

# Mast Cells, Histamine, GCMN, and...me?

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I have spent this past weekend at the 20th Anniversary Nevus Outreach conference/family reunion. Anybody impacted by Giant Nevi in any way knows how meaningful these conferences are for many reasons. There is the meeting of other families on your exact journey, seeing children unashamed and unafraid for their nevus to be seen, there is the meeting up of friends who have truly become an extended family. And there are research updates. Yeah, about those. Some years ago, Dr. Reyes et al. had a paper published (<https://www.ncbi.nlm.nih.gov/pubmed/24679055>) which, in a nutshell, unveiled his findings that people with giant nevi have, on average, 30-40% more mast cells than the general population, yes, even in their unaffected skin. That finding made me sit up and take notice.

Many of my friends are aware I have a condition called “Mast Cell Activation Disorder/Syndrome” (MCAS for short). Mast cells serve several functions, the research presented by Dr. Silver at our conference dealt primarily with their function in wound healing (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3898956/>) , and how a mast cell inhibitor (stabilizer?) infused into the silk used in stitches resulted in noticeably improved appearance of a scar after surgery. So there is THAT. In my case, mast cells tend to make my life miserable by behaving badly and, once in a while, sending me into anaphylactic shock. Mast cells release histamine as one of their functions, and, in people with MCAS, they tend to all release at once...a party called “degranulation” (<https://www.ncbi.nlm.nih.gov/pubmed/9281467>). So much fun. Why is this important to people with giant nevi? You know, the very ones who have WAY more mast cells than I? Because there is a subset of people with giant nevi who have a complication with severe itching. I mean itching that compromises your well-being every day. An itch that doesn't go away. So, what is causing that itching? Could it be the over abundant mast cells releasing their histamine?

(Dr. Reyes is always good at reminding me that medicine and treatment is truly an art, that while one treatment may work for one person, it doesn't necessarily mean it will work for another. FYI.)

But...what if following the same diet I must follow, the Low-Histamine Diet (here is one list of foods – there are several -

<http://www.histamineintolerance.org.uk/about/the-food-diary/the-food-list/>),

could give relief to at least *some* of that itchy subset of people with GCN? Could mast-cell stabilizers or inhibitors be an effective tool for some of them?

Ketotifin is one readily available drug, and is often used in stabilizing mast cell disorders with *some* amount of success in *some* people. It is commonly found in OTC “allergy” eye-drops, BTW, not that I am recommending you use it for any other reason. And then there is cannabis.

About that. I am a boring person. I have never even smoked a cigarette. I had never been drunk until my mid-40's, and only then by accident (long and funny story. Really). So when a friend of mine asked if I wanted to try one of his pot-laced gummy bears to see if it would help my condition, my immediate reaction was, “nope”. ( I am strongly in favor of legalization, BTW, since I believe the scientific body of evidence shows that pot can be extremely helpful for certain conditions.) Anyway, then I thought about it, and wanted a good excuse why I absolutely couldn't risk it, since most deep leafy greens are high in histamine, and marijuana is, you know, a PLANT. So I went online - because if you find it on the internet is HAS to be true - and discovered that, instead of giving me an easy out, cannabis has, in several studies, been shown to be an effective mast cell stabilizer. (<http://www.mastcelldisease.com/mast-cell-disease-medical-marijuana/>) Back to GCN. What if rubbing CBD oil into the nevus could stabilize the mast cells therein? It may be an effective, and less expensive, alternative to some of the ludicrously pricey medications currently available (makers of Xolair, I'm talking to YOU). Maybe? What if following a low-histamine diet could improve the itching suffered by my friends with this known complication of possessing a GCN?

I know that my musings are problematic from a scientific study point of view, and have NO idea on how to go about setting up a study. I realize that *how* a

drug is delivered can vary results. I know that there can be topical treatments, it might be inhaled, ingested, injected. I have no idea how a dose is measured in the case of cannabis, and that, sometimes, at least a trace amount of THC might make the CBD more effective. Or at least that is what I have read from various sources, some which are likely very biased. In the case of a low-histamine diet, a food diary would be required, along with a patient-reported level of relief (or not). The “Low-Histamine Chef”( <https://healinghistamine.com/histamine-in-food-lists/>) has a few important things to say, though, before you embark on a low-histamine diet. Please read what she has to say. Please.

And, remember, I am NOT a doctor, just a fellow traveler on this interesting road called “life”. But, if you decide to try either, or both, of these options, I would be *very* interested in hearing about your outcome(s).