Quality of Life in Pediatric Participants With HHT

Status: RECRUITING

Eligibility Criteria

Sex: ALL
Age: 2 years to 25 years old
Healthy Volunteers: This study is NOT accepting healthy volunteers
Inclusion Criteria:

- • Patient aged 2-25 years with a confirmed (either genetic or clinical) diagnosis of definite HHT
    - Parent or legal guardian willing and able to complete the caregiver survey for patients aged 2-17.
    - For patients >18, willing and able to complete the patient survey.
    - Receipt of care through CCHMC (at least one visit with genetic counselor or director of HHT Center)
    - Ability to complete survey in English
    - For self-report: patient age greater than or equal to 8 years old that assent to survey.

Exclusion Criteria:

- Patients that are older than 25 years old.
- Patients that are younger than 2 years old.
- Individuals without definite HHT diagnosis.

Conditions & Interventions

Conditions:
Hereditary Haemorrhagic Telangiectasia (HHT)
Keywords:
HHT, QOL, Pedatric

More Information

Description:
This observational study evaluates health-related quality of life (HR-QoL) in pediatric and young adult patients aged 2-25 years with Hereditary Hemorrhagic Telangiectasia (HHT). Eligible participants are patients receiving care at Cincinnati Children's Hospital Medical Center and / or their caregivers. Participants will complete validated quality-of-life questionnaires assessing physical, emotional, social, and disease-specific functioning over the past 30 days. A paired retrospective chart review will assess disease severity and clinical utilization, including procedures and imaging studies. The primary objective is to describe mean QoL scores for this population. Secondary objectives include evaluating associations between QoL scores, disease severity, and clinical utilization.

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