Granulomatous Mastitis

Granulomatous Mastitis is an under-practiced and poorly understood, yet emerging condition, affecting 2.4 women per 100,000 worldwide and growing.

Granulomatous Mastitis Diagnosis:

Granulomatous Mastitis (GM) is a chronic inflammatory disease process occurring in the breast in a response, often caused from or related to an antigen (foreign invader) or influenced condition. It's important to know the difference between acute and chronic inflammation. The diagnosis is often based on the pathology identifying granulomas, which is actually often due to infection BUT can be caused by other immune system or inflammatory conditions.

Cystic Neutrophilic Granulomatous Mastitis (CNGM) is a rare subtype of granulomatous mastitis with a highly distinct histological pattern often associated with Corynebacterium species.

Idiopathic Granulomatous Mastitis (IGM) has been determined that no known cause was typically found to cause the GM. This diagnosis should only be accepted if ALL other testing (including genetic sequencing or analytical specialized pathology testing outside of commonly routine gram stains or cultures) has been done properly.

Testing options:

Initially, many of us see our doctor with symptoms of lumps that can be accompanied with tenderness or even sharp pains. We are often ordered a mammography, maybe an MRI, and an ultrasound guided biopsy to collect a tissue sample. Once a GM diagnosis has been given, many of us have gram stains (microscopic type testing) or cultures (see if a pathogen will grow). Like many of us, these either show suspicion of a pathogen like Corynebacterium, which is normally found in skin flora BUT not always (as in my case being a pathogenic strain which I will discuss), OR they result nothing.

We HIGHLY recommend, at biopsy, requesting a **16s rRNA pathology test** (test is a highly sensitive sequencing test able to identify bacteria at the species level or DNA if you will) or **MALDI-TOF test**. Please note that Corynebacterium is often difficult to grow in lab so sufficient time for testing should be allowed/requested.

Therapies (these are some examples but not limited to the following):

Antibiotics: Breast tissue is often dense and antibiotics are not known to not easily penetrate the tissue…which can require a longer course of antibiotic therapy, PLUS we must consider how long we had an active infection without our knowledge. Some patients need 9 months on antibiotics. The one used by members of our group with success is Doxycycline.

Methotrexate: Methotrexate is a chemotherapy drug that has had some success in members of our group.

Steroids: Steroid are another drug prescribed to help manage your symptoms (but not necessarily cure). We typically avoid using steroids unless absolutely necessary. Steroids can have lots of side effects. They can be taxing on your liver, can cause weight gain, plus most patients symptoms return when the steroids are tapered off. They can also weaken the immune system and should NOT be given if a bacteria is found. A new way some members have been treated is by steroid injections which target the area better to relive symptoms.

Surgery: Surgery is used is some cases to get a better sample, especially when a biopsy needle has not been able to. Mastectomy's have also been done for several members who have had no help with other therapies or simply the pain and time has just been too great to deal with.

Time: Some members simply wait and treat symptoms themselves when possible.

Homeopathic/Other (recommended by members):

Curcumin (with black pepper)
CBD oil
Castor oil packs
Hot compresses
AIP or Anti Inflammatory diet
Manuka Honey

Other Information:

GM/IGM are not easy to live with and can cause several side effects including joint pain, lethargy, stabbing pains, decreased appetite, and more. Most of these symptoms are normal to been seen in GM patients but they are not necessarily caused by GM itself. Some symptoms can be caused by a bacterial infection that can cause an array of symptoms (like flu-like symptoms), but when fever begins there is usually an infection so we recommend getting in with your doctor immediately. Also, GM can last for 6 months to a few years depending on the individual. While GM is NOT associated with Breast Cancer we highly recommend keeping track of your symptoms and lumps with regular checkups because prolonged inflammation can raise your risks. While not common we have had about 3 of our members develop BC following GM occurrences.

Diseases Affiliated with Granulomas

1) Prolactin Levels/Pituitary Tumor (seen with GM)
2) Bacterias (Staph/E-Coli/Corynebacterium Kroppenstedtti; as examples)
3) Tuberculosis
4) Leprosy
5) Schistosomiasis (parasite)
6) Histoplasmosis (fungus; very common in Ohio Valley especially)
7) Crytococcosis (fungus)
8) Cat Scratch Disease/Bartonella (bacteria)
9) Rheumatic Fever
10) Sarcoidosis (inflammation cells; collections of, in different areas of body)
11) Crohn's
12) Listeria Monocytogenes (infant)
13) Pneumocytis (yeasts within granulomas on lung biopsies)
14) Aspiration Pneumonia
15) Rheumatoid Arthritis
16) Granuloma Annulare
17) Foreign Body Granuloma…splinter, glass, metal that pentrates body's soft tissue
18) Coccidioides (Coccidioidomycosis) often referred to as Valley Fever; very common in the Southwest U.S., Mexico & South America, caused by a fungus. Can survive in seawater as well, soil dwelling, saline soil.

Disclaimer: We are not doctors. Our opinions are from our group experience to help provide you with information to take to your doctor for review, diagnosis, treatment and healing.