Session IV – Linking Policy to Practice Through Collaborations & Partnerships**

Moderator: Angela Odoms-Young, PhD. Associate Professor, Cornell University

3:45 – 4:00 PM | **Closing Remarks & Next Steps**

PROGRAM SCHEDULE

8:15 AM – 9:00 AM | **Registration & Breakfast Networking**

9:00 AM – 10:00 AM | **Opening Remarks & Keynote Addresses**

Opening Remarks: Emmanuel Peprah, PhD. Director, Implementing Sustainable Evidence-based Interventions through Engagement (ISEE Lab) & Associate Professor, NYU School of Global Public Health (SGPH)

Welcome NYU GSOM: Gbenga Ogedegbe, MD, MPH. Director, Institute for Excellence in Health Equity (IEHE) & Professor, NYU Grossman School of Medicine (GSOM)

Welcome NYU SGPH: Michael H. Merson, MD. Interim Chair, Department of Social and Behavioral Sciences & Clinical Professor of Global and Environmental Health, NYU SGPH

Keynote Address: Michelle S. Davis, PhD. Deputy Commissioner Office of Public Health New York State Department of Health

---

10:00 – 11:00 AM | **Session I – Health Equity in Sickle Cell Disease: Addressing Systemic Disparities with Clinicians, Community, and Government Partners**

Moderator:
- Naheed Ahmed, PhD, MPH. Assistant Professor, NYU GSOM

Panelists:
- Dr. DaMia Harris-Madden, Commissioner, NYS Office of Children and Family Services
- Lewis Marshall, MD. Chief Medical Officer (CMO), NYC Health + Hospitals/Lincoln
- Kusum Viswanathan, MD, FAAP, CMO, One Brooklyn Health (OBH), Brookdale, Director, Comprehensive Pediatric Sickle Cell Program-OBH, Professor of Clinical Pediatrics SUNY- Downstate Health Sciences University
- Nana Osei-Tutu, MPH, SCD Patient and Advocate Infection Preventionist NYC Health + Hospitals/Kings County

---

11:00 AM – 11:15 AM | **Morning Break, Networking**

11:15 AM – 12:15 PM | **Session II – Policy Solutions for Sickle Cell Disease**

Moderator:
- Jose Pagan, PhD. Professor and Chair, NYU SGPH

Panelists:
- Kenneth Rivlin, MD, PhD. Vice Chair, Dept. of Pediatrics, NYC Health + Hospitals/Jacobi
- Ravi Singh, Vice President, Market Access, Advocacy & Policy, Genetix Biotherapeutics
- Melinda Rushing, PhD, LMSW. Assistant Professor, Rutgers University
- Amy Cohen, MPH SCD Patient and Advocate

PROGRAM SCHEDULE

12:15 PM – 1:30 PM | **Lunch, Networking & Poster Session**

1:30 PM – 2:30 PM | **Session III – Enhancing Care Delivery Across the Lifespan**

Moderator:

- Torian Easterling, MD. Senior Vice President of Population & Community Health/Chief Strategy & Innovation Officer, One Brooklyn Health

Panelists:

- Henny H. Billett, MD. Director, Hemophilia Treatment Center, Montefiore/Albert Einstein College
- Tartania Brown, MD. Director, Palliative Care & Clinical & Assistant Professor, MJHS Hospice and Palliative Care Albert Einstein College of Medicine, Candice Sickle Cell Foundation
- Toni Eyssallenne, MD, PhD. Deputy Chief Medical Officer, NYC Department of Health and Mental Hygiene
- Sharee Turpin, SC Patient Navigator, University of Rochester Medical Center (URMC) Golisano Children Hospital

---

2:30 PM – 2:45 PM | **Afternoon Break & Networking**

2:45 PM – 3:45 PM | **Session IV – Linking Policy to Practice Through Collaborations & Partnerships**

Moderator:

- Angela Odoms-Young, PhD. Associate Professor, Cornell University

Panelists:

- Jamillah Hoy-Rosas, MPH, RD. Head of Population Health, Ronald McDonald House–NYC
- Andrew D. Campbell, MD. Director, Comprehensive Sickle Cell Center & Associate Professor, Children's National Hospital & George Washington University
- Gladys A. Magee, Director, Sickle Cell Advocates of Rochester, New York
- Maia Z. Laing, Chief Policy Officer, Sick Cells
- Ify Osunkwo, MD. Chief Patient Officer Novo Nordisk

3:45 – 4:00 PM | **Closing Remarks & Next Steps**

Next Steps: Angela Odoms-Young, PhD. Associate Professor, Cornell University

Closing Remarks: Emmanuel Peprah, PhD. Associate Professor, NYU SGPH

SESSION TOPICS

Session I – Health Equity in Sickle Cell Disease: Addressing Systemic Disparities with Clinicians, Community, and Government Partners

- **Objectives:**
  i. Disparities & Determinants – Examine inequities and social drivers in SCD outcomes.
  ii. Collaboration – Showcase joint efforts by clinicians, communities, and advocates.
  iii. Equity in Action – Share systemic and policy strategies to improve care.

Session II – Policy Solutions for Sickle Cell Disease

- **Objectives:**
  i. Policy Impact – Examine how legislation shapes SCD care and outcomes.
  ii. NYS Focus – Highlight key Senate bills and their role in care coordination.
  iii. From Policy to Practice – Explore strategies to translate laws into improved care delivery.

Session III – Enhancing Care Delivery Across the Lifespan

- **Objectives:**
  i. Lifespan Care – Strategies to strengthen SCD management from childhood through adulthood.
  ii. Transition Focus – Address challenges in moving from pediatric to adult care.
  iii. Early Detection & Gaps – Improve outcomes through timely diagnosis and closing care gaps.

Session IV – Linking Policy to Practice Through Collaborations & Partnerships

- **Objectives:**
  i. Collaborative Care – Engage patients, advocates, and crosssector partners in SCD management.
  ii. Patient-Centered Approaches – Promote culturally responsive, community-informed strategies.
  iii. Policy into Practice – Leverage partnerships to advance holistic, equitable care.

SPEAKERS & MODERATORS

Naheed Ahmed, PhD, MPH
Assistant Professor, NYU GSOM

Dr. Naheed Ahmed, (she/her) is an Assistant Professor in the Department of Population Health at the NYU Grossman School of Medicine. She is a mixed methods researcher with an interdisciplinary background in family science, public health, and medical anthropology. She studies discrimination, digital health, chronic diseases, mental health, and comorbid disorders. Her research uses community-engaged approaches and is primarily with immigrant and minority racial/ethnic populations with a focus on South Asian and Muslim communities.

Henny H. Billett, MD
Director, Hemophilia Treatment Center,
Montefiore/Albert Einstein College

Dr. Henny Billett has been Chief of the Division of Hematology since 2012 and Professor of Clinical Medicine and Pathology since 2002. Dr. Billett's clinical research interests are in risk factors for thrombosis and microvascular disease, with emphasis on epidemiological aspects and outcomes research. Her recent investigations have focused on hemolysis patterns in CF-LVAD patients and their association with device thrombosis (collaboration with Dr. Ulrich Jorde, Cardiology), evaluation of CNS function and cognition in patients with sickle cell disease (collaboration with Dr. Craig Branch, Gruss, magnetic Resonance Research Center), priapism in murine and human models of sickle cell (collaboration with Dr. Kelvin Davies), multicenter studies, P-Selectin therapy in sickle cell disease, and viral co-infections, paraproteinemia and thrombosis.

SPEAKERS & MODERATORS

Tartania Brown, MD
Director, Palliative Care & Clinical & Assistant Professor
MJHS Hospice and Palliative Care, Albert Einstein College of Medicine, Candice Sickle Cell Foundation

Dr. Tartania Brown is a board-certified physician in Internal Medicine and Hospice & Palliative Medicine, with specialized training in pain and palliative care from Montefiore Medical Center. She holds a B.A. from NYU, an M.D. from SUNY Downstate, and a certification in Bioethics from Yeshiva University. Dr. Brown currently serves as Director of the Palliative Care Provider Practice at MJHS Health System and is licensed to prescribe medical cannabis for chronic pain.
An advocate for patients with non-visible disabilities, including sickle cell disease, Dr. Brown is a board member of the Candice Sickle Cell Fund and has lobbied for healthcare policy reform. She is also an author, motivational speaker, and recipient of the 2020 BBC Inspirational Award.

Andrew Campbell, MD
Director, Comprehensive Sickle Cell Disease Program
Children's National Hospital, Washington, DC

Dr. Andrew Campbell is an internationally recognized expert in SCD and serves as Director of the Comprehensive Sickle Cell Disease Program and Global Health Research Lead at Children's National Hospital in Washington, DC. He is also an Associate Professor of Pediatrics at the George Washington University School of Medicine and Health Sciences. A graduate of Morehouse College and Case Western Reserve University School of Medicine, Dr. Campbell completed his pediatric residency at Massachusetts General Hospital and a Pediatric Hematology/Oncology Fellowship at Northwestern University's Lurie Children's Hospital. His research focuses on translational science, population health, and health outcomes to improve care for individuals living with SCD. Dr. Campbell has been a featured speaker at the Science Summit at the United Nations General Assembly (2023, 2024) and the U.S. Department of Health and Human Services' inaugural SCD Summit (2024). He serves on the Government Relations Committee of the American Society of Gene and Cell Therapy and has contributed to national advocacy efforts, including the Sickle Cell Treatment Centers Act and Congressional briefings on SCD.

SPEAKERS & MODERATORS

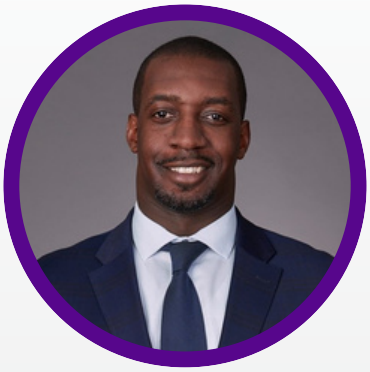
Amy Cohen, MPH
SCD Patient and Advocate

Amy Cohen is a dedicated patient advocate and public health professional who founded The Patient Room, a consultancy specializing in trust-centered patient engagement for clinical trials. Living with SCD, she leverages personal insight and over a decade of professional experience leading patient recruitment and engagement initiatives across hospitals, academic centers, and nonprofits. Amy helps industry partners rebuild trust, recognizing it as essential to designing inclusive clinical trials and achieving better health outcomes. Among her professional accomplishments are testifying at the Massachusetts State House to improve sickle cell care, advising leading organizations, and speaking nationally on research equity. Amy holds a Master of Public Health in Policy and Management from NYU, where she was one of the inaugural students of the Implementing Sustainable Evidence-based Interventions through Engagement (ISEE) Lab. She also earned a Bachelor of Science in Public Health from Texas A&M University. Her mission is to elevate patient voices and transform systems of care through partnership, innovation, and evidence-based strategy. Through The Patient Room, Amy seeks to reshape clinical trial engagement by centering patient trust, ultimately fostering more equitable and effective healthcare research and delivery. Her work bridges the gap between patients and healthcare industry stakeholders by ensuring patient perspectives guide future advancements in medicine and policy.

Michelle S. Davis, PhD
Deputy Commissioner
Office of Public Health
New York State Department of Health

Dr. Michelle Davis is a former federal executive and served as chair for the SCD Federal Interagency Working Group and SCD portfolio lead. She has held leadership positions as an HHS Regional Health Administrator, USVI Commissioner of Health, PA Deputy Secretary for Health and Philadelphia Deputy Health Commissioner where she provided leadership and oversight for programs serving vulnerable populations. She has served in leadership roles with state and national professional public health organizations and has received awards for her public health service. She received her graduate education in epidemiology and is certified in Diversity, Equity. Inclusion and Accessibility.

SPEAKERS & MODERATORS



Torian Easterling, MD
Senior Vice President of Population & Community Health, Chief Strategy & Innovation Officer One Brooklyn Health

Dr. Torian Easterling is a family medicine and public health physician currently serving as Senior Vice President for Population and Community Health and Chief Strategic and Innovation Officer at One Brooklyn Health (OBH). OBH is a three-hospital system and extensive network of primary and specialty care providers dedicated to preserving and enhancing healthcare delivery in Central Brooklyn. Prior to joining OBH, Dr. Easterling served as First Deputy Commissioner and Chief Equity Officer at the New York City Department of Health and Mental Hygiene (DOHMH). In this role, he led the City's COVID-19 equity response, ensuring fair vaccine access for the hardest-hit communities, and advanced anti-racist public health practices through the agency's Race to Justice initiative. During his seven-year tenure at DOHMH, he directed efforts to reduce premature mortality and close racial gaps in preventable deaths. Previously, he was an Assistant Professor of Family Medicine at Rutgers New Jersey Medical School, training future clinicians and leading community health initiatives. Dr. Easterling holds degrees from Morehouse College, Rutgers New Jersey Medical School, and the Icahn School of Medicine at Mount Sinai, where he also completed a residency in Preventive Medicine.

Toni Eyssallenne, MD, PhD
Deputy Chief Medical Officer
NYC Department of Health and Mental Hygiene

Dr. Toni Eyssallenne graduated from the University of Rochester School of Medicine and Dentistry's Medical Scientist Training Program (MSTP). She served as faculty in both Internal Medicine and Pediatrics at the University of Miami, where she also founded and directed their Global Health Tracks. She created a pediatric residency program in Haiti focused on evidence-based and critical care medicine, continuing to train pediatricians for the workforce. Dr. Eyssallenne was Program Director of the Internal Medicine-Pediatrics Residency Program at the University of Miami/Jackson Memorial Hospital and Capstone advisor for MD/MPH and MPH students at the University of Miami School of Public Health Sciences. Before joining DOHMH, she was NY Market Medical Director at CityBlock Health, focusing on complex, integrated care for historically marginalized communities. After serving as Senior Medical Advisor in the Office of the Chief Medical Officer at the DOHMH, she now serves as Deputy Chief Medical Officer in the Center for Health Equity and Community Wellness.

SPEAKERS & MODERATORS

Dr. DaMia Harris-Madden
Commissioner
NYS Office of Children and Family Services

Dr. DaMia Harris-Madden is the Commissioner of the New York State Office of Children and Family Services. She has spent 20 years working at the intersections of government, education, business and the non-profit sectors. Dr. Harris-Madden is an experienced nonprofit and community leader who previously served as Executive Director of the Westchester County Youth Bureau and served in four mayoral cabinets in the City of Mount Vernon where she expanded the city's services significantly. She has served as a federal and local grant reviewer and a New York State 21st Century Community Learning Centers Program evaluator. Dr. Harris-Madden has earned numerous degrees, including a B.A. in English and African American studies, a Masters of Business Administration (M.B.A.), a Master of Science in Human Resource Management (M.S. H.R.M.) and a Doctorate in Education and Executive Leadership (Ed. D.). She is a longtime community leader who has served on a number of professional boards.

Jamillah Hoy-Rosas, MPH, RDN, CDCES
Head of Population Health Ronald McDonald House – NYC

Jamillah Hoy-Rosas is a healthcare and nonprofit leader with deep expertise in population health, clinical operations, and health equity innovation. She serves as Head of Population Health and Healthcare Experience at Ronald McDonald House New York (RMH-NY), where she leads initiatives that expand community partnerships, strengthen care coordination, and build sustainable funding models to advance health equity for families across New York City. Since joining RMH-NY in 2023, Jamillah has positioned the organization as a trusted community-based partner in the New York State Health Equity Reform Medicaid Waiver, securing contracts with three Social Care Networks serving all five boroughs. Under her leadership, RMH-NY launched Medicaid-funded services addressing food insecurity, transportation, and housing—improving care coordination and outcomes for children, families, and pregnant and postpartum individuals. She also helped design RMH-NY's Medical Respite program for medically vulnerable young women and leads partnerships with Columbia University's School of Nursing and Elmhurst Hospital. Previously, Jamillah served as Chief Health Officer at City Health Works and began her career directing a WIC program on the Lower East Side. She holds degrees from the University of Pennsylvania and New York University.

SPEAKERS & MODERATORS

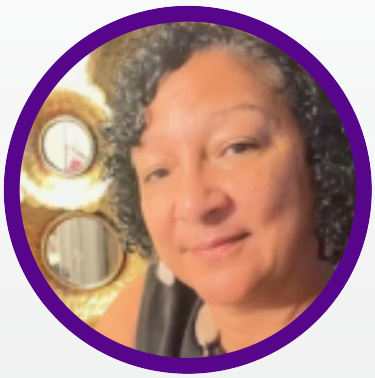
Maia Z. Laing, MBA
Chief Policy Officer
Sick Cells

Maia Laing brings over 25 years of experience in healthcare leadership, combining professional expertise and lived experience with SCD to advance health equity and patient-centered care. As an individual living with SCD, she has a deeply personal connection to the cause and a profound understanding of the challenges faced by those managing chronic conditions. This perspective fuels her lifelong commitment to improving healthcare access and outcomes for vulnerable populations. During her tenure at the U.S. Department of Health and Human Services (HHS), Maia played a pivotal role in developing programs to address health disparities and expand care for underserved communities. In the private sector, she held strategic leadership roles at UnitedHealth Group and Optum, where she led initiatives to transform healthcare delivery, promote value-based care, and develop data-driven health equity solutions. Maia holds an MBA from Simmons Graduate School of Management in Boston and has spearheaded numerous initiatives aimed at reducing health disparities. Her professional expertise and personal advocacy align with Sick Cells' mission to amplify patient voices and advance equitable, inclusive healthcare systems.

Lewis Marshall, MD
Chief Medical Officer
NYC Health + Hospitals/Lincoln

Dr. Lewis Marshall received his medical degree from Howard University School of Medicine, as well as a Master of Science from NYU's Robert F. Wagner Graduate School of Public Service, and a Juris Doctorate from Fordham University School of Law. He is board certified in Emergency Medicine as well as Disaster Medicine, Legal Medicine, and Internal Medicine — specialties that are more relevant today than ever before. He has spent his career caring for New Yorkers. After periods at hospitals in Brooklyn and Queens, he spent fifteen years at Brookdale University Hospital in Brooklyn, first serving as the Chair of the Department of Emergency Medicine and then of the Department of Ambulatory Care and Community Services. Most recently, Dr. Marshall served as the Medical Director of N's Student Health Center for nearly 60,000 undergraduate and graduate students.

SPEAKERS & MODERATORS



Gladys A. Magee
Director
Sickle Cell Advocates of Rochester, New York

Gladys Magee began her work as a Community Support Coordinator lead for the Sickle Cell Support group at the University of Rochester Pediatric Hematology Oncology Division for 5 years. She is currently on staff at the University of Rochester, Psychiatry Department for the past 3 years. In addition to working within the Psych Department as Executive Assist., she is also the Director of Sickle Cell Advocates of Rochester (SCAR) for the past 5 years. SCAR is a 501c Non-for-Profit community base grassroot organization in Rochester, New York. As the Director of SCAR, she directs and promotes educational programs for sickle cell awareness. Encourage national and local legislative advocacy with patient and community leaders. Host community engagement events at local churches, coordinate walks for awareness, partner with American Red Cross for community blood drives, partner with local recreation center to host a vase array of events such as Box – fighting for sickle cell, Run/Race for Cure for Sickle Cell/Basketball tournament. She also partners with pharmaceutical companies to educate the sickle cell communities regarding treatment options for sickle cell.

Micheal H. Merson, MD
Interim Chair, Department of Social and Behavioral Sciences & Clinical Professor of Global and Environmental Health, NYU SGPH

Dr. Michael Merson is Interim Chair of the Department of Social and Behavioral Sciences and a Clinical Professor of Global and Environmental Health at NYU. He is also the William Joklik Emeritus Professor of Medicine and Global Health at Duke University, where he was founding director of the Duke Global Health Institute and Vice President/Vice Provost for Global Affairs. His current research focuses on pandemic policy, including evaluating Paxlovid rollout in low-income countries and restoring public trust in health. Previously, he was Yale's first Dean of Public Health. From 1980 to 1995, he directed WHO programs on Diarrheal Diseases, Acute Respiratory Infections, and the Global Program on AIDS. He has authored over 150 articles, is senior editor of the textbook Global Health: Disease, Programs, Systems, and Policies, and lead author of The AIDS Pandemic: Searching for a Global Response.
He has advised UNAIDS, WHO, Global Fund, World Bank, WEF, and the Gates Foundation, among others. Dr. Merson holds two honorary degrees and is a member of the National Academy of Medicine.

SPEAKERS & MODERATORS

Angela Odoms-Young, PhD
Associate Professor
Cornell University

Dr. Odoms-Young's research explores how social and structural factors contribute to community and population-level variations in dietary intake and diet-related chronic diseases in the United States, with a particular focus on how systemic inequities shape dietary risk. Central to her work is the application of community-engaged research approaches to inform the development and evaluation of programs and policies that empower communities to build sustainable and equitable food systems, enhance nutritional well-being, and promote whole-person health across the life course.
Dr. Odoms-Young has played an active role in shaping national food and nutrition policy. She has served on several advisory committees and boards including the National Academies of Sciences, Engineering, and Medicine (NASEM) Food and Nutrition Board. She also served on the NASEM committees charged with developing nutrition standards for the National School Lunch Program and School Breakfast Program and revising the food packages for the Supplemental Nutrition Program for Women, Infants, and Children (WIC). Additionally, Dr. Odoms-Young recently served as vice chair for the 2020 Dietary Guidelines for Americans Scientific Advisory Committee.

Gbenga Ogedegbe, MD, MPH
Director, Institute for Excellence in Health Equity &
Professor, NYU Grossman School of Medicine (GSOM)

Dr. Gbenga Ogedegbe is the inaugural and founding director of the Institute for Excellence in Health Equity (IEHE) at NYU Langone Health. He is the Dr. Adolph & Margaret Berger Professor of Medicine and Population Health at NYU Grossman School of Medicine. He is a leading NIH-funded scientist in health equity research. He has led numerous NIH-funded studies for cardiovascular disease risk reduction with a focus on developing and evaluating clinic-community linkage models of care to address inequities in health outcomes both domestic and international. Dr. Ogedegbe is a member of the National Academy of Medicine and the United States Prevention Services Task Force (USPSTF). He is a Fellow of many scientific organizations including the American Heart Association, American College of Physicians and the Academy of Behavioral Medicine.

SPEAKERS & MODERATORS

Ify Osunkwo, MD
Chief Patient Officer, Novo Nordisk

Dr. Ifeyinwa (Ify) Osunkwo, Chief Patient Officer for Rare Disease at Novo Nordisk, leads efforts to transform the lives of patients with rare diseases through equitable access to care, innovative treatment solutions, and strengthened partnerships with global patients and community stakeholders. With over 30 years of experience as a hematologist, clinical trialist and sickle cell expert, Dr. Osunkwo has dedicated her career to addressing health disparities and building holistic, patient-centered healthcare solutions. At Novo Nordisk, she plays a pivotal role in driving the company's patient-centric portfolio approach to rare diseases, emphasizing collaboration, empowerment, and health equity. Dr. Osunkwo's extensive expertise in population health and health literacy positions her to deliver lasting impacts for patients and communities, reflecting Novo Nordisk's commitment to redefining care for rare disease patients worldwide. Her leadership in patient advocacy strategy spans the entire development continuum, ensuring that patient voices are integral to every stage of the process.

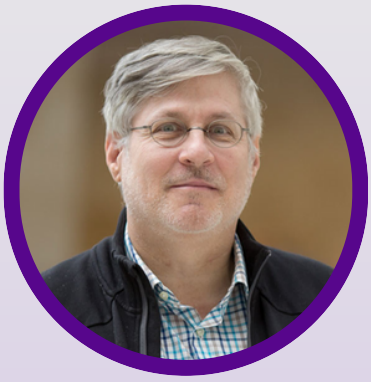
Jose Pagan, PhD
Professor and Chair, NYU SGPH

Dr. José A. Pagán, is Professor and Chair of the Department of Public Health Policy and Management in the NYU School of Global Public Health. He is also Chair of the Board of Directors of NYC Health + Hospitals, the largest municipal health care system in the United States. Dr. Pagán is a member of the National Academy of Medicine. He is a health economist and health services researcher who has led research, implementation, and evaluation projects on the redesign of health care delivery and payment systems. He was a member of the Board of Directors of the Interdisciplinary Association for Population Health Science and the American Society of Health Economists.

SPEAKERS & MODERATORS

Emmanuel Peprah, PhD
Director, ISEE Lab & Associate Professor
NYU School of Global Public Health (SGPH)

Dr. Emmanuel Peprah's research explores why and how evidence-based interventions work in some populations and not others. His work focuses on contextual factors influencing adoption of evidence-based interventions (EBI) for people living with SCD, HIV/AIDS and maternal health. Dr. Peprah collaborates with multidisciplinary teams globally to address SCD, HIV/AIDS and NCD comorbidities. He is founder of the Baakoye Foundation, serving communities in sub-Saharan Africa, and co-founder of the Washington Leaders Index (WLI), which supports emerging leaders through inclusive education and health programs. Before joining GPH, Dr. Peprah was a senior program official at the NIH, where he led strategic planning, research initiatives, and managed a $10M HIV/AIDS portfolio at the National Heart, Lung, and Blood Institute. He has received multiple awards for his leadership in large-scale NIH programs in translational research, implementation science, and global health.



Kenneth Rivlin, MD, PhD
Vice Chair, Department of Pediatrics
NYC Health + Hospitals/Jacobi

Dr. Kenneth Rivlin is the Director of the Division of Pediatric Hematology and Oncology. He has a strong interest in SCD and a member of the New York Sickle Cell Advisory Committee. He has served as Principle Investigator on HRSA Sickle Cell Grants and was a member of the NIH Planning Committee for the Consensus Statement on Use of Hydroxyurea. Dr. Rivlin is the Principle Investigator of two studies, Randomized Double Blind Trial of Rivipansel in the Treatment of Vasoocclusive Crises in Hospitalized Patients with Sickle Cell Disease and An Open-Label Extension Study to Evaluate The Safety of Rivipansel in the Treatment of One or More Vasoocclusive Crises in Hospitalized Patients with Sickle Cell Disease. Dr. Rivlin has worked in the Caribbean and Guyana on improving comprehensive sickle cell care. Dr. Rivlin is board certified in Pediatric Hematology-Oncology and he is an Assistant Professor of Pediatrics at the Albert Einstein College of Medicine.

SPEAKERS & MODERATORS

Melinda Rushing, PhD, LMSW
Assistant Professor
Rutgers University

Dr. Melinda Rushing joined the Bloustein School as an Assistant Professor in September 2024. She is an applied data scientist who utilizes various quantitative methods to identify inequitable practices in the delivery of and access to health services among marginalized communities. She recently completed a Post Doctoral Fellowship at the Susan B. Meister Child Health Evaluation and Research Center (CHEAR) at the University of Michigan, where her research focused on improving access and quality of care among individuals with SCD as well as the application of various data science techniques to evaluate patient outcomes among this patient population. Dr. Rushing received her Ph.D. in Health Promotion and Behavioral Science and a Data Science Certificate from the School of Public Health at the University of Texas Health Science Center. She also holds a Master's in Social Work from the University of Houston Graduate College of Social Work.

Ravi Singh
Vice President Market Access,
Advocacy & Policy
Genetix Biotherapeutics

Ravi Singh is an accomplished professional in the life sciences sector with extensive experience in market access, advocacy, and policy. Currently serving as Vice President of Market Access, Advocacy & Policy at bluebird bio since November 2018, Ravi has held various leadership roles within the company including VP of Advocacy & Alliance Development and Senior Director positions. Prior to bluebird bio, Ravi worked at Biogen from May 2014 to October 2018, where roles included Associate Director of Global Market Access. Earlier professional experience includes consulting at IMS Consulting Group and Simon-Kucher & Partners, as well as a position as a Junior Professional Fellow at the United Nations University. Ravi holds a Bachelor of Arts in Economics and Hispanic Studies from Columbia University, earned between 2006 and 2009.

SPEAKERS & MODERATORS

Sharee Turpin
SC Patient Navigator
University of Rochester Medical Center (URMC), Golisano Children's Hospital

Sharee Turpin has a background in Communications/Journalism and is a recent graduate of the S.I. Newhouse School of Public Communications at Syracuse University. Sharee has served as a co-project lead with physicians on a National Institute of Health case study and has helped start a local support group for children and adults living with Sickle Cell Anemia. She has a personal interest in healthcare, seen in her service as an advocate for patients with chronic pain disorders. Sharee has a love for storytelling and has been a freelance journalist for the past several years. She believes in healthcare quality, and she wants to be a part of the future of healthcare. In her role, Sharee will help AHP accurately and systematically collect and organize network data, as well as use her background in communications to improve how AHP interacts with our network.

Nana Osei-Tutu, MSc
SCD Patient and Advocate
Infection Preventionist
NYC Health + Hospitals/Kings County

Nana Osei-Tutu is currently working as a Level I Infection Preventionist at the Kings County Hospital Center under NYC Health + Hospitals. She has 5 years of clinical experience, most of which was in clinical research, CVDs, and patient outcomes and holds a Master of Science in Epidemiology. She is excited to pivot from noncommunicable (NCDs) and chronic diseases to infectious (or communicable) diseases.

Kusum Viswanathan, MD, FAAP
Chief Medical Officer, One Brooklyn Health (OBH), Brookdale
Director, Comprehensive Pediatric Sickle Cell Program-OBH
Professor of Clinical Pediatrics, SUNY Downstate Health Sciences Uni.

Dr. Kusum Viswanathan is the Chief Medical Officer of One Brooklyn Health–Brookdale Hospital Medical Center and serves as Chair of Pediatrics and Director of Pediatric Hematology/Oncology across the OBH system. She is also a Professor of Clinical Pediatrics at SUNY Downstate Health Sciences University, board-certified in Pediatrics and Pediatric Hematology/Oncology. Dr. Viswanathan earned her medical degree from AIIMS (New Delhi, India) and completed pediatric residency and fellowship training before joining Brookdale's faculty in 1986. Her clinical and research focus includes sickle cell disease, anemias, and pediatric cancers. She has led multiple state and federal grant-funded programs for sickle cell care, education, and transition services, totaling over $4 million. A dedicated advocate, she collaborates with patient groups, leads OBH's Bioethics Committee, and participates in national clinical trials. She has received the Brookdale Medal, lifetime achievement awards, and is featured in Castle Connolly's Best Doctors and US News Top Doctors lists. Dr. Viswanathan is a fellow of the AAP, a member of leading hematology societies, and serves on the Make-a-Wish Foundation's Medical Advisory Board.

POSTER ABSTRACTS

We are pleased to feature poster presentations from public health researchers in SCD management.

Digital cognitive behavioral therapy vs. education intervention in population with sickle cell disease experiencing pain: a systematic review

- *Introduction:* Chronic pain in sickle cell disease (SCD) patients impairs daily functioning and quality of life, despite advances in pharmacological treatments. Digital cognitive behavioral therapy (dCBT) and educational interventions present promising nonpharmacologic strategies. This systematic review assesses the efficacy of these interventions, as well as their potential for digital delivery in SCD pain management.

- *Methods:* Following PRISMA guidelines, we screened randomized controlled trials (RCTs) from PubMed MEDLINE, CNKI, Scopus, Web of Science, Cochrane, EMBASE, and CINAHL (01/20/2025). Our PROSPERO-registered protocol (CRD42025650053) guided selection.

- *Results:* From 142 studies, 81 were screened, 13 underwent full-text review, and two RCTs (n=470) met eligibility criteria. Studies from the US and Canada assessed dCBT versus education for SCD pain over six months in adults and adolescents, primarily Black/African American females. Neither intervention significantly reduced post-treatment pain, anxiety, or depression. However, cognitive behavioral therapy (dCBT) demonstrated superior mood improvements at six months and greater reductions in fatigue.

- *Conclusion:* These findings highlight critical factors influencing intervention effectiveness, including sample size, age, engagement, and intervention type. Future research should optimize dCBT implementation and engagement strategies to enhance outcomes. Understanding these elements is essential for developing effective digital interventions for SCD chronic pain management.

Authors:
- *Carla Isabella Miret Durazo, Centro de Estudios Universitarios Xochicalco*
- *Joceline Isabel Almeida Hidalgo, Universidad Técnica de Ambato*
- *Manju Ramakrishnan, Rollins School of Public Health, Emory University*
- *Michelle Sámano Sánchez, Universidad Autónoma de Sinaloa*
- *Linda Estefania Cordero Velez, Universidad del Azuay*
- *Ornella Gimena Provenzano, Universidad Nacional de Córdoba*
- *Hanny Corvalan, Universidad Tecnológica Equinoccial*
- *Ada Lizandra Motino Villanueva, Universidad Católica de Honduras*
- *Vaidarshi Abbagon, St Vincent's Medical Center / Quinnipiac University*
- *Shreya Shambhavi1, Rutgers Health / Community Medical Center*
- *Ernesto Calderón Martínez, Universidad Nacional Autónoma de México*

POSTER ABSTRACTS

Efficacy and Safety of L-Glutamine for Reducing Complication in Sickle Cell Disease: A Systemic Review and Meta-Analysis

- *Introduction:* Sickle cell disease (SCD) is a blood disorder that is genetic and can lead to cyclical occurrences of vaso-occlusive crises (VOCs). Hydroxyurea is the current standard of treatment, although emerging novel therapies like L-glutamine have shown potential in reducing the frequency of VOCs. This meta-analysis aims to evaluate the safety and efficacy of L-glutamine in reducing VOCs while also improving secondary outcomes.

- *Methods:* Studies were obtained from PubMed, Cochrane, Scopus, Web of Science, EMBASE, CINDAHL, and CNKI. The primary outcome was VOC frequency and reduction in pain, while the secondary outcomes included hematologic parameters, patient-reported quality of life, hospitalization rates, and biomarkers. A random effect model meta-analysis was performed using R version 3.4.3 (R Core Team)

- *Results:* We included three studies comprising a total of 352 patients. The L-Glutamine group showed a significant reduction in hospitalization rates (MD -0.72 95% CI: -1.26 to – 0.18, p = 0.009, I2 = 0.0%) and VOC frequency (MD -0.75; 95% CI: -1.41 to -0.09, p = 0.02, I^2 = 58.2%). However, serious adverse events were noted in all studies, without any significant differences between the two groups (RR 1.09; 95% CI: 0.93 to 1.29, p = 0.14, I^2 = 0.0%). Heterogeneity was moderate to high for VOC outcomes but low for hospitalization and adverse events.

- *Conclusion:* Our findings suggest that L-glutamine can reduce VOCs and hospitalization rates in SCD patients, potentially being used as an adjunctive therapeutic. However, due to the limited sample size in existing studies there remains a need for large-scale and long-term RCTs to confirm is safety and efficacy. Such studies would provide more definitive evidence to support its use in clinical practice.

Authors:
- *Ajay Kumar, Isra University Faculty of Medicine and Allied Medical Sciences, Hyderabad, Sindh, Pakistan*
- *Barbara Abreu Lopez, University of Carabobo, Venezuela*
- *Khaled Mahmoud Ali, Ilia State University, Tbilisi, Georgia*
- *Rakan Fawwaz, Ilia State University, Tbilisi, Georgia*
- *Balamurali Krishna Muralee Dharan Veena, Tbilisi State Medical University, Tbilisi, Georgia*
- *Ibrahim Sallam, Ilia State University, Tbilisi, Georgia*
- *Koussay Gharbi, Ilia State University, Tbilisi, Georgia*
- *Mohamed Khalil, University of Science and Technology, Faculty of Medicine, Sudan*
- *Vaidarshi Abbagoni, St Vincent's Medical Center / Quinnipiac University*
- *Shreya Shambhavi, Rutgers Health / Community Medical Center*
- *Ernesto Calderon Martinez, Biomedical Informatics, Universidad Nacional Autónoma de México, Mexico City, Mexico*

POSTER ABSTRACTS

Improving Hydroxyurea Prescription Rates in Pediatric Sickle Cell Patients

- *Introduction:* Hydroxyurea is the standard treatment for eligible patients with sickle cell disease (SCD) which helps prevent and decreases vaso-occlusive crises, hospitalizations, acute chest syndrome, and other complications. While hydroxyurea's efficacy has been well-researched for decades, it has not been as widely prescribed as recommended. This study's goal was to document hydroxyurea prescription rates and reasons it was not prescribed in eligible pediatric patients with SCD since 2017. We also sought to show how various QI processes including the development of a SCD note template, creation of an SCD-specific tab in the EMR, and educational initiatives for providers affected prescription rates.

- *Methods:* All patients with an SCD diagnosis seen in outpatient clinic since 2017 with an eligible genotype (HbSS or HbS-βo-thalassemia) were identified. Patients with the hereditary persistence of fetal hemoglobin (HPFH) genotype were excluded. Chart review of patients with eligible genotypes identified dates patient was followed in clinic, date of first hydroxyurea prescription, dates of chronic transfusions if applicable, and reasons why eligible patient had not been prescribed hydroxyurea. Patients were only deemed eligible for hydroxyurea each year if they were seen in clinic, had an eligible genotype, >9 months old, and not on chronic transfusions or had a history of stem cell transplant.

- *Results:* Hydroxyurea prescription rates did not significantly change from 2017 to 2021 but improved every year after 2021: from 57% at end of 2021 to 79% in 2023 ($p<.005$) to 91% by end of 2024 ($p<.0001$). This increase correlated with the development and encouragement to use an SCD note template and SCD data tab in 2022. Prior to 2022 the primary reasons eligible patients were not on hydroxyurea were provider-related; providers did not initiate discussion of hydroxyurea and believed patients with elevated fetal hemoglobin and milder phenotypes did not require hydroxyurea. However, after these various QI initiatives in 2022, hydroxyurea was discussed with nearly every eligible patient and reasons shifted to parental hesitation as parents worried about side effects and starting a lifelong medication, especially if their child had a milder phenotype. In addition, some patients initially thought to have the HPFH genotype were found to not be HPFH and encouraged to start hydroxyurea.

- *Conclusion:* The development of a standardized SCD note template with embedded treatment guidelines, building an EMR data tab to facilitate data acquisition, and education of hematology providers to use these tools correlated with a significant improvement in hydroxyurea prescription rates. This improvement also correlated in a shift in reasons eligible patients were not on hydroxyurea: from providers not initiating discussion of hydroxyurea to parental hesitation. It is also noteworthy that the hematology group has had significant turnover in providers from 2021 to date.

Authors:
- *Cornelius Tyrrell, UMass Chan Medical School*
- *Nura El-Haj, UMass Chan Medical School*
- *Megan Mcdavitt, UMass Chan Medical School*

POSTER ABSTRACTS

Outcome Measures in Transfusion Care Cohorts Within the SCDIC-II Registry Database: Reported Pain and Opioid Utilization.

- *Introduction:* Sickle cell disease (SCD) comprises a group of inherited blood disorders causing significant morbidity and mortality for >100,000 patients in the United States.1 Disease-modifying treatments are available, including chronic and acute blood transfusion care2 and multiple approved drug options.3 Red blood cell exchange (RBCX) is a mainstay of long-term SCD care supported by multiple randomized controlled trials (RCTs).4 The SCDIC-II Registry tracks over 1600 SCD patients from 8 leading academic centers, providing a rich source of publicly available patient data.5 To date, no analysis of SCDIC Registry data has specifically examined differences between transfusion care modalities. The aim of this study was determine whether the SCD patient cohort receiving only RBCX therapy reported different health outcomes versus patients receiving only simple transfusion (ST) or a combination RBCX+ST therapy.

- *Methods:* De-identified, summary patient data from the SCDIC-II registry (accessed 05/28/25), was queried for participants having undergone transfusion therapy with completed medical records and survey responses across a two-year study period. Data for all transfusion patients were included regardless of drug therapy, co-morbidity, and mental health status.

- *Results:* Demographic results: n = 1655 patient records, 98.8% Black or African American, 58.1% were female and 41.9% male, age range 14-72, with median age = 27. During the preceding 12 months, n = 180 patients exclusively received RBCX therapy, n = 274 patients received simple transfusion care, and n = 66 patients received combined RBCX and simple transfusions. Chi-squared analysis identified significant differences between transfusion treatment groups for both the five-level pain interference with day-to-day activities survey result and the pain medication use MRA results. There is a clear trend for the RBCX only treatment group to report a lower overall level of pain interference and a trend towards lower reliance on both fentanyl and acetaminophen/oxycodone in the RBCX treatment group compared to the other transfusion modalities. All three transfusion care groups lack sufficient numbers within the registry to meet individual group statistical significance for these measures.

- *Conclusion:* Demographic data from our SCDIC-II transfusion cohort was similar to prior reports.6 This analysis demonstrates that the choice of transfusion care for SCD patients may impact important patient health and quality of life outcomes, yet definitive analysis is hampered by low enrollment of patients managed with transfusion care. This reinforces the documented underutilization of transfusion care for SCD patients and RBCX specifically.7,8 These results encourage expansion of the SCDIC Registry and other registries for SCD patients and presents a novel question for follow-on research efforts.

Authors:
- *Aaron Haubner, PhD, MBA, Department of Patient Access, Terumo Blood and Cell Technologies*
- *Sebastian Mendoza, BS, MBA, Department of Patient Access, Terumo Blood and Cell Technologies*
- *Nicholas Mendola, PhD, MPH, Department of Patient Access, Terumo Blood and Cell Technologies*

POSTER ABSTRACTS

Improving access to care for patients with sickle cell disease in a municipal safety net health system

- *Introduction:* People living with sickle cell must navigate a clinical landscape marred by decades of disinvestment and misconceptions about patients with SCD due to structural racism. Efforts to improve SCD care are an essential step in pursuing racial health equity. New York City Health and Hospitals (NYC H+H), the nation's largest municipal healthcare system, is well positioned to support this population. Of the approximately 10,000 individuals living with SCD across New York state, 1,765 (17.65%) received care at NYC H+H from June 2024 to June 2025. As a key provider of sickle cell care in NYC and a mission driven system committed to social and racial equity, NYC H+H is uniquely poised to impact care for people with SCD. Our key objective is to enhance adult SCD care through primary care engagement, prescription of disease modifying therapy, integration of psychosocial support, and access to outpatient infusion services for pain episodes as needed.

- *Methods:* Clinical data was used to describe patient volume, ED utilization and PCP engagement. Stakeholder input from disease experts across the system coupled with system data highlighted gaps in care and opportunities for improvement. Using these resources, project leadership developed a proposal including a business plan to enhance SCD care for adults with an eye on the patient experience, quality of care, and cost-effectiveness.

- *Results:* Clinical data showed that in CY 2023, 1122 unique patients with SCD were seen in the ED, accounting for >5,000 ED encounters. In Manhattan and the Bronx, 471 unique patients were seen in the ED accounting for 2606 ED encounters. 79% of pediatric patients with SCD had PCP engagement, while only 40% of adult patients with SCD had PCP engagement. Prior to this work, H+H had 6 pediatric sickle cell care centers and 2 adult sickle cell care centers. In partnership with stakeholders across the system, project leadership developed a business plan to enhance adult SCD care through investment in existing centers and the development of a new adult sickle cell center in Harlem. Additional investment included staffing each adult care site with a new CHW and LMSW to prioritize accessible and longitudinal psychosocial support for patients living with SCD. These CHWs will also be key facilitators of a new pediatric to adult SCD transition workflow to reduce attrition seen during this time. In addition, the new site in Harlem will be staffed with a provider specializing in SCD care, a CHW, and LMSW. Projections estimate that through driving increased patient volume and value-based payments, this expansion will be a cost-effective strategy for enhancing patient care.

- *Conclusion:* This initiative successfully engaged stakeholders and system leadership to secure an investment in adult sickle cell care at NYC H+H. Further studies could explore the impact of these investments on patient satisfaction, prescription of disease modifying agents, ED utilization, PCP engagement, and continuity of care from childhood to adulthood.

Authors:
- *Leo Eisenstein, MD, New York City Health and Hospitals*
- *Candace Alphonso, MPH, New York City Health and Hospitals*
- *Kenneth Rivlin MD, New York City Health and Hospitals*
- *Nichola Davis, MD, MS, New York City Health and Hospitals*

POSTER ABSTRACTS

Rebuilding the Bone in Sickle Cell Disease: A Systematic Review and Meta-Analysis of Bisphosphonate Therapy

- *Introduction:* Bone pain, avascular necrosis, and low bone mineral density (BMD) are frequent yet under-recognized causes of chronic morbidity in sickle cell disease (SCD). These skeletal complications lead to disability and reduced quality of life, particularly in low- and middle-income settings where orthopedic and rehabilitative resources are limited. Bisphosphonates—potent anti-resorptive agents used in osteoporosis—may reduce pain and improve BMD in SCD, but evidence remains sparse and safety concerns, especially regarding vaso-occlusive crises (VOC), have limited clinical use. We systematically synthesized human data on bisphosphonate therapy in SCD and quantified its effects on bone pain, BMD, and adverse events.

- *Methods*: Published studies and meeting abstracts through October 2025 were identified via PubMed, Embase, Cochrane, and manual searches. Pediatric and adult cohorts were included. Pain-response proportions were pooled using a random-effects logit model (DerSimonian–Laird). BMD and safety outcomes were summarized descriptively where heterogeneous scales precluded pooling.

- *Results*: Five studies met inclusion: two pediatric cohorts (intravenous zoledronic acid ± pamidronate), one adult intravenous zoledronic acid series, and two adult oral alendronate cohorts. Pain: Across three analyzable cohorts (n = 132), the pooled proportion of patients with significant pain improvement was 0.78 (95 % CI 0.70–0.84; I^2 = 0 %). BMD: Pediatric cohorts showed mean lumbar-spine and total-body-less-head Z-score gains of ≈ +0.4 ± 0.5–0.6 after ~1.5 years. Adult alendronate studies ranged from stable LS BMD (Δ −0.01 ± 0.07 g/cm²) to 12-month T-score improvement (+1.2). The pooled standardized mean change favored bisphosphonates but was highly heterogeneous (I^2 ≈ 99 %). Safety: Pediatric acute-phase reactions occurred in ≈ 22 % and hypocalcemia ≈ 4 %, with no infusion-related VOC, ACS, or ONJ. Adult cohorts reported mild transient events (10–15 %) and one atypical femur fracture after long-term alendronate.

- *Conclusion*: Bisphosphonates—particularly intravenous zoledronic acid and pamidronate—appear safe and clinically beneficial for SCD-related bone pain and low BMD without triggering vaso-occlusive events. Although current evidence is limited and mostly retrospective, findings highlight an accessible, low-cost intervention for skeletal morbidity in SCD. Integrating bisphosphonates into multidisciplinary pain- and bone-health programs, especially in resource-limited settings, may improve quality of life and reduce long-term disability. This meta-analysis demonstrates that bisphosphonates can safely reduce bone pain and enhance bone health in SCD, offering a scalable, affordable strategy to improve outcomes globally.

Author:
- *Adarsh Vardhan Tangella, MBBS Department of Medicine, MedStar Washington Hospital Center*

POSTER ABSTRACTS

Structural Inequities in Emergency Analgesia for Sickle Cell Disease: A Meta-Analysis of System-Level Delays

- *Introduction:* Timely analgesia is a core quality metric in sickle cell disease (SCD) management. Despite evidence-based guidelines, emergency departments (EDs) continue to show prolonged wait times for SCD pain control, reflecting structural gaps in acute care delivery. Our goal was to quantify delays in time-to-analgesia among patients with SCD compared with other acute pain conditions, and to evaluate the impact of protocolized interventions and timeliness on hospitalization outcomes.

- *Methods:* We performed a meta-analysis of comparative and interventional studies (2008–2025) reporting ED pain management metrics for SCD. The primary outcome was mean difference (MD) in minutes to initial analgesic administration versus long-bone fracture (LBF) or renal colic (RC). Secondary analyses examined pre/post protocol effects and associations between timely opioid dosing and hospitalization. Random-effects (DerSimonian–Laird) models were applied for continuous outcomes, while proportions and adjusted odds ratios (aORs) were summarized narratively.

- *Results:* Across three comparator studies (n ≈ 1,000 visits), the pooled delay for SCD versus LBF/RC was +18.7 minutes (95% CI −1.7 to +39.2; I^2 = 88%). Implementation of individualized or standardized pain protocols reduced time-to-first-opioid by ≈ 87 minutes (95% CI −99 to −75). In 4,578 pediatric visits, only 48 % received the first opioid within 60 minutes, and 15 % received a second dose within 30 minutes. Among pediatric cohorts, timely dosing (≤ 60 + ≤ 30 min) was associated with a 40 % reduction in hospitalization (aOR ≈ 0.62, 95% CI 0.52–0.75).

- *Conclusion:* Structural inequities in SCD pain management include diagnosis-linked triage delays, absence of standardized analgesia protocols, and inconsistent adherence to timeliness benchmarks—system-level factors that prolong treatment and worsen outcomes. These disparities are organizational rather than individual, underscoring the need for national adoption of protocol-driven ED workflows and inclusion of door-to-analgesia metrics in quality reporting. Future initiatives should integrate these measures into hospital performance dashboards to promote equitable, timely, and evidence-based SCD pain care.

Author:
- *Adarsh Vardhan Tangella Department of Medicine, MedStar Washington Hospital Center*

POSTER ABSTRACTS

From Advisors to Investigators: A Community-Led Study to Improve Resident Attitudes Toward Patients with Sickle Cell Disease

- *Introduction:* For decades, academic researchers and community members have had a largely unidirectional relationship, with communities advising on studies designed by investigators. To create a more equitable, bidirectional model, a Community Advisory Board (CAB) affiliated with a national research network initiated this study to investigate a priority area identified by members: the impact of clinician attitudes on care for patients with Sickle Cell Disease. Patients with SCD often report that their pain is not believed and that they feel disrespected, especially in the Emergency Department. Stigma profoundly affects patient–provider relationships and health outcomes, and many ED physicians hold negative attitudes toward SCD patients, highlighting the need for targeted educational interventions. We aim to evaluate whether a targeted, CAB-designed educational intervention could improve resident physician attitudes toward patients with SCD.

- *Methods:* This CAB-led study used a pre-test/post-test design. Participants were Internal Medicine and Pediatrics residents (n=41) at a large urban public hospital. The General Perceptions About Sickle Cell Disease Patients Scale, a validated survey instrument, was adapted to measure attitudes before and after an educational module. Data were analyzed using paired t-tests, with $p < 0.05$ indicating significance.

- *Results:* The intervention produced significant improvements in 11 of 18 survey items. CAB-prioritized outcomes related to patients' pain being believed and perceptions of drug-seeking all improved. Residents were less likely to view a patient "appearing comfortable while in severe pain" or requesting a specific narcotic as drug-seeking. Overall perception that patients are "drug-seeking when they come to the hospital" also declined. Residents shifted from focusing on individual failings to recognizing systemic problems, reporting greater concern about "the way some doctors treat patients with SCD" and acknowledging "inadequate pain management by doctors and nurses" as systemic issues.

- *Conclusion:* CAB-directed stigma education effectively reduced negative attitudes, consistent with prior research. Previous studies showed knowledge gains without attitude change regarding drug-seeking behavior. In contrast, our CAB-designed intervention improved attitudes on this key outcome, suggesting patient co-designed interventions may better target relevant biases. While prior work reported increased positive attitudes, our study did not, indicating that broader clinical pressures such as the opioid crisis and systemic burnout may limit brief interventions' impact on positive affect, even while addressing specific stigmas.

Authors:
- *Kennith Rivlin, NYC Health+Hospitals/Jacobi*
- *Dina Abdelhamid, NYC Health+Hospitals/Queens*
- *Stamatia C Vorri, NYC Health+Hospitals/Jacobi*
- *Linda Bulone, NYC Health+Hospitals/Queens*
- *Sindy Mora Garavito, NYC Health+Hospitals/Jacobi*
- *Melanie Aviles, NYC Health+Hospitals/Jacobi*

POSTER ABSTRACTS

Unequal Burden: Geographic and Temporal Differences in Sickle Cell Disease Hospitalizations in New York State from 2009–2022

- *Introduction:* Sickle cell disease (SCD) disproportionately affects racial and ethnic minority groups in the United States and is associated with high morbidity and health care utilization, yet little is known about population-level geographic differences in outcomes. This study aims to assess temporal and regional patterns of SCD hospitalizations in New York State from 2009 through 2022.

- *Methods:* This study analyzed SCD hospitalizations from the New York State Statewide Planning and Research Cooperative System (SPARCS) database. The analytic sample included 42,271 hospitalizations for SCD patients after exclusions for missing demographic, cost, or facility data. Exposures include hospitalization with SCD across eight state-defined Health Service Areas (HSAs) between January 1, 2009, and December 31, 2022, and main outcomes and measures were the regional distribution of hospitalizations, mean length of stay, mean total charges, and trends in severity and mortality. Demographic and regional distributions were compared using χ^2 tests, and differences in severity and mortality proportions were evaluated using the Marascuillo procedure.

- *Results:* Over the 14-year period, 42 271 hospitalizations, mostly occurred among individuals aged 18–29 years (40%) and 30–49 years (32%) and those identifying as Black (83%). New York City accounted for the largest proportion of SCD hospitalizations. Central New York and the Hudson Valley had the longest average stays, while Long Island had the highest mean total charges. The proportion of hospitalizations involving major severity and mortality (3% to 13%) increased steadily, peaking in 2022 ($p < .001$), while major mortality cases rose from 3% to 13%. Long Island had the highest proportion of major mortality (10%), whereas New York City showed moderate mortality despite high hospitalization rates.

- *Conclusion:* Significant geographic differences in SCD hospitalizations were observed across New York State over a 14-year period. Regions with limited access to specialized care were associated with prolonged stays, greater severity, and higher costs. Region-specific, equity-focused interventions are needed to improve care continuity, reduce preventable mortality, and optimize healthcare resource use for individuals living with SCD.

Authors:

- *Chukwuemeka Iloegbu, Dept. of Global & Environmental Health, ISEE Lab, NYU SGPH*
- *Jonathan Odumegwu, Dept. of Global & Environmental Health, ISEE Lab, NYU SGPH*
- *Joyce Gyamfi, Dept. of Global & Environmental Health, ISEE Lab, NYU SGPH*
- *John Patena, Dept. of Global & Environmental Health, ISEE Lab, NYU SGPH*
- *Dorice Vieira, Dept. of Global & Environmental Health, ISEE Lab, NYU SGPH*
- *Xinyu Wang, Dept. of Global & Environmental Health, ISEE Lab, NYU SGPH*
- *Etornam Amesimeku, Dept. of Global & Environmental Health, ISEE Lab, NYU SGPH*
- *Prince Amegbor, Dept. of Global & Environmental Health, ISEE Lab, NYU SGPH*
- *Andrew Campbell, Children's National Hospital/ George Washington University School of Medicine & Health Sciences*
- *Folasade Ogunlesi, Children's National Hospital/ George Washington University School of Medicine & Health Sciences*
- *Uju Ozoh, University of Lagos, Lagos University Teaching Hospital, College of Medicine*
- *Emmanuel Peprah, Dept. of Global & Environmental Health, ISEE Lab, NYU SGPH*

POSTER ABSTRACTS

Music-based interventions for Sickle Cell Disease: A systematic review

- *Introduction:* Sickle Cell Disease (SCD) is the most common inherited genetic blood disorder. Over 8 million people live with SCD globally, with more than 75% residing in low- and middle-income countries. People living with SCD encounter significant stigma from their family members, the public, and healthcare providers which adversely impacts their quality of life, reduces trust in healthcare, and discourages proactive health-seeking behaviors – ultimately contributing to increasing hospitalizations and mortality. Music presents a model for culturally-centered interventions for public engagement and behavior change that has been shown to increase quality of life and address mental wellbeing. To our knowledge, this is the first systematic review to identify and synthesize evidence on the impact of music-based interventions for SCD populations. This review aimed to examine the types of music-based interventions implemented and the health outcomes they targeted, including pain management, mental health support, and stigma reduction.

- *Methods:* We conducted a systematic review of articles that reported on music interventions, music therapy, music medicine, or any music-related search term and SCD. Studies had to utilize experimental, observational, or qualitative study designs. We identified articles using medical subject headings and keywords from the following databases in June 2024: CINAHL, Cochrane, EMBASE, Global Health, Music Index, OVID, PubMed/Medline, and Web of Science.

- *Results:* A total of 185 articles were reviewed, and 8 were included in the final analysis. All the studies were conducted in hospitals in the United States. Five of the studies utilized music therapy involving a board-certified music therapist facilitating sessions on listening to music, creating music, or teaching/reinforcing skills using music. The remaining studies gathered descriptive data on SCD patients' preferences for music-based interventions. All but one study explored outcomes around pain. Only three studies captured mental health outcomes including anxiety symptoms and perceived stress. The remaining outcomes centered around self-efficacy, quality of life, SCD knowledge, and coping skills.

- *Conclusion*: Music-based interventions for SCD populations are promising in addressing stigma and mental health barriers to health care. There is an opportunity to explore music-based health communication interventions to leverage the influence of music on attitudes and behaviors towards people living with SCD.

Authors:
- *Carlos Chirinos, PhD, NYU Steinhardt*
- *John Pateña, DrPH, MPH, MA, NYU School of Global Public Health*
- *Subomi Ige, MPharm, NYU School of Global Public Health*
- *Tania Hameed, MPH, MSW, NYU School of Global Public Health*
- *Emeka Iloegbu, MSc, MPH, NYU School of Global Public Health*
- *Dorice Vieira, MLS, MA, MPH, NYU School of Global Public Health*
- *Joyce Gyamfi, EdD, MS, NYU School of Global Public Health*
- *Emmanuel Peprah, PhD, NYU School of Global Public Health*

SPOTLIGHT ON THE ISEE LAB

IMPLEMENTING SUSTAINABLE EVIDENCE-BASED INTERVENTIONS THROUGH ENGAGEMENT

The ISEE Lab at NYU School of Global Public Health's mission is to cultivate leaders equipped to synthesize, generate, and translate evidence into culturally-appropriate, sustainable, and scalable interventions that improve health outcomes and well-being for patients, families, and communities. Our research is guided by rigorous established implementation science principles, theories, frameworks, and measures to advance global research in the areas of Sickle Cell Disease (SCD), Maternal Health, and HIV Syndemics.

The ISEE lab is one of the most diverse at the NYU GPH, bringing together students, researchers, and faculty from varied racial, ethnic, cultural, and disciplinary backgrounds. We intentionally recruit individuals with different perspectives and lived experiences, recognizing that inclusive collaboration produces more relevant and impactful public health solutions. We also prioritize equity by building partnerships with community organizations and global institutions that serve historically marginalized populations, ensuring that our research reflects and responds to those most affected by health disparities. Our track record includes successfully mentoring a diverse cadre of MPH and doctoral students, many of whom have gone on to leadership roles in research, policy, and practice. By fostering inclusive mentorship and training environments, we create a pipeline of diverse public health leaders equipped to address inequities and promote social justice. Through these sustained efforts, the ISEE Lab not only strengthens its internal culture of equity, diversity, and inclusion but also contributes to building a more equitable public health workforce and system.

ISEE Lab Website: https://publichealth.nyu.edu/w/isee

Leadership:

- **Emmanuel Peprah, PhD;** ISEE Lab Director, Associate Professor of Global Health
- **Joyce Gyamfi, EdD, MS;** Director, ISEE Lab SGPHF Mentorship Program; Section Leader, Implementing Evidence-Based Interventions for Sickle Cell Disease (ISCD), Senior Research Scientist
- **Dorice Vieira, MLS, MA, MPH;** Section Leader, Evidence Synthesis & Literature Searching (ESLS)
- **Emeka Iloegbu, MSc, MPH;** Section Leader, Advancing EBI to Improve Outcomes for People Living with HIV/AIDS (IPWH)
- **John Pateña, DrPH, MPH, MA;** Senior Research Associate
- **Tania Hameed, CHW, MPH, MSW;** Project Manager

SPOTLIGHT ON IEHE

NYU LANGONE HEALTH'S INSTITUTE FOR EXCELLENCE IN HEALTH EQUITY

NYU Langone Health's Institute for Excellence in Health Equity (IEHE), strives to achieve excellence in health equity research, clinical care, and medical education. Our vision is to become the leader in the development, implementation, and dissemination of evidence-based solutions to advance excellence in health equity, and to be a renowned magnet for talent.

We believe inclusivity and excellence in research, medical education, and clinical care are paramount to our success. As such, we strive to build a culture of inclusivity and excellence by facilitating and enabling the recruitment, training, and development of individuals who are underrepresented in medicine (URiM). In doing so we aim to become an incubator for world-class leadership in health equity research, medical education, and clinical care. Our core pillars are structured to address our multifaceted approach to help us achieve our vision.

Core Pillars:

Our institute is organized into four pillars that leverage the academic talent and resources across NYU Langone and develop programs designed to accelerate the careers of the next generation of trainees and faculty dedicated to advancing health equity:

- research
- medical education
- clinical care
- community engagement

IEHE Website:
https://med.nyu.edu/departments-institutes/excellence-health-equity/

Leadership:

- **Olugbenga G. Ogedegbe, MD, MPH;** Director, Institute for Excellence in Health Equity; The Dr. Adolph and Margaret Berger Professor of Medicine and Population Health
- **Yaa Haber, PhD;** Executive Director
- **Antoinette M. Schoenthaler, EdD;** Professor, Departments of Population Health and Medicine; Associate Director, Research, Institute for Excellence in Health Equity
- **Cristina M. Gonzalez, MD;** Population Health Co-Director, Medical Education, Beyond Bridges, Associate Director, Medical Education, Institute for Excellence in Health Equity

VENUE INFORMATION

Building Address:

New York University (NYU) Medical Science Building
Schwartz Hall E
540 1st Avenue
New York, NY 10016

Parking:

- NYU Langone / Schwartz Garage (530 1st Ave)
  - Underground garage next to the building.
  - Approx. rates: $15 (30 min), $25 (1 hr), $50 (24 hrs)
- iPark Garage (479–493 1st Ave)
  - A few blocks away. Valet parking only.
  - Other garages nearby
  - Reserve spots via SpotHero or ParkMe.
- Street parking
  - Limited metered parking available; check signs for restrictions.

Public Transportation:

- 28th Street – 6 Train
  - About a 5–6 minute walk.
- Grand Central – 4, 5, 6, 7, S Trains
  - About a 15-minute walk.
- Buses
  - M15 (1st Ave) and M34-SBS (34th St) stop nearby.

Contact Information:

Symposium Coordinators:

- Emmanuel Peprah, PhD
- Tania Hameed, MPH

Email:

- ep91@nyu.edu
- tah1001@nyu.edu

SPONSORS & SUPPORTERS

The SCD 115 Years Later Symposium at NYU is made possible through the generous support of:

SPECIAL THANKS

We extend our gratitude to all volunteers, staff members, and participants who made this symposium possible.

SCD Symposium Planning Committee Members:

Joyce Gyamfi, EdD, MS

Emmanuel Peprah, PhD

Angela Aifah, PhD

John Pateña, DrPH, MPH, MA

Nafesa Kanneh, MPH

Tania Hameed, CHW, MPH, MSW

Thank you to all of our moderators, panelists, speakers, and attendees.

SURVEYS & EVENT EVALUATION

As part of the SCD Symposium, NYU is collaborating with partners to improve health outcomes for individuals living with SCD. We invite you to contribute by completing the brief surveys linked below. Please scan the QR codes to access the research questionnaires and event evaluation form. Your feedback is invaluable in helping us strengthen our research efforts and enhance future SCD initiatives..

BEAT-SCD Survey:

This anonymous survey assesses the knowledge, attitudes, and beliefs (KABs) about Sickle Cell, and the potential impact of music and mental health for disease management.

Food as Medicine Survey:

Cornell University's Nutrition Liberation Lab is interested in learning more about the food and nutrition challenges experienced by people living with sickle cell disease and their caregivers. We are also interested in the types of food and nutrition programs that would be most helpful to you. Please take a few minutes to complete the survey below.

Conference Evaluation Survey:

Your feedback will help improve future events and strengthen collaborations that advance equity, research, and care for individuals and families affected by Sickle Cell Disease (SCD). This survey should take approximately 7–10 minutes to complete.

NOTES

NOTES