Global Patient Registry of Inherited Retinal Diseases

Status: Recruiting

Eligibility Criteria

Sex: Male or Female
Age Group: Not specified

Inclusion Criteria:

- at least 3 years old - documented genetic diagnosis of X-linked retinitis pigmentosa (XLRP) or Achromatopsia (ACHM) with any signs or symptoms of disease - Caregiver participants must be at least 18 years old and identified by the participant as the primary care giver

Exclusion Criteria:

- received a treatment in an Inherited Retinal Disease (IRD) related interventional trial, or is being screened for an IIRD-related interventional trial - Caregiver participant has an IRD and has visual impairment

Conditions & Interventions

Conditions:
Children's Health, Vision & Eyes

More Information

Description: The purpose of this research study is to collect timely and relevant data that will support the evolving research needs of the Inherited Retinal Disease community (IRD), in order to provide insights that can be used to improve patient management, and to inform development of future treatments. No visits, assessments, or procedures are mandated, and follow-up will be captured as part of your standard of care. The planned length of registry is of 8 years with a potential to extend the duration as needs evolve.
Study Contact: Meaghyn Kramer - krame706@umn.edu
Principal Investigator: Sandra Montezuma
IRB Number: SITE00001950