The Congenital Dyserythropoietic Anemia Registry (CDAR)

Status: RECRUITING

Eligibility Criteria

Sex: ALL
Age:
Healthy Volunteers: This study is also accepting healthy volunteers
Inclusion Criteria:

- Diagnosis of Congenital Dyserythropoietic Anemia (CDA), whether a genetic mutation is identified or not
- Evidence of congenital anemia/jaundice or a positive family history
- Evidence of ineffective erythropoiesis
- Typical morphological appearance of bone marrow erythroblasts
- All ages (ages 0-99)

Exclusion Criteria:

- Diagnosis of cancer
- Myelodysplasia
- Secondary dyserythropoiesis: e.g.; vitamin B12 deficiency or drug-related.

Note1: Patients with rare band 3 (SLC4A1) mutations recently described to be associated with dyserythropoiesis will be eligible since the mechanisms appear to involve direct participation of band 3 in the erythroblast mitosis and cytokinesis.

Note2: Siblings, parents, and family members of patients with confirmed CDA diagnosis are encouraged to participate in the study.

Conditions & Interventions

Conditions:
Congenital Dyserythropoietic Anemia (CDA)

More Information

Description:
The investigators have created and maintain a comprehensive registry for patients with the diagnosis of Congenital Dyserythropoietic Anemia (CDA) in North America. The goal of this registry is to collect long-term confidential data on patients with CDA in the US, Canada, and Mexico and maintain a bio-repository of de-identified patient blood and bone marrow specimens as a tool for the investigation of epidemiology, natural history, biology, and molecular pathogenetic mechanisms of CDA.

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