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Help With Blood Test Results

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Started by jbeilfuss, March 16, 2015

13 posts in this topic ibeilfuss

- Community Member
- Advanced Members
- . .
- 27 posts
- Gender:Male

Posted March 16, 2015

Sorry everyone to ask the same thing that so many others have asked - I swear I tried to page through the forum some to see if anyone had blood test results similar to mine. I couldn't find any

Anyway, I have been having trouble with my relationship with food over the last 6 - 12 months and last fall, I did a low FODMAP diet with my wife for a while (amazed at how much I felt better on it and it pretty much eliminated gluten). Of course, then along came Christmas and with all the junk food, parties, etc. I fell off the wagon and stopped the diet. By the middle of January, I was getting the same nausea that I have been experiencing before. I had one day I ate out at a restaurant for lunch and I got major bloated (I could like barely fit into my pants by that afternoon - ugh!), so I started up the low FODMAP thing again which all but eliminated gluten containing foods. Not quite two weeks after I started up the diet again, I have my annual physical and explained what was going on to my primary care physician. He decided to have some Celiac blood tests done as part of my testing. Here are the results (I had this done at LabCorp, BTW):

Deamidated Gliadin Abs IgA - result was 31 units (reference range is 0 - 19 with moderate to strong positive defined as > 30 units) and the notes on it for me read "Above High Normal"

Deamidated Gliadin Abs IgG - result was 7 units (reference range is 0 - 19, so this one was "normal")

tTG IgA - result was 5 U/ml (reference range is 0 - 3) with notes that read "Above high normal. Below the test results they had an additional ranges defined where 0 - 3 was negative, 4 - 10 was "weak positive" and >10 was positive. It also included the note "tTG has been identified as the endomysial antigen. Studies have shown that endomysial IgAantibodies have over a 99% specificity for gluten sensitive enteropathy"

That's all the Celiac related bloodwork he had done. Thoughts? I did go back to my GI doctor and now I am on the gluten challenge (no kidding!!!!!) for the next 8 weeks preparing for an endoscopy. Boy, mid-May can't come soon enough.

I would also add that about 13 years or so ago, I had some mysterious body pain and tingling of extremities with stiff joints. I got tested for a variety of conditions, but they finally found my bone density was low and I started taking Actenol and calcium to combat it. A few years ago, I also found the reason I was so tired was that I have low iron. I have been taking iron and vitamin C since that time.

Is Celiac possible or likely here, given what I have said?

Thanks in advance for the responses.

ravenwoodglass

Advanced Community Member





- Advanced Members
- 1.247
- 14,643 posts
- Gender:Female
- Interests: Gardening, photograpy, painting and drawing, textile arts, glass art, reading
- Location:Upstate NY

Posted March 17, 2015

This result :Deamidated Gliadin Abs IgA - result was 31 units (reference range is 0 - 19 with moderate to strong positive defined as > 30 units) and the notes on it for me read "Above High Normal" is specific to celiac.

No matter what the results of your biopsy are you are in the right place. Keep your doctor in the loop as to your reactions to the challenge. If they are severe enough some doctors will stop the challenge. As soon as the biopsy is done you can start back on the gluten free diet. No need to wait for the results.

Do be sure to read the Newbie 101 thread as it has a lot of good advice on how to keep yourself safe once you can return to the diet.

nvsmom

Moderator

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- Advanced Members
- 332
- 4,636 posts
- Gender:Not Telling

Posted March 17, 2015

Welcome to the board.



Two positive test results most likely means celiac disease. No, they aren't super high like some celiacs get, but some celiacs are seronegative - your results aren't out of the ordinary for a celiac. Plus you had been gluten-free for a short while before testing and that may have brought your results down.

It is quite common for a celiac to positive in one test yet negative in another, that's why doctors run so many tests. The sensitivity of many of the celiacs tests is often around 80%, meaning they miss about 1 in 5 celiacs (including the endoscopic biopsy). The tests aren't perfect, but it looks like they caught you.

Here is some info on the tests (pages 7-13)

: http://www.worldgastroenterology.org/assets/export/userfiles/2012_Celiac%20Disease_long_FINA_L.pdf

When you get the biopsy done, you may as well retest. These are all of the tests:

- tTG lgA and tTG lgG
- DGP IgA and DGP IgG
- EMA IgA (very similar to the ttG IgA but detects more advanced disease)
- total serum IgA (a control test)
- AGA IgA and AGA IgG (anti-gliadin antibodies) older and less reliable tests which was largely replaced by the DGP tests
- endoscopic biopsy minimum 6 samples taken

You actually did get most of the good tests done. I think the tTG lgG, and EMA are the only additional celiac disease tests worth doing, besides the lgA control test (which is probably normal since you had some positive lgA based celiac tests).

To me, it looks like celiac disease. The DGP IgA and tTG IgA are both very specific to celiac disease. A positive result, along with celiac disease symptoms, probably means celiac disease,

Good luck with the endoscopy.



ibeilfuss

- Community Member
- Advanced Members
- . 1
- 27 posts
- Gender:Male

Posted March 17, 2015

Thanks, nvsmom and ravenwoodglass for your input - I'm very new at this and appreciate being able to draw on the experience and knowledge of others who have been through it. I'm kind of obsessing about learning about what this means to me.

For now, I'll just keep getting ready for this endoscopy and hope to be able to handle the nausea along the way. At least week 1 is almost down, and I guess I'll look at this as possibly my last hurrah to eat gluten containing foods. But man, the breakfast sandwich I made with an English muffin this morning is plotting against me right now.

I have been trying to eat two meals a day that have some gluten in them (crackers or bread mainly) and then I give myself a mini break on the third meal by omitting gluten and that has seemed to keep

things bearable at this point. I can certainly understand why people can't do one of these challenges for weeks on end. Still, I want my biopsy to be accurate when that time rolls around.

Again, thanks for your responses.

nvsmom

Moderator



- **Advanced Members**
- 332
- 4,636 posts
- Gender:Not Telling

Posted March 17, 2015

Be aware that your gluten challenge is quite long for a biopsy, 2-4 weeks (or as long as 6) is much more common. Because yours is so long, you can probably eat a bit less gluten. Gluten requirements range from 1/2 to 4 slices of bread per day with 1-2 slices of bread (IMO) being the norm. You could probably get by with 1/2 slice, or 1 slice, per day, but I understand wanting to "gluten load" so the tests have a stronger chance of being accurate.

Consider eating gluten later in the day so it doesn't disrupt your day too much.

Have a big pub style burger and a beer for me!



ibeilfuss

- **Community Member**
- **Advanced Members**
- 27 posts
- Gender:Male

Posted March 18, 2015

Taking your advice nvsmom, as I have finished week one of the "challenge". I had to pretty lousy days - first one, for lunch last week I ate a delicious cheese burger at Five Guys (love that place) and yeah, I had a chocolate donut. It was downhill that afternoon into the evening. I was nauseated well into the night and resolving to never eat one of those donuts again! Then yesterday I ran to the

Costco snack bar and got a slice of combo pizza for lunch - I love all the vegies and toppings and it has been the only way I can get them as usually with the family, we order something simpler since they don't like green peppers and onions. Anyway, it went slowly downhill throughout the afternoon and by the time I got home from work, I wasn't really nauseated and I was just in pain and agony. Sharp cutting pains in my stomach that radiated throughout my trunk. I felt a little better laying down, but boy, that was bad!!!

I called the GI doctor I'm going to have the endoscopy with and spoke with his medical assistant and she did give me permission to cut down on wheat. She advised that I did not need to eat what I would have normally eaten in the past, but just have a slice or bread or other serving of something containing gluten each day. So, I am going to try to eat that right before bed and then just be careful the rest of the days. They really want me to continue going with this for the entire next 8 weeks, so I will give it a shot again tonight.

I can't believe how much pain that pizza caused me last night though. I can't even picture eating that again!

nvsmom

Moderator



- **Advanced Members**
- 332
- 4,636 posts
- Gender:Not Telling

Posted March 19, 2015

That's a too bad that you aren't feeling well. It would be nice if you could enjoy your last weeks of gluten, eh? (1)

Good luck with it! (!)



jbeilfuss

- Community Member
- **Advanced Members**

- 27 posts
- Gender:Male

Posted May 1, 2015

Hi,

I'm just checking in and decided to do so on my own original thread I started here back in mid-March. The thought is that perhaps this thread will prove to be of some value to somebody getting diagnosed and that it might be helpful to see the process through for one person on a single thread.

Anyway, I am now under two weeks away from the endoscopy which is slated for May 14. I should also mention that I am in the United States since I see posts from all over the world here. By the time I have the endoscopy, I will have been on the gluten challenge for nine weeks, and yes, it has been a challenge with some pretty horrid days in there. The way I have I managed best with all of this is by glutening myself in the evening before I go to bed. I'm not trying to overdo getting gluten in my system -- just trying to have some type of consistency. I have one or two slices of toast or a full pita bread, a full serving of crackers or basically whatever is at least considered a full serving of a food containing wheat. I have had maybe two or three days in this gluten challenge cycle that I skipped eating wheat containing foods because I felt so bad. Still I feel pretty good about having stuck with this and I haven't missed any work in the process, electing to tough it out. I guess I should mention that I'm a guy in his early 50s if that helps anyone.

This week I started going through the paperwork I am to complete for the upcoming biopsy and the following questions came to mind that I asked the GI doctor in an email. He had his medical assistant call me back and I have provided the answers as well:

- 1. When they do the small intestinal biopsy to check for Celiac, how many samples are to be taken? I have read on some online forums that sometimes too few are taken and a definitive diagnosis cannot be made. I just want to make sure that enough samples are taken so that whatever shows up in the biopsies, that the number of samples taken does not come into question as a factor in the diagnosis. **Answer: They will take a minimum of 6.**
- 2. How long does it generally take to get the results of the biopsy for Celiac diagnosis? *Answer: 7 to 10 days.*
- 3. Will a Celiac panel (blood test) be done at the same time? I am thinking that I need to get some type of "baseline" on what the chemistry of my blood is while eating gluten. That way, if follow up blood tests are done to see how I am doing (if a gluten free diet is recommended), there is something to compare those against. Answer: No, they are going to use my original test back in February for my baseline. They said a blood test would be done after I go gluten free for two or three months to see how I am doing on the diet. She mentioned that my doctor monitor tTG IGA and that is what they will test for. I wondered to her if they should also do the DGP IGA test since in my case that seems to have a larger range to be able to see improvement. She said they will only do the tTG IGA. I may ask about this one when I go into the surgery.

Finally I should add that through the gluten challenge, I have had the classic symptoms that one would expect (stomach pain, nausea). I also get flu-like body aches that can be quite strong on the really bad days and

fatigue. I run 3 1/2 miles each day (30 minutes or so) and try staying as active as a software development manager can during the day. I suppose I'll update this after the biopsy. I'm kind of wanting to see what they say about my upper GI as I also combat acid reflux and take omeprazole daily for that.

cyclinglady

Advanced Community Member



- Moderators
- 741
- 5,723 posts
- Gender:Female
- Interests:CD diagnosis: 3/2013, DGP IgA positive only, Biopsy: Marsh Stage IIIB, Hashimoto's Thyroiditis, Diabetes, Osteoporosis, Thalassemia
- Location:Orange County, CA

Posted May 1, 2015

Thanks for paying it forward! You are bound to help someone with your response!

jbeilfuss

- Community Member
- Advanced Members
- '
- 27 posts
- Gender:Male

Posted May 14, 2015

I just wanted to say that I had my EGD today. It went down something like this:

- 1. He checked out my esophagus. This was a good thing since seven years ago, I got a piece of steak stuck in my throat and had to go to the emergency room to get it out. That is when I found out that I had eosinophilic esophagitis and acid reflux. This came back normal now, so I am glad this confirms that by taking omeprazole daily in the morning, that seems to be addressing it and keeping my esophagus healthy.
- 2. My stomach is normal he checked that out and it looks fine.
- 3.Duodenal villi he took six samples and I'll hear back in a week to 10 days what the results were. I'm not sure if you can tell with the naked eye, but he told my wife when I was out that it looked like flattened villi. He also admitted that looking at it just on sight and making that judgement, GI doctors are correct about 2/3 of the time and it has to be confirmed on the microscopic level. I

have heard that if there is a lot of damage, it can be visible, but we'll just have to wait and see what results come back.

We celebrated the end of the gluten challenge by going to Red Lobster and using the gift card my daughter and son-in-law gave us for Christmas. I intend for this to by my last "gluten containing" meal. The deep fried shrimp was pretty good at the time, but now I've got a stomach ache. I'm ready to move on and get healing.

jbeilfuss

- Community Member
- Advanced Members
- 1
- 27 posts
- Gender:Male

Posted May 20, 2015

Okay folks,

I am just reporting back because I got the results of the biopsy today and it is pretty much what I expected. I now have the "gold standard" celiac diagnosis – positive blood tests with a positive biopsy. I'm not so sure how that is supposed to make me feel at this point. On one hand it's a real bummer to know that now I really have to commit to NO gluten for the rest of my life and the hassle that will mean buying groceries, eating out, and socializing. So much of what we do in the US revolves around food!

On the other hand, getting a diagnosis does provide some level of peace of mind and explains a lot of what I have been through in the past. I mentioned that I had mysterious tingling in my body and pain about 13 years ago. Back at that time, I got tested for a myriad of things. I had MRIs and other scans to check for brain tumors or other neurological problems, a spinal tap to check for multiple sclerosis, various tests to check for different types of arthritis, blood tests for lupus, and who knows what else. Finally, I just kind of gave up. I ran daily which seemed to help me get my day started and just dealt with it and the worst of the symptoms just seemed to subside. Eventually I was at a health fair at work and got my bone density checked. It came back low and I ended up going to the doctor again to get a more comprehensive scan. Long story short – I started taking calcium supplements and Actenol (medicine to combat osteoporosis mainly in women post menopause; it was interesting picking that prescription up each month \odot).

I am glad to know so I have some kind of road map going forward. Hopefully by applying the gluten free diet and eliminating lactose (they want me to do that to), I can heal and have more energy.

To any who may read this in the night hours, frustrated with what they are going through, hand in there as you work to get a diagnosis and don't let doctors rule out or not even consider celiac as a possibility of your health problems. Get the appropriate tests.

Good luck and my prayers are with you.

nvsmom

Moderator



- **Advanced Members**
- 332
- 4,636 posts
- Gender:Not Telling

Posted May 20, 2015

Glad you know for sure! I hope your recovery is short. (!)



Best wishes.

ravenwoodglass

- **Advanced Community Member**



- **Advanced Members**
- 1,247
- 14,643 posts
- Gender:Female
- Interests: Gardening, photograpy, painting and drawing, textile arts, glass art, reading
- Location: Upstate NY

Posted May 21, 2015

Now you know and can start to heal. Keep in mind that any neuro issues you still have may take more time to heal than the rest so be patient with your body. Make sure your doctor does vitamin and mineral panels so you know what you may need to supplement.

The gluten free lifestyle does take some adjustment and we do often go through a bit of a grieving process. It can help to treat yourself with safe gluten free items that you might enjoy. Chocolate is my go to when the diet restrictions get me down. Enjoy Life makes nice gluten-free allergan free chocolate chips that were my go to for a while.

Hang in there while it wasn't great news at least it you have answers. Feel free to vent if needed and ask any questions you need. Be sure to read the Newbie 101 thread at the top of the coping section if you haven't already.