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
## Care Team

<table>
<thead>
<tr>
<th>Role</th>
<th>Name</th>
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<tbody>
<tr>
<td>Medical Director, Hematology/Oncology</td>
<td>Elliott Vichinsky, MD</td>
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<tr>
<td>Pediatric Endocrinologist</td>
<td>Tariq Ahmad, MD</td>
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<tr>
<td>Pediatric Gastroenterologist</td>
<td>Paul Harmatz, MD</td>
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<tr>
<td>Pediatric Cardiologist</td>
<td>Greg Kurio, MD</td>
</tr>
<tr>
<td>Director, Thalassemia Clinical Program</td>
<td>Ash Lal, MD</td>
</tr>
<tr>
<td>Administrative Director/Associate Hematologist/Oncologist</td>
<td>Lynne Neumayr, MD</td>
</tr>
<tr>
<td>Pediatric Cardiologist</td>
<td>Howard Rosenfeld, MD</td>
</tr>
<tr>
<td>Associate Hematologist</td>
<td>Sylvia Titi Singer, MD</td>
</tr>
<tr>
<td>Director, Blood and Marrow Transplant Program</td>
<td>Mark Walters, MD</td>
</tr>
<tr>
<td>Nutritional Scientist, Certified Bone Densitometrist</td>
<td>Ellen Fung, RD, CCD, PhD</td>
</tr>
<tr>
<td>Senior Thalassemia Outreach Coordinator/Child Life Specialist</td>
<td>Laurice Levine, MA, CCLS</td>
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<tr>
<td>Clinical Coordinator</td>
<td>Raquel Manzo</td>
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<tr>
<td>LCSW</td>
<td>Wendy Murphy</td>
</tr>
<tr>
<td>RD, CSR Dietician</td>
<td>Connie Schroepfer, MS, RD, CSR</td>
</tr>
<tr>
<td>Thalassemia Nurse Practitioner</td>
<td>Stephanie Welty, PNP</td>
</tr>
<tr>
<td>SQUID/Ferritometer Study Coordinator</td>
<td>Marcela Weyhmiller</td>
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## 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.

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**Stay connected to us**

- [http://thalassemia.com](http://thalassemia.com)
- [http://Facebook.com/CHRCOThal](http://Facebook.com/CHRCOThal)
- [http://Twitter.com/ThalassemiaCom](http://Twitter.com/ThalassemiaCom)
- [http://thalassemia.com/SOC](http://thalassemia.com/SOC)
- [http://www.youtube.com/user/ThalassemiaOutreach](http://www.youtube.com/user/ThalassemiaOutreach)
- [http://thalassemia.com/blog.aspx](http://thalassemia.com/blog.aspx)
- [http://NorCalThal.blogspot.com](http://NorCalThal.blogspot.com)

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

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*UCSF Benioff Children’s Hospital Oakland*

*Northern California Comprehensive Thalassemia Center*