

# Alpha 1 Antitrypsin MZ Information & Research

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## News & Research Update

Mar 30, 2024

### Website status and research update

Dear subscribers,

First of all, have a good easter holiday!

This week, we continued our discussion with the B12 group of medical professionals. This time, with the group's geneticist, which was a very pleasant discussion, we agreed to continue working together and start a study on B12 patients to check the prevalence of Alpha1.

We are doing this for two reasons: 1. to find one of the root causes of B12 deficiencies, and 2. to find a way to detect Alpha1 heterogenous patients in an early phase. (Note that it is extremely difficult/impossible for a physician to diagnose Alpha 1 MZ based on our symptoms.)

Please note that this will take some time, and most likely some funding as well.

### **Alpha 1 MZ & Pregnancy / Cholestasis.**

In the last couple of days, we have done some more research on cholestasis during pregnancy. The outcome is not a very nice story, but it is important for all SZs and MZs because when you know, you can act!!

First, cholestasis (slowing or stalling of bile flow through the biliary system) during pregnancy is known, and patients with cholestasis can experience complications, such as obstructive jaundice (narrowed or blocked bile tract, preventing the normal drainage of bile from the bloodstream into the intestines), cholangitis (inflammation of the bile duct system), and pancreatitis (inflammation of the pancreas).

Searching, we found a high prevalence in the UK biobank, which caught my attention, and this week, when I was talking to a Geneticist in the UK, it also showed up in a database in Finland with a high prevalence under Alpha1 Heterogenous.

In a paper about this specific subject, the researchers mentioned a higher probability for Alpha 1 Heterogenous during pregnancy to get Biliary Tract issues like cholestasis.

The conclusion in this paper shows: "The Z carrier frequency was calculated to be 6.8%, which is much higher compared to the general population of 2.3%,"

Although the results of the paper were based on only 100 patients, the Biobank data (250.000 patients) actually confirms the much higher prevalence.

And because we see a much higher prevalence of biliary tract issues in Heterogenous Alpha's (independent of pregnancy), this all makes perfect sense.

So, when you are an Alpha 1 MZ or SZ, take good care of your liver before and during your pregnancy. Mention this to your physician. Try to offload your liver as much as possible to keep it in good health. Remember that the liver regenerates in about a year, so get your liver in excellent condition before your pregnancy and start as early as possible.