

## Fibromyalgia Summit Q&A

### Fibro related to other conditions

1. Is fibromyalgia related to endometriosis? No, they are not related. But fibromyalgia can cause abdominal and pelvic pain that can sometimes be confused with endometriosis. A definitive diagnosis of endometriosis is made through laparoscopy.
2. Is fibromyalgia common in families with rheumatoid arthritis? yes, studies show that if you have rheumatoid arthritis you have a 30 percent chance of developing fibromyalgia
3. Is arthritis pain part of fibromyalgia? Fibromyalgia and osteoarthritis are separate conditions that often occur together in the same patient. Fibromyalgia is a chronic pain syndrome of the muscles, tendons and ligaments--it does not involve the joints themselves. Osteoarthritis is the degeneration of joint cartilage and underlying bone. Dr. St. Amand believes that all fibromyalgia that is not treated with guaifenesin will lead to later osteoarthritis. He and I have found that osteoarthritis is very common in fibromyalgia patients-- indeed it is not unusual for 20 year old patients with fibromyalgia to have evidence of osteoarthritis on x-ray. Happily he and I have found that once patients are on a dose of guaifenesin that decreases the size of their nodules the progression of any osteoarthritis they may have stops.
4. Can menopause trigger fibromyalgia? Any major stress can trigger the onset of fibromyalgia, but I believe you have to have the underlying genetic predisposition to fibromyalgia first (since every woman goes through menopause, if menopause itself triggered fibromyalgia there would be a LOT more women with the syndrome!)
5. Is there any connection between fibromyalgia and mononucleosis? Same answer as #4--mono can be a major stress to the system, and that can cause some people with an underlying genetic disposition to fibromyalgia to develop their first symptoms. University of Cincinnati researchers have found an area on chromosome 17 that may code for fibromyalgia

### Phosphates

1. Re phosphate: I am on dialysis and take Renuella phosphate binders. Would it work in conjunction with the guaifenesin protocol? It might work in conjunction--it certainly wouldn't hurt.
2. Can one measure the amount of phosphate (in the urine) excreted? Yes, but this is not a standard lab test that could be ordered on a patient (in other words it is not commercially available). Dr. St. Amand did this when he was testing the effects of guaifenesin. Here is what Cheryl (the RN in Edmonton Canada who runs Fibrofree and was taught how to map by Dr. St. Amand) says: I have two members that work in a lab. One is a tech and the other a lab manager. They both checked their urine before the protocol and when they thought they were clearing (using 24 hour urine tests), and they both said there was a huge amount of phosphate excretion. One reply when I asked was "oh...over the top!"

3. Will your bloodwork show increased phosphate or abnormal renal function? Phosphate levels are normal in fibromyalgia. The body regulates the phosphate levels in the blood (through the parathyroid gland), so excess phosphate is tucked away in our muscles and tissues. Kidney function is normal in people with fibromyalgia (of course there are many conditions that cause abnormal kidney function, but fibromyalgia is not one of them).
4. Have any other binders of phosphate been tested? No, because guaifenesin works so well. Also phosphate binders are strong medications that can have very serious side effects.
5. Being that our kidneys do not excrete phosphate effectively would such medications such as phosphate binders decrease the symptoms of fibromyalgia? Possibly, but they would not be worth the risk. Guaifenesin is extraordinarily safe--it is approved for children as young as 2 years of age.
6. What is the name of the enzyme(s) that control phosphate excretion in the kidneys?  
Unknown
7. What foods are high in phosphate? Here is a quote from Dr. St. Amand's nurse, Claudia Marek about this issue in the online guaifenesin support group on 4/6/2004;" Dr. St. Amand is aware that people could get a slight benefit from avoiding dietary phosphates. It's possible that if someone was very careful they might be able to take a half a pill less of guaifenesin a day.

But the point is: when you take away topical salicylates, and you put about half your patients on a diet they must follow...you are already making a difficult protocol for people to adhere to especially when they are not feeling well.

To make it more complicated with a phosphate diet too...when all you could hope to achieve would be, say, maybe 300 mg. less of guai a day.... would it be worth it ??

We would have to teach all that, we would have to monitor all that, on top of the already difficult protocol.

So we have NOT chosen to work with eliminating dietary phosphates out of choice. On purpose.

Claudia Marek"

## TESTS/RESEARCH

1. My neurologist Dr. Ramos says there is a blood test to test for fibromyalgia. However it is thousands of dollars and one needs a series of tests. Do you have any knowledge of this, and if so, can you call it on how this relating to fibromyalgia. Currently there is no blood test that can accurately diagnose fibromyalgia. In 2013 Dr. Bruce Gillis (Epi Genetics) developed a test, but it has not been found to be sensitive or specific enough to reliably diagnose fibromyalgia. For a test to be reliable it has to be extremely accurate--indicating that you have fibromyalgia

2. There is a recent disclosure that researchers have discovered nerves in blood vessels that cause pain. Do you have any knowledge of this, and if so, can you comment on this relating to fibromyalgia? Yes, but the nerves are not IN blood vessels, but AROUND them. In 2013 scientists at Integrated Tissue Dynamics found “the pathology exists of excessive sensory nerve fibers around specialized blood vessel structures located in the palms of the hands,” according to Dr. Frank Rice, the senior researcher on the study. He says; “This discovery provides concrete evidence of a fibromyalgia-specific pathology which can now be used for diagnosing the disease, and as a novel starting point for developing more effective therapeutics.” In other words fibromyalgia is “not imaginary after all, as some doctors have believed.” The study was published in the journal Pain Medicine. This adds to the list of unique physical findings in fibromyalgia that I discussed in my summit presentation.

#### Guaifenesin Questions:

1. I used Mucinex for 3 years and did not notice much results. Should I try it now? No, for 2 reasons: firstly Dr. St. Amand and I have wondered for years why some people did not make good progress on Mucinex. Dr. St. Amand did some research and found that blue dye #1 has been reported entering the mitochondria and interfering with the formation of ATP. Presumably this can make the cell less able to work properly including excreting phosphates. Secondly, Mucinex has a fast acting layer, which some people cannot tolerate, and we need a certain amount of long acting guaifenesin in our systems to clear our nodules and feel better. Dr. St. Amand and I recommend that all of our new patients take the compounded dye free guaifenesin capsules--they are available at the Marina del Rey Pharmacy ([www.fibropharmacy.com](http://www.fibropharmacy.com) ). We KNOW this form of guaifenesin is all long acting and works well.
2. Dehydration. Guai seems to dehydrate the body. Concerned about taking large amount of guai (600mg daily).-- Some people feel slightly dry when they are on guaifenesin, and feel better when they drink a bit more water. Guaifenesin is an expectorant, and is not known to have an overall body drying effect. Make sure you do not use guaifenesin that has a decongestant with it - the decongestant can have serious side effects. The dose of guaifenesin that is recommended to take when you have a cold is much higher than the dose that most people need to take to reduce their nodules and feel better. The FDA has approved guaifenesin for ages 2 years and older. It is an extremely safe medication with no known long-term side effects. Dr. St. Amand has used guaifenesin for 25 years in thousands of patients with no side effects. It can certainly be taken for the long term, as thousands of people around the world have done it and are currently doing it.
3. I will answer these questions together: do you have to continue with guaifenesin for the rest of your life? Dosage change? diet restrictions? this one stay on guai forever? You do not need to be on guaifenesin for the rest of your life, but nodules start to return after you've been off guaifenesin for 4 months. Most of us are happy to stay this safe, effective medication that helps us feel so much better. There are no diet restrictions with guaifenesin--you can eat normal food quantities of any food except for mint. Some people need to increase their dosage of guaifenesin as the years go on to continue

clearing well, but many people can stay on their initial clearing dose--it is an individual thing.

4. Doc said I may or may not have fibro. So can I still take this med without any harm to my body? Yes, but it is best to be mapped first to confirm / deny the presence of fibromyalgia. Talk to Vicki!
5. Does guai have another form other than the "tablet" form? Injection? Fluid? Chewable? yes there are many forms of guaifenesin, but the only forms that decrease our nodules are the long-acting tablet and long-acting capsule.

#### Medication Questions:

1. Is Ambien OK to use for sleep when you have fibromyalgia? Many people with fibromyalgia take ambien to help with sleep--it does not block guaifenesin. There are many sleep medications - talk to your doctor about the best one for you.
2. Must I stop taking opiates for migraines (30 milligrams) to go on the protocol? No, opiates do not contain salicylates so they will not block guaifenesin.

#### Fibro Symptoms:

1. I've notice fog and other weather plays a part of my symptoms. Do others? Yes, I have heard this--it is an individual thing. Many patients tell me that as they clear well on guaifenesin they are not as sensitive to weather changes (they generally feel better all around)
2. Is it typical to have increased fatigue while taking guai - such as sleeping 12h at night and increased depression? it is typical to have an intermittent temporary increase in any symptoms you have had before starting the guaifenesin. Talk to your doctor before you start the protocol to have a plan for what you can do if you have increased symptoms--especially depression. Keeping your blood sugar steady on the HG diet and getting consistent aerobic exercise are often excellent ways to increase energy and stabilize mood.

#### Diet Questions:

Here is the whole bunch: So all oils contain salicylates? Coconut oil? What about cooking with oil, olive oil, coconut oil?

What about essential oils? Noni lotion? Essential fatty acids from vegetable sources?

This would be so difficult - I use coco oil for many things

Regarding the diet: What would be the best source of protein if you're vegan? And will continue to be a vegan...

Ok--to review--on the guaifenesin protocol (used to reduce the size and number of nodules and therefore feel better) you can eat normal food quantities of anything except mint (which is very high in salicylates). When you eat a food, even though it has salicylates, the liver processes the salicylates and the remaining amount of salicylates is so low it does not block the action of guaifenesin. Now if you eat (swallow) more than normal food quantities of plants (such as supplements echinacea, astragalus, or drink tea) the liver cannot process all of the salicylates

and guaifenesin's action is blocked. Go to Dr. St. Amand's website at [www.fibromyalgiatreatment.com](http://www.fibromyalgiatreatment.com) and look for Claudia's QUICK CHECK to easily check products.

So you can eat normal food quantities of anything except mint but you cannot put plant oils, gels, and extracts on your skin-- because these products go right from the skin to the bloodstream and the liver does not have an opportunity to decrease the salicylate level. The exceptions are plant oils, gels and extracts made from corn, rice, oats, wheat, or soy--they are fine to use

So, referring to the above question--yes--you can cook with normal food quantities of any oil--you just cannot put it on your skin. Inhaling essential oils are fine - you just cannot let them fall on your skin.

The HG diet is important for blood sugar control in patients who have the tendency for fluctuating blood sugar - to see if this is you read Chapter six and Dr St. Amans book. The diet is totally separate from the guaifenesin protocol in that eating to keep your blood sugar steady does not effect the size of nodules. Keeping your blood sugar steady is necessary for fibromyalgia patients with carbohydrate intolerance to feel better, but it does not change nodule size.

Regarding vegans on the HG diet: you can have all forms of unsweetened soy--such as tofu, edamame, soy milk, nuts (allowed kinds of nuts and amounts are listed in Dr. St. Amand's book), oatmeal, and seeds (such as chia). The first two months you can add lentils, beans, quinoa, amaranth, hemp, tempeh, tahini, etc (anything else you would like to eat) and keep them in your diet if you do not have increased symptoms.

About 2 years ago, re-read the book, started the diet, was afraid to start guai because I was barely functioning, still needed to work. I lost 65 lbs and was exercising daily. But I still had GI issues and food that was to be good for me made me sick. Frustrated!! A year ago April could not exercise. Need Hope! In answer to this--most people feel tolerably worse on guaifenesin, so As Dr. St. Amand says, "the way you feel during the first 4 months on guaifenesin is no different than the way you will feel everyday in five years if you do not start the protocol." You have so much help available with the folks from iFoG--they can help you through it! Perhaps you needed a digestive enzyme and probiotic to help with the IBD that most of us with fibromyalgia have? The folks from iFoG may be able to recommend a healthcare professional who could help you with this.

Therapies:

1. Are you familiar with Floatation R.E.S.T. therapy? And it's benefits for fibromyalgia? No, I am not familiar with it, but I know that any therapy that can help keep the body more in balance can help us feel better
2. Does acupuncture help fibromyalgia? It can, but it is an individual thing. Acupuncture was an extremely helpful therapy for me during the first year after I was diagnosed with

fibromyalgia--now I I do not need acupuncture treatments nearly so often because guaifenesin helps keep my body in such good balance.

#### Mapping

1. Where do you go to get mapped? Can you provide a POC please? The amazing and talented mapper Vicki Mauk can help you. She has been mapping for years, and is currently training mappers to help her