International Registry of Patients with Alpha Thalassemia

Inclusion: Any diagnosis of alpha thalassemia, including Hb H, non-deletion Hb H, and alpha thalassemia major

Parents, patients, or providers caring for a patient with alpha thalassemia may contact

Billie.Lianoglou@ucsf.edu or
Tippi.Mackenzie@ucsf.edu
(415) 476-2461

Specimen donations to advance this work may be coordinated at pregnancy termination, delivery, or postnatally.

ClinicalTrial.gov: NCT04872179

Program Goals

- Identify patient outcomes of therapies
- Improve clinical management of patients with ATM
- Improve medical decision making
- Improve quality of care
- Enable future cures (gene therapy/ gene editing for alpha thalassemia)

Join our community of experts at the International Alpha Thalassemia Consortium quarterly meetings

UCSF Benioff Children's Hospitals
Center for Maternal-Fetal Precision Medicine

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Treat Alpha Thalassemia Major Prenatally with In Utero Transfusion (IUT)

Serial IUTs provide functioning red blood cells that can successfully deliver oxygen to fetal tissue.

After birth, postnatal therapy is similar to beta thalassemia.

MISCONCEPTIONS about ATM

- Untreatable and fatal disease
- Termination of affected pregnancy is the best option
- 100% have poor outcomes due to lack of sufficient oxygen

WHAT WE KNOW IUTs for ATM can:

- Correct hydrops
- Prevent pregnancy complications
- Increase survival
- Improve neurologic outcomes

For pregnancies at risk for alpha thalassemia major, consider PUBS at the onset of hydrops to confirm anemia and discuss initiating in utero transfusions.

v. 10-2022

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