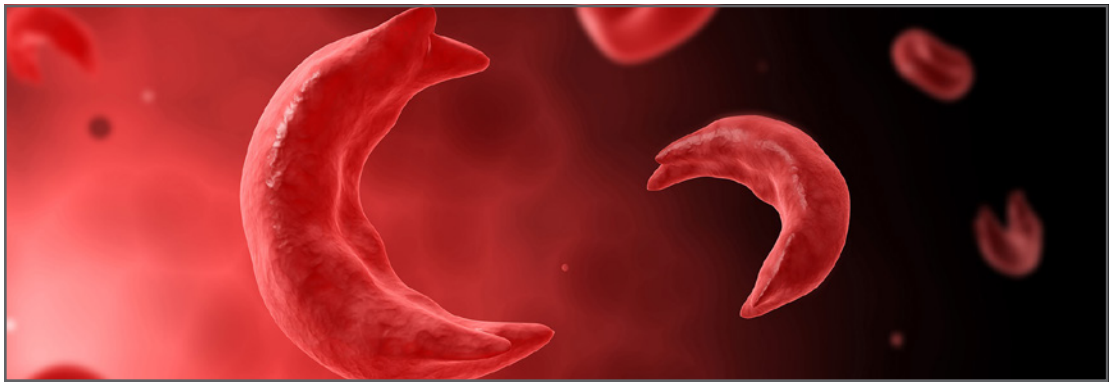

National Human Genome Research Institute

# INSIGHTS



## 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 Bonham Lab

We are excited to share our Winter 2024-25 INSIGHTS newsletter with you! We have many updates in the lab that we want to share with you. We have closed the INSIGHTS study and are busy analyzing the data. We thank you for your contribution to research on sickle cell disease. We are working hard to publish the findings from the research study and share with you and the sickle cell community. Our goal is to have a better understanding of this disease and how it's affected by your genes, environment, and social well-being. I want to send a special thank you to Ashley Buscetta for her ten years working on the INSIGHTS study, you will be missed. Please feel free to reach out with any questions or comments. We would love to hear from you!


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


I would like to share with you that my Bonham Era is coming to a close. I am not going far- just over to the extramural program at the National Cancer Institute. I want to thank each and every one of you for spending time with me through the INSIGHTS Study and teaching me everything that I know about sickle cell disease. You left me inspired, determined, and committed to making a difference.

I will be forever grateful to Vence and the entire Bonham Lab Family for the opportunity to make an impact on each other and on sickle cell research.

**Ashley Buscetta, N.P.**

## INSIGHTS Study Updates

Participants from all over the US (281 people!) and Sierra Leone (124 people!) have completed the INSIGHTS study and we are excited to announce that we have completed study recruitment! Participants travelled to the Clinical Center in Bethesda, MD; Montefiore Medical Center in the Bronx, NY; and to Freetown and Kono in Sierra Leone to complete our study and provide research samples. We can now turn our full attention to analyzing all of the data that was collected from everyone and hopefully find some answers to why there is so much variation in sickle cell complications, especially leg ulcers.

## A Snapshot of Members of the INSIGHTS Research Team

### Jacob Aickareth

Jacob was a postbaccalaureate fellow in the lab. His research focused on medical mistrust, SCD-related stigma, and how to measure disease severity in SCD. He is currently in medical school at Texas Tech University.

### Tiffany Jackson

Tiffany was a postbaccalaureate fellow in the lab. Her research focused on leg ulcers related to SCD, complex collaborations with community organizations, and dietary factors related to health and SCD. She is currently in medical school at the Philadelphia College of Osteopathic Medicine.

### Devan Stoeling

Devan is a new post-baccalaureate fellow in the lab, joining us in November 2024. She graduated from Spelman College in 2023 with a bachelor's in health sciences. Devan has a deep passion for community health and is interested in public health research focusing on health disparities.

### Marilyn Baffoe-Bonnie

Marilyn was a predoctoral fellow in the Bonham Lab and Department of Bioethics. She successfully defended her Ph.D. in sociology at Rutgers University in the spring of 2024 and is currently completing a fellowship at the University of Pennsylvania. She studies genetic technologies and sickle cell disease.

### Diba Seddighi

Diba was a postbaccalaureate fellow in the lab. Her research focused on community-engagement, social network analysis, and utilization of race in clinical practice. She is currently pursuing her Masters degree in Global Health through a Fulbright Fellowship at Koç University in Istanbul, Turkey.

# Current Projects

## Democratizing Education for Sickle Cell Disease Gene Therapy

A lot has happened since we launched the Democratizing Education for SCD Gene Therapy website in 2022…. In December of 2023, the Food and Drug Administration (FDA) approved two gene therapies to treat SCD. This means that gene therapy is now available commercially, and not just through clinical trials. Clinical trials for gene therapy continue though as we continue the research in younger patients and discover better ways to deliver the therapy. With all of these happenings, we wanted to update the educational content on our webpages to reflect the changes. Our updated pages include information on the two FDA approved therapies and videos to help explain some of the more complex topics, like the different gene therapy approaches.


## Podcast Alert

Over the summer, Dima Hendricks and Wunmi Bakare and the team at Through the Pain launched a 6 episode podcast series called Through the Genes. The podcast features our very own, Vence Bonham, who discusses the history of SCD in episode 1. Wunmi and Dima go on to interview patients who underwent transformative therapies, caregivers, NHLBI researchers, and other clinicians who all share their own perspective.

#ThroughTheGenes PODCAST

Wunmi and Dima continue to share their stories and were recently interview by the DNA Today podcast. This episode is an insightful look into the Through the Genes podcast and definitely worth a listen!

# Recent Bonham Lab Publications

### Bidirectional Relationship Between Sickle Cell Disease and Food Insecurity: Scoping Review

Health Equity

Authors: Ashley Buscetta, Khadijah Abdallah, K Jameson Floyd, Faeben Wossenseged, Corinne Conn, Hasmin Ramirez, Vence Bonham

At the start of the pandemic, we surveyed adults living with SCD across the nation about how they were being impacted. We used some of the same surveys in the INSIGHTS study and were able to compare results before and during the pandemic. This paper focused on psychological resilience and found that while resilience decreased during COVID, it was associated with better mental and physical health and lower perceived stress and emotional distress.

### Patient perspectives on noninvasive prenatal testing among black women in the United States: a scoping review

BMC

Authors: Shameka Thomas, Madison Keller, Tiara Ranson, Rachele Willard

Dr. Shameka Poetry Thomas was a post-doctoral fellow in the lab from 2020-2022. Dr. Thomas' is a medical sociologist and reproductive health equity scientist. Her research in the lab focused on patient-perceptions of noninvasive prenatal testing among Black women with sickle cell disease.

Dr. Thomas conducted 40 semi-structured interviews with Black women with and without SCD on their attitudes, perspectives, acceptability and willingness to participate in NIPT screening. This is the first empirical study to engage Black women with and without SCD in the United States. Key themes identified the complexities based on lived experiences of SCD, prenatal care, lack of interaction among health providers and decision-making. She also found that even when Black women with SCD share common lived experiences navigating their condition and motherhood, they perceptions of NIPT screening were different.

### "Resilience?" perspectives from adults living with sickle cell disease


Authors: Corinne Conn, Melissa Creary, Stacy Desine, Vence Bonham

A study led by former fellow and now psychiatry medical resident, Dr. Corinne Conn, using data from INSIGHTS. The paper explored new dynamic definitions of resilience in those living with SCD as "not giving up", "how one deals with challenges", and "moving forward". Findings revealed the current definitions of resilience do not meet the needs of the SCD community and encourages SCD providers to have conversations about how people approach different challenges.

### Leg ulcers are indicators of systemic dysfunction in individuals with sickle cell disease


Authors: Tiffany Jackson, Ashley Buscetta, Hasmin Ramirez, Vence Bonham, Caterina Minniti

Tiffany Jackson wrote a letter to the editor of the American Journal of Hematology using data from the INSIGHTS study to share her findings on the clinical associations with leg ulcers. This paper reveals that those with leg ulcers had wider pulse pressures, higher markers of hemolysis and inflammation, and potential connection to kidney dysfunction. Leg ulcers can be a sign that there are more systemic health problems that lie beyond the borders of the wound.

### Views of adults living with sickle cell disease on the theoretical return of secondary genomic findings


Authors: K. Jameson Floyd, Faeben Wossenseged, Ashley Buscetta, Grace-Ann Fasaye, Vence Bonham

Jameson Floyd was a postbac fellow in the lab from 2020-2023. He interviewed 30 adults living with SCD on their views and perspectives of receiving actionable secondary genomic findings.

*What are actionable secondary genomic findings? When researchers are studying your DNA, there is a chance they can incidentally find changes in the gene (variants) that has potential medical value but is not related to your medical condition.*

This was the first study to focus on the views of adults living with SCD. The paper shares that the majority of participants favored receiving these results but also discussed the barriers and burdens that come with this type of information. As genetic testing becomes more widespread, it's important to understand the views of a diverse population so researchers can better understand the care that is needed and help to eliminate health disparities related to these findings.

### Patient Perceptions on the Advancement of Noninvasive Prenatal Testing for Sickle Cell Disease among Black Women in the United States


Authors: Shameka Thomas, Faith Fletcher, Rachele Willard, Tiara Ranson, Vence Bonham

Dr. Thomas also published in the American Journal of Empirical Bioethics on this topic helping to expand the ethical discourse on the social implications of this genetic technology on the health of Black women. The findings revealed a complex intersection of lived experiences, prenatal care, and decision-making.

### An examination of John Henryism in adults Living with sickle cell disease


Authors: Khadijah Abdallah, Kayla Cooper, Ashley Buscetta, Hasmin Ramirez, Harold W. Neighbors, Vence Bonham

Past and current Bonham Lab members published a paper in collaboration with Dr. Harold W. Neighbors, about John Henryism among INSIGHTS participants. John Henryism is a term used to describe a coping mechanism some individuals use to respond to certain social stressors and structural racism. It is believed that John Henryism refers to a tendency to work harder in response to stressors which can impact your health. The term was created by Dr. Sherman James, who found that John Henryism was related to blood pressure among Black Americans with low socioeconomic status under certain conditions. For our study, we used data from the INSIGHTS study to study sleep and John Henryism. We found that John Henryism was associated with higher sleep dysfunction. To our knowledge, this is the first study of its kind and believe further research is important to understand John Henryism active coping and the management of mental and physical health of individuals living with sickle cell disease.

### Examining resilience of individuals living with sickle cell disease in the COVID-19 pandemic

BMC Psychology

Authors: Ashley Buscetta, Khadijah Abdallah, K Jameson Floyd, Faeben Wossenseged, Corinne Conn, Hasmin Ramirez, Vence Bonham

At the start of the pandemic, we surveyed adults living with SCD across the nation about how they were being impacted. We used some of the same surveys in the INSIGHTS study and were able to compare results before and during the pandemic. This paper focused on psychological resilience and found that while resilience decreased during COVID, it was associated with better mental and physical health and lower perceived stress and emotional distress.

### Ancestry-independent risk of venous thromboembolism in individuals with sickle cell trait vs. Factor V Leiden

blood advances

Authors: Keng-Han Lin, Julia M. Granka, Anjali Shastri, Vence Bonham, Rakhi Naik

At the beginning of September, Mr. Bonham and colleagues published a paper that found that being a carrier for sickle cell trait increases an individual's risk of blood clots. This is the largest and most diverse study of sickle cell trait to date, with data from over 19,000 people. Data included in the study were from participants of 23andMe, Inc., a direct-to-consumer genetics company, with most participants being from the United States (~90%).

## Other clinical trials

### Sickle Cell Disease and Diet Study

Our friends in the Translational and Biobehavioral Health Disparities Unit in the Clinical Center at NIH are conducting a study for adults living with SCD to examine how diet affects disease. You are eligible if you're 18 years or older, have SCD, and are NOT pregnant. The study can be done in person at the Clinical Center in Bethesda, MD or via telehealth. It involves a clinic visit, bloodwork, and surveys. Compensation is provided. If you are interested please contact Ashley Buscetta at ashley.buscetta@nih.gov or Nicole Farmer, MD at nicole.farmer@nih.gov

## INSIGHTS Team Members

**Vence Bonham,** Study Director
**Ashley Buscetta,** Research Nurse Practitioner
**Hasmin Ramirez,** Research Coordinator
**Corina Galindo,** Program Specialist
**Devan Stoeling,** Postbac Fellow

**2023-2024 Fellows**

**Marilyn Baffoe-Bonnie,** Pre-Doctoral Fellow
**Diba Seddighi,** Postbac Fellow
**Tiffany Jackson,** Postbac Fellow
**Jacob Aickareth,** Postbac Fellow