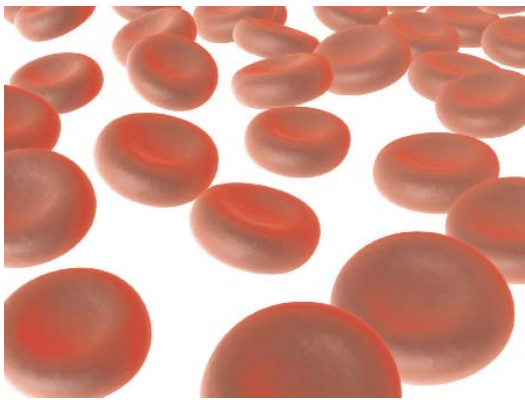
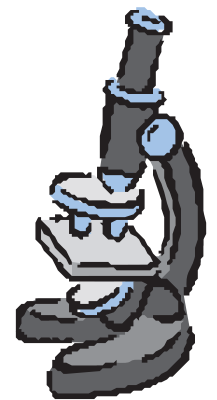


Being seen yearly at a TTC allows patients access to the latest advances in thalassemia management and non-invasive iron measurement technology (if eligible). New MRI technology is available at most TTCs to measure cardiac and liver iron content. "T2*" (pronounced tee-two-star) utilizes MRI technology to determine the degree of iron overload in the heart. "R2" also uses MRI technology and can determine the degree of iron overload in the liver.



Blood safety is a crucial issue for thalassemia patients. As a result of efforts by CAF, the federal government has established a Blood Safety and Surveillance program. The Program benefits the population at large by allowing the Centers for Disease Control and Prevention (CDC) to rapidly identify potential threats to the nation's blood supply. Patients who receive treatment at one of the TTCs are strongly encouraged to enroll in this program.

CAF fought to establish the Thalassemia Clinical Research Network (TCRN), a program run by the National Heart Lung and Blood Institute. The TCRN involves a wide range of medical professionals in thalassemia care and offers clinical trials for patients with thalassemia. To find out more information on current studies and eligibility criteria, please contact us. We also list some current clinical studies in our Medical Update.



The Cooley's Anemia Foundation Patient Services Department is here for you. But we can't help if we don't know what challenges you're encountering.

Please contact us at (800) 522-7222 or info@cooleysanemia.org with any questions or concerns you have. Let's see what we can do together.



Cooley's Anemia

FOUNDATION

Leading the Fight Against Thalassemia

Patient Services

Department

Listening.

Responding.

Informing.

Connecting.

...Caring.

The CAF Patient Services Department is here to assist individuals with thalassemia and their families meet the challenges of living with thalassemia.

We do this by:

Making connections between fellow patients and/or families.



CAF realizes that speaking to someone else who has gone through the same things you're going through can be a great source of support. Eva Chin-Li, our Patient Services Manager, can put you in touch with other patients and parents. In addition, our Program Coordinator, Eileen Scott, is a parent of a child with thalassemia. She is also available to help families and provide advice.



Every spring, our patient run support group, Thalassaemia Action Group (TAG), hosts a Patient and Family Conference that brings together patients and families from all over the United States. This is also a great opportunity to meet leading physicians in the field of thalassemia and learn about the most current treatment options.

Offering professional support in dealing with the challenges associated with thalassemia.

CAF recognizes that thalassemia impacts patients and families in different ways. Our social worker, Kathleen Durst, is committed to improving patient compliance.

We also can refer your questions and concerns to our Medical Advisory Board to obtain informed answers from the leading doctors in the field.



Encouraging patients to achieve higher goals.

CAF offers Incentive Awards for U.S. thalassemia major or intermedia patients interested in pursuing higher education on the vocational, undergraduate or graduate level. Applications are available on our website (www.cooleysanemia.org).



Providing Access to Health Care.



Our team will assist with pump repairs and will help with the loan or purchase of a pump.

We are also happy to help you navigate insurance issues and concerns and to provide many other services.

One of our primary goals is ensuring that patients receive the best possible care from the most experienced providers. Enclosed in this information pack is a contact sheet for the major Thalassemia Treatment Centers (TTC). We urge all patients to visit one of the TTC's for a Comprehensive Care Evaluation at least once a year.

We realize that not all patients are able to seek continual care at these Centers. However, visiting a Center annually will enable you to make sure that your current treatment is on track. In addition, these specialists can work with your home based hematologist to ensure you receive optimal care. If you do not live near a TTC, there may be a satellite center closer to your location. Please contact CAF for additional sites.

