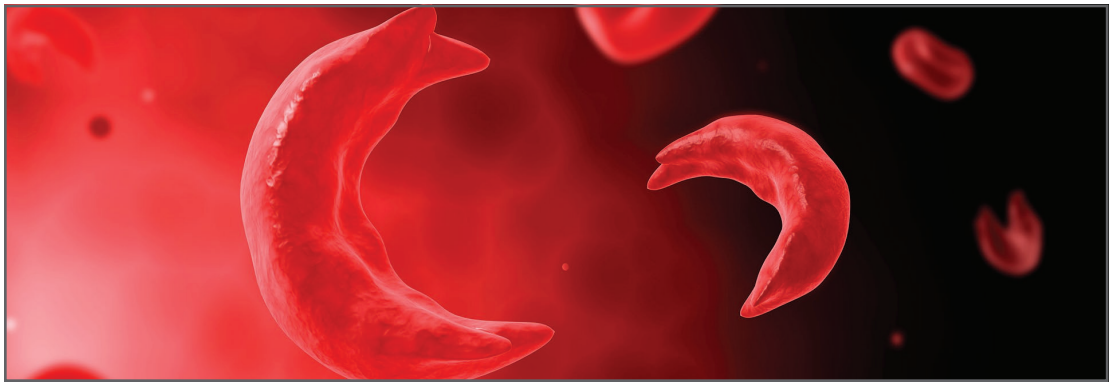


National Human Genome Research Institute

INSIGHTS

Page 1 *Welcome*

Page 2 *Study Updates*

Page 2 *Introducing...*

Page 3 *Current Projects*

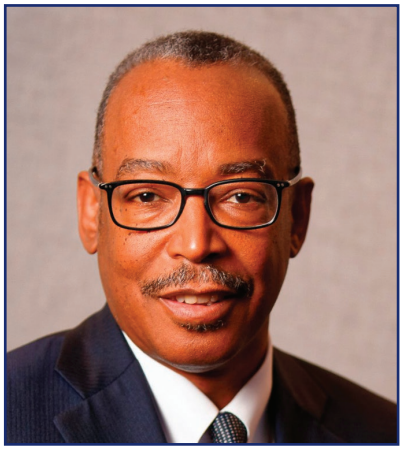
Page 4 *General Health Resources*

Page 4 *New SCD Findings / Publications*

Greetings from the INSIGHTS Study!

A lot of exciting things have happened since our last newsletter. We want to share news about current projects and are excited to introduce the new members of our research team!

Welcome from the Bohnam Lab



Happy New Year! I hope you and your loved ones are happy and healthy in these challenging times! My team has been focused on our research to advance the science for the sickle cell disease community. I am excited to share our latest INSIGHTS newsletter with you. Please feel free to reach out with any questions or comments. We would love to hear from you.

Vence L. Bonham, JD., Principal Investigator
Email: **bonhamv@nih.gov**

INSIGHTS Study Updates

We sincerely appreciate our study participants! Although the COVID-19 pandemic put the INSIGHTS Study on hold, we are gearing up to see study participants at the Clinical Center later this year. We have 24 more people to see before we meet our goal of 200 INSIGHTS participants. In early 2020, our second research site at Montefiore Medical Center in the Bronx, New York, met their goal of 100 participants. Special thanks to the Montefiore research team, led by Dr. Caterina Minniti, for their dedication to the INSIGHTS Study's success and the sickle cell disease (SCD) community. We opened a third research site in Sierra Leone. That team plans to see 250 INSIGHTS participants. If you know anyone with SCD, please inform them about our study. We can be reached at **scdlegulcerstudy@mail.nih.gov**.

Our friends at the National Institute of Allergy and Infectious Diseases (NIAID) are studying how genes affect our blood vessels. **They are looking for adults with Sickle Cell Trait to participate in their study at the Clinical Center in Bethesda, Maryland.** Persons interested can email **alpha.study@nih.gov** or call **301-761-5667**.

We have partnered with researchers in the NIH Clinical Center and are happy to announce we are starting a new study looking at Dietary Behavior in adults living with SCD. If you are interested in participating or would like more information, please contact Ashley Buscetta at **240-381-9453** or **ashley.buscetta@nih.gov**.

Introducing the New Members of the INSIGHTS Research Team

Hasmin Ramirez, MPH

Hasmin is our new research coordinator in the Bonham lab. She completed her MPH at George Washington University Milken Institute School of Public Health this past spring.

Jameson Floyd

Jameson has been a post-baccalaureate fellow in the Bonham lab since August 2020. He received his bachelor of science in physics from Morehouse College and plans to enter medical school in fall 2023.

Kiana Amini

Kiana has been a post-baccalaureate fellow in the Bonham lab since August 2020. She is originally from Chicago, and she graduated from the University of Chicago in 2020 with a bachelor of arts in sociology. She plans to apply to graduate/professional school in the upcoming year.

Faeben Wossenseged

Faeben has been a post-baccalaureate fellow in the Bonham lab since August 2020. She received her bachelor of science in biology from the University of California, Santa Barbara in 2020. She plans to apply for medical school in the upcoming year.

Shameka Poetry Thomas, Ph.D

Shameka is an early-career medical sociologist and intramural postdoctoral fellow who focuses on noninvasive prenatal testing (NIPT) among Black women with and without genetic conditions, such as sickle cell disease.

Related: **Storytelling Through Narrative Medicine: Measuring the Lived-Experiences of Black Women's Reproductive Health**

Corinne April Iolanda Conn

Corinne is a former post-baccalaureate fellow in the Bonham lab and now a fourth year medical student at University of California, San Francisco, returning to work with the Bonham lab as a special volunteer through July 2022.

Marilyn Baffoe-Bonnie

Marilyn is a third-year sociology doctorate student at Rutgers University and predoctoral fellow in the Bonham lab and Department of Bioethics. She studies genetic technologies and sickle cell disease.

Anitra Persaud

Anitra Persaud is a former post-baccalaureate fellow in the Bonham Lab and is now a fourth-year medical student at University of Pennsylvania, returning to work with the Bonham lab as a special volunteer through December 2022.

Current Projects

INSIGHTS in Sierra Leone

We extended our SCD research efforts to Sierra Leone! Our collaborator, Dr. Cheedy Jaja, Ph.D., MPH, has expertise in SCD research and is committed to building healthcare infrastructure for the SCD community in Sierra Leone. Dr. Jaja and his dedicated team plan to see 250 INSIGHTS study participants in both Freetown and Kono. All participants will receive free medical care at the SCD clinics that Dr. Jaja has helped to established, creating and ensuring continuity of care for SCD individuals.

Living With SCD During COVID-19 Survey

When the pandemic sent us all home to telework and put the INSIGHTS Study on hold, we pivoted and opened the "Living with Sickle Cell Disease in the COVID-19 Pandemic" study online. In this study, we ask questions about general health and well-being, healthcare utilization, COVID vaccines, and trust in institutions. We invited adults living with SCD in the United States to take the survey every 6 months over the course of 2 years. We are currently in the third round of the survey and are busy analyzing the data we collected from the first two rounds. We hope to share more with you in the next newsletter.

Psychological Resilience in Adults Living with Sickle Cell Disease (SCD)

The Bonham lab has been studying resilience as a psychological capacity within the SCD community since the development of INSIGHTS and began collecting participant narratives about resilience in 2018. We have begun to analyze these stories to illustrate how our community understands their own resilience as it relates to SCD. We are excited to spotlight the ways in which resilience relates to aspects of our participant's lives and their own identities. The interviews collected are currently being used to re-define what resilience means for people living with SCD and contribute to the broader understanding of what affects psychological resilience in other chronic disease states.

Institutional Medical Mistrust

Medical mistrust in institutions like healthcare organizations and governments can prevent the implementation of public health strategies like vaccination and contact tracing. Therefore, measuring medical mistrust is key to develop interventions that rebuild trustworthiness. We created the Institutional Medical Mistrust Scale (IMMS), which includes three separate subscales to measure medically related mistrust in health care organizations, local and state governments, and the federal government. We draw on two waves of data from a longitudinal study on the social and psychological experiences of people living with SCD in the United States during the COVID-19 pandemic. Wave 1 had 186 participants and focused on COVID-19 vaccine trial participation and wave 2 had 142 participants and focused on willingness to accept/receive the COVID-19 vaccine. The results confirmed strong consistency and validity for these three subscales and that each subscale can be interpreted with a single factor solution. These findings underscore the ability of the IMMS to be used across different assessments of medical mistrust as well as the bioethical and theoretical need to define medical mistrust more precisely in future studies.

Return of Results and Secondary Findings

Our team is moving forward with the DNA (whole genome) sequencing phase of the INSIGHTS study. Researchers should check if their participants have a specific list of genetic differences that are linked to a small number of diseases. On the small chance that you have one of these rare DNA differences, we will notify you of these findings. If you have a positive finding, you may want to provide an additional blood or saliva sample so that we can verify the result in a clinical lab. We will also help you understand what the results mean for your health.

We're interested in what these results mean for adults living with SCD. One of our new studies involves interviewing adults living with SCD about DNA sequencing and secondary findings. To better understand the impact of such results, another study will follow the behaviors of participants who have results returned. Through this research, we hope to give voice to the SCD community on one of the most important topics facing genomics researchers today.

Democratizing Education for SCD Gene Therapy

With the expansion of gene-based therapies to reduce the symptoms or restore blood cells to normal shape and eliminating severe pain episodes, our team is our team is organizing a project to create open-source, high-quality and accessible educational materials for patients and families to use to learn more about gene therapy. To gather information for these materials, we will host a multi-day workshop with stakeholders from industry, government, researchers, health professionals, patients and advocacy groups. By gathering diverse perspectives, we will be equipped to create educational materials that will allow individuals living with SCD to make informed decisions about gene therapy. We are in the process of recruiting participants for this project.

Sickle Cell Trait Associated Clinical Outcomes

In 2018, the Bonham lab and collaborators published a systematic review on complications associated with sickle cell trait (SCT). SCT is largely thought of as a carrier state with little to no associated complications; however, this systematic review found varying strengths of evidence that SCT increases the risk of certain clinical outcomes. Building off this, we are planning a study in collaboration with NIH's All of Us Research Program to determine how often SCT-associated complications occur and external factors that may increase risk of occurrence among a cohort of SCT carriers. All of Us aims to build a diverse health database to help researchers determine the effects that environment, lifestyle and biology have on health.

Current Projects (cont'd)

Examining Black Women's Perceptions of Non-Invasive Prenatal Testing (NIPT) for Sickle Cell Disease

Advances in reproductive health technologies, such as non-invasive prenatal testing (NIPT), have not only become standard prenatal care in the United States, but also are being developed to screen for SCD. NIPT screening procedures are considered non-invasive because they use cell-free DNA to detect for genetic conditions and reduces procedure-related miscarriages. The majority of NIPT clinical trials, enroll predominately white cohorts, which fundamentally exclude the varied experiences of Black women with genetic conditions, such as SCD. This study examines the degree to which NIPT uptake and decision-making processes can still become socially invasive for Black women (with and without SCD). This study investigates racial disparities regarding how Black women navigate and negotiate NIPT, as patient-perceptions of NIPT vary across social identities and illness experiences. Our study design employs a narrative-medicine approach that functions as a social scientific method, allowing patients to interpret their own healthcare experiences. Data collection is completed.

General Health Resources

COVID-19 Boosters (CDC)

COVID-19 Vaccine Dosing Recommendations (The Medical Letter)

Flu Shots (CDC)

New SCD Findings/Publications

Bonham Lab Publications

- Lower Hair Cortisol Among Patients With Sickle Cell Disease May Indicate Decreased Adrenal Reserves
- Insights Into the Skin Microbiome of Sickle Cell Disease Leg Ulcers
- Social Support Networks of Adults With Sickle Cell Disease
- Emergency Department Utilization for Patients Living With Sickle Cell Disease: Psychosocial Predictors of Health Care Behaviors
- Cultivating Diversity as An Ethos With An Anti-Racism Approach in the Scientific Enterprise
- Splenic Infarction in Sickle Cell Trait: A Comprehensive Systematic Review of Case Studies
- Returning Genomic Research Results to Low-Resource Research Participants. Public Health Genomics

INSIGHTS Team Members

Vence Bonham, Study Director
Ashley Buscetta, Research Nurse Practitioner
Hasmin Ramirez, Study Research Coordinator
Faeben Wossenseged, Post-Baccalaureate Fellow
Kiana Amini, Post-Baccalaureate Fellow
Jameson Floyd, Post-Baccalaureate Fellow
Shameka Poetry Thomas, Post-Doctoral Fellow
Corinne Conn, Special Volunteer
Marilyn Baffoe-Bonnie, Pre-Doctoral Fellow
Anitra Persaud, Special Volunteer