

(TCRN) protocols should be eligible to have these tests covered by the Network. Start by checking with the Center where you wish to have the test performed and see what they can tell you.

*Some people are going to find out from these tests that they're doing great. But what if I find out that I've got way too much iron?*

Nobody likes to find out "bad" news about their iron load, but it's always better to know the exact state of your health so that things can be done to improve it. Making changes to your therapy can stop and sometimes reverse damage caused by excess iron. With accurate information about the iron in your body, your doctor can prescribe treatments that will help you.

*Non-invasive iron measurement is one of the most important advances to come along in the treatment of individuals with thalassemia. CAF strongly encourages all eligible patients to take advantage of this technology to help ensure that you receive the treatment you need to keep you healthy.*

*If you have questions about non-invasive iron measurements and thalassemia, please contact CAF (800-522-7222 or [info@cooleysanemia.org](mailto:info@cooleysanemia.org)). If we cannot answer your question, we will be happy to put you in touch with one of the Thalassemia Centers of Excellence.*



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*The information in this publication is for educational purposes only and is not intended to substitute for medical advice. You should not use this information to diagnose or treat a health problem or disease without consulting a qualified health care provider. The Cooley's Anemia Foundation strongly encourages you to consult your health care provider with any questions you may have regarding your condition.*

# Non-Invasive Iron Measurements

by Susan M. Carson, RN, CPNP, and Craig Butler

## Living with Thalassemia

Issues in Thalassemia Care

***Why are iron measurements important?***

If you have thalassemia and want to stay healthy, you have to deal with iron overload - from blood transfusions, from iron in the food you eat and from other issues related to the disease and its treatment.

All that extra iron can cause big problems. It can hurt your heart, liver and other organs, and create other complications.

Excess iron won't go away on its own, which is why thalassemia patients go through chelation therapy. And that therapy will be more effective if a doctor has the most complete and accurate measurements of the iron in your body as possible. S/he'll know whether the therapy is working fine or whether s/he needs to make some changes in it.

***Aren't serum ferritin measurements all that I need to know about the iron in my body?***

No. Serum ferritin levels give a good general idea of how well chelation therapy is working and are valuable for day-to-day decisions. But they only measure the iron in the blood, they don't necessarily tell you how much iron is in your heart and liver.

***What about a liver biopsy?***

In a liver biopsy, a tiny piece of the liver is removed to see how much iron it has. But a liver biopsy can cause discomfort. Also, you

may not get a clear picture of liver iron from a biopsy; sometimes some parts of the liver may have a lot of iron and some may have only a little. You may get a sample from a part that has very little iron and think that your liver is fine, when that may not be the case. Also, you can't really tell much about cardiac (heart) iron from a liver biopsy.

The non-invasive iron measurement technology discussed in this pamphlet is generally a better way to obtain information; however, for patients who are can't use this technology, a liver biopsy can provide valuable information.

### *So what's involved with a non-invasive iron test?*

Essentially, you're using an MRI (magnetic resonance imaging) machine to measure the amount of iron in your liver (using technology called R2) and in your heart (using technology called T2\*).



There are different kinds of MRI machines, but in most cases, they require that you lie down on a flat surface, kind of like a doctor's examining table. You may be asked to hold a water bag between one arm and your chest. A technician will position you on the table so that the machine can get the best "pictures" of the organ in question. Then the table is pushed inside the scanner, which is typically a large machine with a round hole in it.

The technician will let you know when s/he is conducting each scan and will ask you to remain as still as possible during scans. S/he may ask you to hold your breath for as long as you can during some scans.

During the process, which typically takes 30-40 minutes for each organ, the machine will hum and thump quite a bit. This is normal and is just the sound of magnets moving around and of the machine doing its work.

### *What's better, a big measurement or a little one?*

With T2\*, a bigger score means there is LESS iron in your heart. With R2, a bigger score means there is MORE iron in your liver.

### *Are there restrictions on who can have an R2 or T2\* test?*

Most restrictions have to do with whether you have a pacemaker or other metal items. Also, because the tests require a patient to remain still for fairly lengthy periods of time, children under the age of 5 are sometimes excluded, or may need to be sedated. People with claustrophobia may also need to consider whether they will feel comfortable, as most MRI machines are enclosed to a degree; medication can often help a person with claustrophobia to feel more comfortable with the experience.

### *Can I get these tests at any hospital, since it's an MRI?*

No. Many hospitals have MRI machines, but very, very few have the specific technology that is necessary to get R2 and T2\* readings. These tests should be performed at one of the Thalassemia Centers of Excellence, which have the appropriate technology as well as the expertise to analyze and interpret the results and determine if any follow-up is necessary. (For contact information for a Thalassemia Center of Excellence, call or email the Cooley's Anemia Foundation (CAF) at (800) 522-7222 or [info@cooleysanemia.org](mailto:info@cooleysanemia.org).)



### *How often should these tests be performed?*

Ideally, these tests should be performed yearly, as part of a thalassemia patient's annual comprehensive care examination.

### *Are these tests covered by insurance?*

Many patients run into problems in this area, which CAF and the Centers involved are working to resolve. Patients who are enrolled in the Thalassemia Clinical Research Network