

***The goal of our study is to understand the social factors that may influence health communication about sickle cell disease and sickle cell trait.***



**Why participate?**

You and all of the relatives you refer to our study who participate will each receive compensation as a token of our appreciation for willingness to take part in our study. We want to learn more about how families with sickle cell disease and trait interact.

The results of this study may help us identify families' needs and develop ways to help families in the future.

**You can participate if:**

- You have sickle cell disease or trait OR You are related to someone with sickle cell disease or trait
- You are 18 years or older
- You are willing to share your family health history
- You are willing to answer questions about how your family shares information about sickle cell disease and sickle cell trait

**What can you expect?**

Our study will include:

- A 45-60 minute phone interview.
- A 45-60 minute online survey.
- We will ask you to invite your family members to take part in our study.

Your participation is completely voluntary. You do not have to answer any questions you do not feel comfortable with.

All of the information that you share with us will be kept confidential, meaning no one outside of our research team, including members of your family, will have access to your responses or comments.



For more information  
on sickle cell disease  
resources please visit:

Sickle Cell Information Center  
[https://scholarblogs.emory.edu/  
scinfo/](https://scholarblogs.emory.edu/scinfo/)

CDC Sickle Cell Disease  
National Resource Directory  
[http://www.cdc.gov/ncbddd/  
sicklecell/documents/sicklecell  
directory\\_508.pdf](http://www.cdc.gov/ncbddd/sicklecell/documents/sicklecell_directory_508.pdf)

Genetics Home Reference:  
Sickle Cell Disease  
[http://ghr.nlm.nih.gov/  
condition/sickle-cell-disease](http://ghr.nlm.nih.gov/condition/sickle-cell-disease)

CDC: Sickle Cell  
Disease Information Page  
[http://www.cdc.gov/ncbddd/  
sicklecell/index.html](http://www.cdc.gov/ncbddd/sicklecell/index.html)

For more information about  
this study, please contact:

1-866-585-7192, ext. 2  
[SickleCellFamilyStudy@mail.nih.gov](mailto:SickleCellFamilyStudy@mail.nih.gov)

*Sharing Family Health  
Information about*

## **Sickle Cell Disease and Sickle Cell Trait**



*A Research Study*



**NIH** National Human Genome  
Research Institute