

Sickle Cell Disease and the Genomic and Gene Therapy Needs of Stakeholders

NCT04416178

Status RECRUITING
Sponsor St. Jude Children's Research Hospital
Enrollment 352 participants

Key Eligibility Criteria

Inclusion (10)

- Group 1 (Survey and Interview) Participants only:
- Parent of child with HbSS, HbS/β⁰thalassemia, or HbSC aged 12 months to 18 years at study initiation, irrespective of clinical severity or patient aged 13-18 with aforementioned SCD genotype.
- Informed consent from parent or legal guardian and assent of adolescent participant.
- Has been previously approached for SCRIPP.
- Group 2 (Focus Group) Participants only:
- ... and 5 more (see full listing online)

Exclusion (3)

- Participants who are unable to converse fluently in English will be excluded. (Permanent)
- Condition or chronic illness, which in the opinion of the PI/Co-I, makes participation unsafe or untenable (i.e. cognitive impairment, concurrent acute morbidity). Participant may be re-evaluated.
- Inability or unwillingness of research participant or legal guardian/representative to give written informed consent.

Locations (1 total)

St. Jude Children's Research Hospital, Memphis, Tennessee, United States