Follow-up Testing

Follow-up testing is conducted to ensure that antibody levels are returning to normal, indicating that the intestine is healing on the new diet. For this reason, repeat intestinal biopsies are no longer necessary. These tests also indicate the extent to which a celiac is avoiding gluten, and can detect when hidden gluten has entered the diet.

How often should follow-up testing occur?
New celiacs should receive follow-up testing twice in the first year after their diagnosis. The first appointment should occur three to six months after the diagnosis, and the second should occur after 1 year on the gluten-free diet. After that, a celiac should receive follow-up testing on a yearly basis.

What tests are needed at follow-up appointments? How are they interpreted?
New guidelines on the diagnosis and treatment of celiac disease by the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition state that tTG-IgA testing should be used for follow-up care. Interpreting this test result is straightforward—a celiac on the gluten-free diet should have a negative test. The numerical value of the test is not important.

The University of Chicago Celiac Disease Center recommends additional testing, because the tTG test can sometimes be inaccurate in people with autoimmune disorders like Type 1 diabetes and thyroid disease. In addition, the tTG can sometimes become negative before a celiac has actually experienced significant healing.

For these reasons, Anti-Gliadin Antibodies (AGA) are also important. There are two types that need to be run: AGA-IgA, and AGA-IgG. In this circumstance, the numerical values of the tests are very important. The numbers should be as close to zero as possible, indicating a minimal antibody response to gluten. The additional advantage of these tests is that the blood can be drawn by any physician and sent to any laboratory.

I was diagnosed 15 years ago, and have never received follow-up testing. Why should I start now?
It’s never too late to begin follow up testing and to learn from the results. Food manufacturing practices change often, and even the most diligent celiac cannot keep up with all the changes. In addition, some celiacs find that current health problems may be related to celiac disease, such as anemia or bone density. The reverse is also true—some find that current health problems they’ve attributed to celiac disease aren’t related, because their
antibody levels indicate that celiac disease isn’t active. In either case, the patient and physician have received valuable information.

While follow-up testing is especially important for people in the first five years after diagnosis (this is when the most serious complications of celiac disease can occur) testing can help all celiacs know that they are doing well with the diet or need to make changes to protect their health.

I worry that I might be feeding my child the wrong foods, and I can’t tell if her stomachaches are from celiac disease or something else. For concerned parents, and for anyone who worries if they are making the right food choices for themselves or their child, follow-up testing can be very helpful. Negative test results reinforce that the family’s approach to a child’s gluten-free diet is working well.

I’ve been having joint pain, and I think it’s from celiac disease. I follow the diet very carefully.

Follow up testing is important, and can be performed when there is a question about whether or not a health condition, like joint pain, could be related to celiac disease. A series of positive antibody tests (indicating gluten in the diet) may indicate that a complication of celiac disease exists, in this case, joint pain. When antibody tests are negative, indicating a strong level of compliance with the diet, it is unlikely that celiac disease is contributing to the worrisome symptom. While this is not an exact science, follow up testing can often clarify whether or not a health condition could be a complication of celiac disease.

Follow Up Test #1:
tTG-IgA: This test result should be negative
The numerical value of the test doesn’t matter as long as the result is negative.

Follow Up Test #2
Anti-gliadin IgA: This result should have a very low negative value
In this case, the numerical value does matter, because a high negative test result still indicates that a patient is eating gluten. A low negative indicates that the diet is working well.

For more information contact the University of Chicago Celiac Disease Center at 773.702.7593 or www.CeliacDisease.net.