

UCSF BENIOFF CHILDREN'S HOSPITAL OAKLAND

NORTHERN CALIFORNIA

COMPREHENSIVE THALASSEMIA CENTER

What is Thalassemia?

Thalassemia is a genetic blood disorder that causes hemoglobin deficiency and severe anemia, starving organs of oxygen, which inhibits their ability to function properly. For more information, go to www.thalassemia.com.

How is thalassemia treated at Children's?

Once universally fatal, today thalassemia can be treated as a chronic disease. The major cause of illness and mortality has shifted from hemoglobin-deficient anemia to iron overload associated with chronic blood transfusion therapy.

Children's offers families a range of therapies to monitor and enhance hemoglobin levels, maintain and improve chelation therapy, and provide support for patients and their families with thalassemia.

With medical advances, leading-edge technology, and scientific research, children with thalassemia are living well into adulthood. As a result, we also provide care to adults with thalassemia.

Each year we host a thalassemia retreat, the only one of its kind that offers psychosocial support to teens and adults from around the country.

Our comprehensive care:

Children's emphasizes a multidisciplinary approach to maintaining good health. We have specialty cardiac, liver, endocrine, eye, dental, hearing and nutrition clinics. In addition, specialized nurses, social workers, genetic counselors, teachers, Child Life specialists, psychologists and other healthcare professionals work closely with the medical staff to provide support to patients and their families.

Our Facilities:

- ▶ 20-bed day transfusion and chemotherapy unit, including a pheresis program
- ▶ 25 inpatient beds on the hematology/oncology unit with private, filtered-air isolation rooms
- ▶ A bone marrow transplant unit and available housing for families during a child's extended treatment.

Our Research:

Children's has a renowned thalassemia research program. Our research allows us to offer patients and families the most up-to-date and innovative therapies. Research done at Children's has led to many advances in thalassemia treatment.

As part of each thalassemia patient's care, we consult with your family about studies your child may be qualified to participate in. Patients are never obligated to join any study; if a family chooses not to participate in a study, their child will still receive high quality healthcare.

Our research and clinical teams work together to provide the highest quality, integrated healthcare possible. We look forward to talking to you and your family about research studies available for patients.



510-428-3347

747 52nd St.
Oakland, CA 94609
www.childrenshospitaloakland.org
www.thalassemia.com

The center provides comprehensive care including:

- Primary through tertiary care for children and adults
- Education, outreach and genetic counseling
- Psychosocial services for patients, families and those at risk for carrying the disease.
- Nutrition education

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Care Team

Elliott Vichinsky, MD
Medical Director, Hematology/
Oncology

Tariq Ahmad, MD
Pediatric Endocrinologist

Paul Harmatz, MD
Pediatric Gastroenterologist

Greg Kurio, MD
Pediatric Cardiologist

Ash Lal, MD
Director, Thalassemia Clinical
Program

Lynne Neumayr, MD
Administrative Director/Associate
Hematologist/Oncologist

Howard Rosenfeld, MD
Pediatric Cardiologist

Sylvia Titi Singer, MD
Associate Hematologist

Mark Walters, MD
Director, Blood and Marrow
Transplant Program

Ellen Fung, RD, CCD, PhD
Nutritional Scientist, Certified
Bone Densitometrist

Laurice Levine, MA, CCLS
Senior Thalassemia Outreach
Coordinator/Child Life Specialist

Raquel Manzo
Clinical Coordinator

Wendy Murphy, LCSW
Social Worker

Connie Schroepfer, MS, RD, CSR
Dietician

Stephanie Welty, PNP
Thalassemia Nurse Practitioner

Marcela Weyhmiller
SQUID/Ferritometer Study
Coordinator

Treatments include:

Chelation Therapy

The goal of chelation therapy is to maintain the total body iron load in a near-normal range. This requires accurate measurements and expert medical management of each patient's iron load.

Iron Measurement: Children's is one of just two locations in the United States with equipment—known as a ferritometer or SQUID—so advanced it can measure the amount of iron stored in the liver using magnetic fields. This non-invasive, painless procedure takes less than 45 minutes. MRI technology is used to evaluate iron overload in the heart and assess cardiac function.

Iron Management: Children's experts help patients to find a chelation regimen suited to their medical needs and personal preferences. We show patients how to administer Desferal, a drug that removes excess iron from the body. Our participation in multiple drug trials led to the approval of Exjade, the first oral iron chelation therapy.

Non-Transfusion Treatment

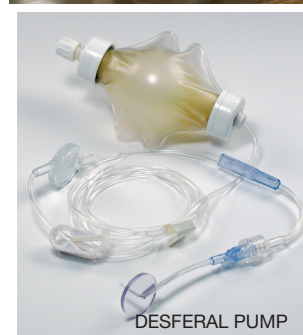
The vast majority of individuals who have thalassemia do not require regular blood transfusions. Children's specialists can manage these patients' disease through medical and psychosocial interventions.

Transfusion Therapy

Children's specialists can help you determine if transfusion therapy is right for a patient, and help you manage the special healthcare needs created by chronic transfusion.

Stem Cell Transplant/Bone Marrow Transplant (BMT)

Some children with thalassemia may be cured by a stem cell or bone marrow transplant. Our BMT program delivered the first cure of alpha thalassemia major in the United States. The program participates in national trials and offers options for using either related and unrelated stem cell donors. The Sibling Donor Cord Blood Program, the first of its kind in the world, offers a unique treatment option to families.



<http://thalassemia.com>



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Scan this with a QR reader app on your smartphone for the mobile version of the Thalassemia Standard of Care.

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Thalassemia Disease and Trait

Thalassemia represents a group of genetic blood disorders with a wide variety of associated symptoms that commonly appear in the first two years of life.

Symptoms may include:

- ▶ Skin with pale, jaundiced or anemic appearance
- ▶ Slow growth
- ▶ Poor appetite
- ▶ Fatigues easily
- ▶ At risk for infections

Thalassemia is a serious medical condition. If left untreated, it can result in medical complications that may lead to death.

Complications may include:

- ▶ Enlarged liver, spleen, and heart
- ▶ Thin and brittle bones
- ▶ Life-threatening infections
- ▶ Heart failure

High-Risk Populations Include:

- ▶ Italian
- ▶ Greek
- ▶ Southeast Asian (Vietnamese, Laotian, Thai, Singaporean, Filipino, Cambodian, Malaysian, Burmese, and Indonesian)
- ▶ Chinese
- ▶ Asian Indian
- ▶ African
- ▶ Middle Eastern
- ▶ Transcaucasian (Georgian, Armenian, and Azerbaijani)

Thalassemia: Quick Facts

- ▶ Thalassemia trait is not an illness and will never turn into one. Thalassemia is not contagious.
- ▶ A trait carrier of thalassemia will always be a trait carrier. The genetic trait is passed down from parents to children.
- ▶ Over 2 million people in the United States carry the genetic trait for thalassemia.
- ▶ There are two types of thalassemia trait: alpha thalassemia trait and beta thalassemia trait.
- ▶ Being a carrier of thalassemia does not cause health problems that require medical treatment. Thalassemia trait will not impair your work, diet, or exercise.
- ▶ Thalassemia carriers have smaller red blood cells that may cause a mild anemia. The anemia is so mild that it does not require medical treatment.
- ▶ Trait carriers do not need to take iron supplements unless a special blood test (serum iron or serum ferritin) confirms iron deficiency.
- ▶ Carriers can donate blood, provided that they are not anemic (do not have a lower hemoglobin than usual).
- ▶ If you and your partner both have thalassemia trait, for each pregnancy, there is a:
 - 25 percent chance that the child will have thalassemia disease.
 - 25 percent chance that the child will have normal hemoglobin levels.
 - 50 percent chance that the child will have thalassemia trait.



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The Northern California Thalassemia Center at UCSF Benioff Children's Hospital Oakland was established in 1991 to deliver comprehensive care to the growing number of thalassemia patients in the region. With more than 200 patients on active follow-up and over 800 patient visits every year, the center is one of the largest thalassemia programs in the country. It is one of the few federally funded centers in the nation. We are also at the forefront of research to develop new treatments for thalassemia.

Thalassemia Trait: Why Get Tested?

Family Planning

- ▶ If you and your partner carry the trait for thalassemia, your children could potentially be born with thalassemia disease.
- ▶ If either you or your partner carries the trait for thalassemia, your child could inherit the thalassemia trait.
- ▶ Pregnant women who carry the thalassemia trait may be more likely to develop anemia during their pregnancies. It is important to discuss this condition with your medical provider.

Your Health Is Important

- ▶ When a trait carrier has a blood test, his or her red blood cells may appear smaller than what is normal. Knowing that you carry the trait for thalassemia can prevent you from having unnecessary diagnostic tests.
- ▶ Doctors often mistake someone who is a carrier for thalassemia as having iron deficiency anemia due to slightly low hemoglobin and the small size of red blood cells. Therefore, they often prescribe iron supplements. Iron supplements do not improve hemoglobin levels in patients with thalassemia trait. Carriers should only take iron supplements if a blood test (serum ferritin) shows that they are iron deficient.

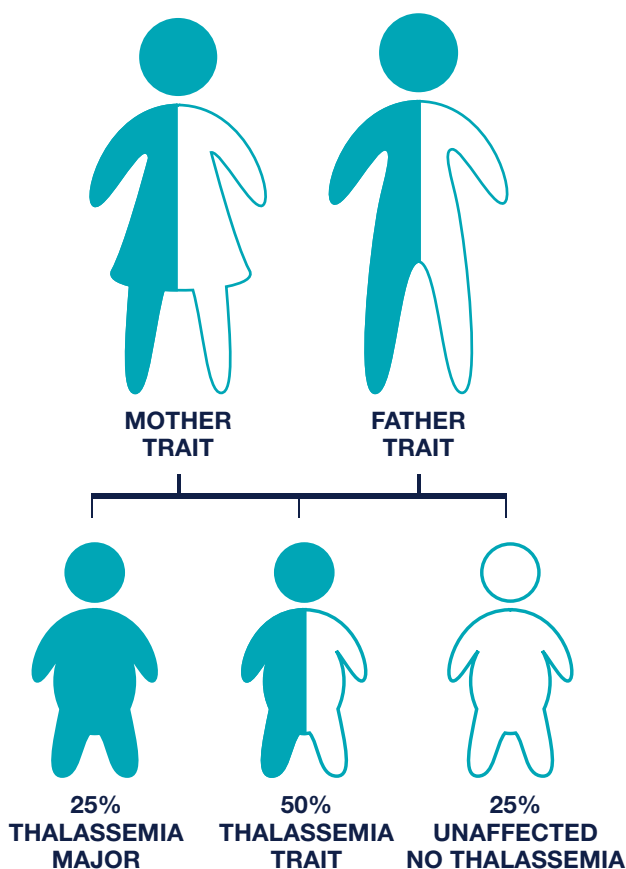
Getting Tested for Trait Is Easy!

If you have not been tested or are unsure of your trait status, it is best to get tested! Trait testing is easy and virtually painless and may be ordered by your health care provider.

- ▶ All you need is a blood test that checks the following:
 - CBC—Complete Blood Count
 - Hemoglobin electrophoresis with quantitative hemoglobin A2

Be Informed

- ▶ For more information, contact your doctor—or you can find a genetic counselor through the National Society of Genetic Counselors at www.nsgc.org.
- ▶ For more information about thalassemia trait and disease, or to find out more about the Thalassemia Outreach Program, please call (510) 428-3885, ext. 5427.
- ▶ If you have thalassemia disease and would like to come to our center for an evaluation, please call (510) 428-3347.



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