

# Meet Kaiulani Facciani

BY LORI LOBER

## **Who are you, where do you live and what's your age, if you don't mind sharing!**

Kaiulani Facciani, Cancer Blogger, Telluride, Colorado, 59

## **Tell our readers who you were before you were diagnosed with breast cancer.**

Research scientist, software executive, entrepreneur

## **How were you diagnosed?**

Diagnosed with DCIS in October, 2007 from biopsy after blood was coming out of my nipple. I had a "preventive" mastectomy.

## **When were you diagnosed with metastatic breast cancer?**

Diagnosed with stage IV five years later (October 2012) after losing full use of my legs and one arm. Tumors had split my sacro-iliac joint in my hip and crumbled five vertebrae as well as populated my lungs, liver, and lymph, every vertebrae of my spine and my pelvic girdle. I was told I likely wouldn't walk again and that I had roughly two weeks to two months to live.

## **Who told you that you had metastatic breast cancer?**

Staff oncologist at hospital that did MRI to find out what was wrong with my hip. A year later (October 2013... who the hell made October Breast cancer month?... I think they cursed me!), I had an MRI for a sore neck and they discovered leptomeningeal carcinomatosis. This particular type of brain metastasis is highly fatal, with a median survival of 2.8 months.

## **What were your initial thoughts?**

Hahahaha. I was deliciously naive. I didn't really accept the prognosis. I thought, "Oh, at least now I know what's wrong with me. I can beat this. If I'm really good, I can dial it back to stage III, then Stage II, then gone." As impossible as they made it seem, that's basically what happened.

## **Were you given any hope by the professionals who gave you the news?**

None at all. My son was overseas on a project I wanted him to complete. I didn't want him to know in spite of them telling me that I would be dead before he returned and that he deserved a chance to say goodbye. I thought "Okay, I'll show you, I just won't die for two months. Give me everything you've got." The funny thing is that



they had taken away so much hope, I probably wouldn't have even done chemo and radiation if I hadn't been in that situation.. what would be the point?

With the "leptomets", they gave me a prognosis of just weeks. No hope, at all. Buying a little time was the best they could offer in both situations.

## **How/why did you decide to take matters into your own hands and incorporate nutrition as part of your journey?**

I had a mixed history with western medicine throughout my life with a variety of ailments. Although I'd had some good doctors, I had had some horrific experiences that almost cost me my life. I had been trained as a research scientist, but I left my career due to inherent corruption in science that exposed published results as not trustworthy. I continue to believe in the scientific method as the best way to control variables to isolate the truth, but I had come to believe that the failings of human beings made it not as reliable as we would hope. I had a healthy skepticism of both doctors and published research and wasn't ready to cede complete control to the doctors. As Dr. Christiane Northrup says, "They have a body of knowledge. You have knowledge of your body."

They gave me sooo much chemotherapy (four products per weekly infusion) and radiation (50 treatments) that I figured my immediate challenge was to survive those. Most of the friends I had lost succumbed to the actual

treatments before cancer had a chance to kill them. It seemed obvious to me that I needed to detoxify and support myself nutritionally, as well as boost my immune system. Being bedridden, I had nothing to do all day but google. I became my own naturopath, creating my own protocol. I spent most days making potions. When you've been given just weeks to live, you don't have time to wait for that clinical trial that is just a gleam in some scientist's eye. So I researched traditional and naturopathic knowledge and opened my mind. If someone credible told me that something worked for them and it would not harm me, I tried it. I had a good starting knowledge of physiology and nutrition and the ability to interpret published scientific articles.

With the diagnosis of leptomets, all western medicine could offer me was WBR (whole brain radiation) which I refused, and Tykerb, a very toxic oral chemo that shut down my liver and pancreas and caused heart irregularities so I couldn't tolerate it. The challenge is to find something to cross the BBB (blood-brain barrier) as most western therapies are too large molecule to do so. I researched natural substances and discovered research that Cannabis crosses, and kills cancer. I had a large supply of CBD oil (which is not psychotropic like THC is) and I figured I had nothing to lose, so I took large amounts daily. Three weeks later (I was supposed to be dead by then), four of my nine tumor/mets were gone without a trace. I was then eligible for targeted radiation (SRS) and I had that on the remaining five. I have been NEAD (no evidence of active disease) since May, 2014... even in the brain, which is extremely rare with leptomets.

## **At what point in time did you BELIEVE that you could beat metastatic breast cancer?**

My favorite quote is by M.H.S. Pourri... "At any given moment, you have the power to say, this is not how the story is going to end."

They were pretty darn convincing that there was absolutely no hope for me (twice). I set about to take care of things in case they were right, but at some level I never really believed their rules applied to me. I had formulated my own view of cancer, it's causes, and potential treatments. We are all bombarded with cancer every day and, for the most part, our immune systems dispatch it with no consequence. But the simple truth is that if you have cancer, then your immune system was not up to the task. It was most likely overwhelmed by stressors

which affect it's ability to function. Stressors such as toxins, carcinogens, genetic mutations, emotions, hormones, pathogens, etc. can combine in unique ways to form a "perfect storm" of factors that creates a "bioterrain" (the environmental landscape of our body) where cancer can thrive. In creating my protocol, I wished to transform my bioterrain from one that is hospitable to cancer to one that is hostile to cancer. That is basically what western treatments are trying to do as well. The problem comes when those treatments are hostile to us as well, degrading our ability to heal ourselves.

My naturopathic regimen to convert my bioterrain operates on six principles:

- Avoid putting toxins in
- Get accumulated toxins out, including parasites
- Correct nutritional imbalances, care for digestive flora
- Boost natural immune system
- Attack cancer with age-old remedies
- Take care of my emotional wellness

Although Nutrition per se is only named in one of those principles, it plays a role in each of them.

**I know that living with/beating metastatic breast cancer is a full-time job. Give us an idea of what your "normal" day looks like:**

When I was actively fighting cancer, I was very strict in following my protocol. Now that I'm NEAD, I relax my rules but I still eat an organic, mostly plant-based diet. I do not indulge in things that suppress my immune system and I do a series of organ cleanses twice a year. I ingest certain supplements and put my "magic powder" (a combination of medicinal mushrooms, Chinese herbs, immune boosters, and detoxifying greens, as well as other ingredients) in my daily fresh fruit and vegetable juice. I continue to take Cannabis oil as a preventive to maintain my NEAD status. Now that I have learned more about how it kills cancer, I use a strain with some THC in it, as well as CBD. Since I don't like to be high, I take it at night before bed. I may have wild dreams but I sleep like a rock and wake up rested.

I figure I owe the universe a pretty big favor so I blog and post to provide information and inspiration for others, all day every day, for no financial compensation. I do, however, receive a lot of love and appreciation. And I hope that I am amassing karmic currency for when I next need it. LOL.

**Tell us about "HOPE" and what it has done for you in your journey.**

People ask me what I did, what I still do, and why (thus the name of my blog... www.

whatiddidandoandwhy.com). I did hundreds of things and I can't honestly tell you with absolute certainty which ones played what roles. But I know there is one thing that if you took away, I would not have survived... Hope.

Hope is not 'being in denial'. As Henry Ford said, "Whether you think you can or you think you can't... you're right." If you think you're gonna prevail, you have a fighting chance and, trust me, no one's gonna laugh at you for hoping when you're gone. And if they do? The joke's on them... you'll be off on your next assignment!

Hope is also not 'blind optimism'. "Hope is the elevating feeling we experience when we see - in the mind's eye - a path to a better future. Hope acknowledges the significant obstacles and pitfalls along that path. True hope has no room for delusion. Hope gives us the courage to confront our circumstances and the capacity to surmount them." - Jerome Groopman, MD, The Anatomy of Hope.

I have this searing memory of being hooked up to chemo and enduring radiation and thinking... if this is living, then I don't want to live. And some other part of me (I'll call her Hope), grabbed me by the lapels, shook me, and said... "Others have done it, you can do it." And it got me through a crucial day. All I needed to know was that it was possible and then I could get through it.

That's why our stories and our work are so important, Lori. Women who have been recently diagnosed with metastatic breast cancer are most likely not being given much hope by their doctors. Women sitting in their chemo chair or lying in their radiation tubes may be close to giving up. They just need to know there might be something on the other side of all the pain and misery, that stories like ours are possible.

**Where do you get your strength on a daily basis to stay positive?**

I believe that positive energy attracts and begets positive energy and that negative energy attracts and begets negative energy. You must choose which vortex you wish to feed. I have learned to trust the universe to return the energy I give.

**If you had to summarize why you're thriving without repeating any of the above, what would you say?**

While it is repeating, perhaps I can summarize to tie everything together... I have taken control of my healing by making Hope my captain and believing in my body's innate ability to heal itself. I incorporate the best of western medicine AND naturopathic and nutritional treatments to create a bioterrain that supports my body's ability to fight cancer and heal.

**What are your goals going forward? How did your metastatic breast cancer diagnosis impact your future?**

Although this is a controversial viewpoint, I look at my journey with cancer as a gift. While I could have done without some of the pain and misery, I would not trade the strength and wisdom I have gained. My upcoming book is titled, "Whatever doesn't kill you, makes you strong" because all the pain and misery I've ever experienced in life, gave me the tools I needed to survive thus far. I don't necessarily believe everything happens for a reason except that I make it so... if something bad happens, it is up to me to turn it into a situation where SOMETHING good comes from it. I will never be a victim.

My goals are to be there for people with MBC that I can positively impact. In addition to my blogs and my Facebook pages, I am working on three books.

**How can others who are diagnosed with metastatic breast cancer be inspired by you and your journey?**

I believe in you and your ability to write the ending of your story. If that belief in you and sharing my story can strengthen your belief in yourself, my work is done. If you'd like to 'like' my Kaiulani Facciani, Cancer Blogger, Facebook page or subscribe to my blog (www.whatiddidandoandwhy.com), you may contact me anytime for support, information and/or inspiration.

**How can fellow metastatic thrivers work together to give anyone who is newly diagnosed hope?**

Tell your story, get the word out that it IS possible to survive and thrive. Be there for your sisters (and brothers).

**Is there anything else you think is important to share with our Breast Cancer Wellness readers?**

I wish to emphasize that I credit BOTH western and naturopathic treatments for my miracles and that I don't believe I could have accomplished them without both. You must choose your own path and to do so you must take charge of your healing and commit to knowing your body... it's smarter than you and can guide your path. Bless you all on the path you choose.

*Editor's disclaimer: Make your healing choices wisely and based on credible information on what's best for YOU.*