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What is thalassemia?

Thalassemia is the name for a group of genetic blood disorders that cause severe anemia. Hemoglobin is the oxygen-carrying component of the red blood cells. It consists of two different proteins, an alpha and a beta. If the body doesn't produce enough of either of these two proteins, the red blood cells do not form properly and cannot carry sufficient oxygen. The result is a severe anemia that begins in early childhood and lasts throughout life.

What type of medical care does a child with thalassemia require?

The different types of thalassemia range from mild to severe in their effect on the body. Individuals with beta thalassemia major (also known as Cooley's anemia) show a reduction or absence of beta protein in the hemoglobin, causing a severe anemia that requires regular blood transfusions (every 2-4 weeks) beginning early in childhood. These extensive, lifelong blood transfusions lead to iron overload which must be treated with chelation therapy to prevent organ failure. Chelation therapy is a medication that removes iron from the body.

If the child you are adopting has thalassemia, it is important to learn as much as you can about the disorder to determine if it is something your family can manage. Some children may be listed as having thalassemia minor or intermedia, which are less severe forms of thalassemia, but are later found to have beta thalassemia major after they are given a DNA test. Only a DNA test can diagnose the type of thalassemia a child has. To learn more about the required medical care for a child with thalassemia, download our [Guide to Living with Thalassemia](#).

Are there any other medical conditions that can be caused by or are associated with thalassemia?

Sometimes there are medical complications that may be caused by the underlying anemia or by iron overload. It is important to know about these possible complications, how to recognize their signs, and how to treat and prevent them.

Is there a cure?

Currently, stem cell transplantation/ bone marrow transplantation is the only approved curative approach to thalassemia. Bone marrow transplantations have the highest success rates when the bone marrow donor is a sibling. In most cases, bone marrow transplantation between siblings is not possible for children in need of adoption because compatible biological siblings are often not available. Gene therapy holds promise for patients without a bone marrow match, but the procedure is still new and

experimental. However, clinical trials are making progress towards a universal cure. To learn more about the available curative approaches for thalassemia, download our [Guide to Living with Thalassemia](#).

What is the life expectancy of a child with thalassemia?

The life expectancy of a child with thalassemia is dependent upon the patient's type of thalassemia and the medical care the individual is receiving. In the United States, medical advancements are allowing people with thalassemia to live into their 50's and 60's. Many doctors now tell U.S. patients with thalassemia that they can expect a normal lifespan – provided that they receive regular transfusions and remain adherent with their chelation therapy. However, without proper treatment, patients are likely to experience medical complications and shortened lifespans. Children with transfusion-dependent thalassemia require frequent blood transfusions and iron chelation therapy, but many countries have severe blood shortages and children do not receive adequate care for their thalassemia. For these children, adoption can mean the difference between a long life and death in childhood.

What type of future can a child with thalassemia expect?

With proper medical care, a child with thalassemia can expect a bright future! Children with thalassemia go to school, play sports, and participate in a wide range of extracurricular activities. Individuals with thalassemia have fulfilling careers and many are now having children of their own. There are several medical and logistical challenges that come with managing thalassemia, but with careful planning and support, families can create routines to manage hemoglobin and energy levels and to remove excess iron from the body. To learn more about managing the different aspects of thalassemia, download our [Guide to Living with Thalassemia](#).

What are some of the factors a parent of a child with thalassemia needs to consider when investigating health insurance coverage?

It is important to review your health insurance plan to determine what the costs of medical care would be for your child. Ask your insurance provider to help you examine all aspects of your coverage. Be sure to assess which medical specialists your child would have access to, which drugs and tests would be covered, and what your co-pay would be. To help you plan your finances, you will want to know in advance about any thalassemia-related medical expenses that are not covered by your insurance policy. To learn more about medical insurance for thalassemia care and financial planning, download our [Guide to Living with Thalassemia](#).

Is there someone at Cooley's Anemia Foundation who I can consult with about the process of adopting a child with thalassemia?

To discuss your plans of adopting a child with thalassemia, you can consult with our Patient Services Manager, Eileen Scott. She can help connect you with thalassemia experts near you and provide other important resources as you go through the adoption process. To contact Eileen, email info@thalassemia.org.

What other resources are useful for families interested in adopting a child with thalassemia?

Some great resources for parents considering adopting, and specifically adopting a child with thalassemia and other special needs are the websites for [Rainbow Kids](#), [No Hands But Ours](#), [LWB Community](#), [MAA Education Resources](#), and [MAA Medical Reference Information](#). You can find interviews with several adoptive families of children with thalassemia on the CAF website at thalassemia.org/adoption.

What questions should I ask the adoption agency about a child with thalassemia who I am considering for adoption?

You will need to know as much as possible about your child's medical history—this would include bloodwork and DNA tests, their history of blood transfusions, and information about any chelation medication that the child has taken.

Is there any way to expedite my adoption process?

The hematologist whom you have selected to care for your child when they arrive in the U.S. may be able to write a letter on your behalf to help expedite your adoption. CAF can also write a letter advocating that your adoption process be expedited to ensure that your child will be able to come home and receive the medical care they need as soon as possible. Our Patient Services Manager, Eileen Scott, can help with this and can be reached by emailing info@thalassemia.org.

How can I prepare my child to travel to the U.S.?

It is recommended that thalassemia patients have their last blood transfusion session as close to their departure date as possible. It is also recommended that you begin consulting with your child's hematologist before travel so that they have your child's medical records and so that medical visits can be scheduled upon your return.

How often should I take my child who has thalassemia to a Thalassemia Treatment Center (TTC)?

There are 10 medical centers in the U.S. that are designated as Thalassemia Treatment Centers (TTCs). These expert centers are able to provide comprehensive care for people with thalassemia. The multidisciplinary team at TTCs includes hematologists and other specialists such as cardiologists, endocrinologists, liver specialists, dietitians, nurses,

social workers and genetics counselors who are experienced with thalassemia-related issues. Many people with thalassemia don't live near a TTC and so they receive their regular treatment through a local hematologist. These individuals should still try to visit a TTC once a year in order to receive a comprehensive care evaluation from experienced specialists. In addition, it can be valuable for their local hematologist to establish a relationship with the hematologist at a TTC. For a map of selected Thalassemia Treatment Centers in the United States, [visit this link](#).

Are there opportunities for a child with thalassemia to meet other children with thalassemia?

The Cooley's Anemia Foundation holds an annual Patient-Family Conference each summer to provide up-to-date information on thalassemia treatment, and to give members of the thalassemia community an opportunity to get to know each other and share experiences. A number of adoptive families participate in the conference each year and share in each other's journeys. CAF offers sponsorships to help defray the costs of attending this conference for those who need financial assistance. For more information on attending the conference and sponsorships, email info@thalassemia.org.

How can I register with the Cooley's Anemia Foundation?

The Cooley's Anemia Foundation is here to help you by keeping you informed about new research and care options, as well as opportunities to participate in events that we sponsor for the thalassemia community. To be added to our U.S. Patient Registry, [visit this link](#).