



INHERENT

International Hemoglobinopathy Research Network



The **International Hemoglobinopathy Research Network (INHERENT)** is an international network that aims to study the role of genetic modifiers in hemoglobinopathies, including sickle cell disease and β -thalassemia, through large multi-ethnic **genome-wide association studies**.

Objectives:

1. Discovery of new modifiers for hemoglobinopathies.
2. Validation of previously reported modifiers.
3. Pooling and analysis of existing data.
4. Standardization of phenotypic definitions across the network.
5. Development of a research resource of GWAS data on hemoglobinopathies.

Target Size:

- >30000 hemoglobinopathy patients (pediatric and adult).

Who Can Participate:

- Any group that can submit a minimum of **30 hemoglobinopathy patients** with their core phenotypic description.
- Local ethical approval will be required for participation.
- Participation either through a Consortium or directly.

Data/Sample Management Principles:

- Data ownership stays with the participant.
- No central storage of samples will be needed.
- Genotyping will be performed centrally to allow for downstream analyses.
- Genotype data (after quality control and imputation) will be sent back to the participants and will be also stored centrally to allow for combined analyses.
- Summary data will be publicly available.

Management Structure:

Formal Consortium structures and procedures will be followed, including a Memorandum of Understanding, Steering Committee, Data Access Committee, Authorship Agreements, International Advisory Board.

Participating Consortia:

- ITHANET
- RADeep
- ARISE
- HVP Global Globin Network
- ClinGen Hemoglobinopathy VCEP
- SADaCC
- SPARCO
- REDAC
- International Health Repository

INTERESTED IN PARTICIPATING?

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