

# HIGHLY SUSPICIOUS OF MALIGNANCY

by Teresa Rhyne

*Treatment for a serious illness in the Inland Empire can be time consuming and frustrating. Why is healthcare more challenging here than in other parts of California and how do we stack up? Riverside resident and attorney Teresa Rhyne shares the story of her search for quality care here and at UCLA.*

**T**he call from my primary care physician came around mid-afternoon on December 23, 2008 — my mammogram results were “highly suspicious of malignancy.” My instructions were to get to the recommended surgeon ASAP. That last part was unnecessary: To the patient, “Highly suspicious of malignancy” equals “ASAP.” Unfortunately the same is not always true for our local medical establishment.

There were already signs of the problems I’d encounter — not just the cancer, but the quicksand that is healthcare in my Inland Empire community. I had found the lump in my right breast in early December; I saw the physician’s assistant on December 18th; she had her office call to get me an appointment for a mammogram and an ultrasound; they gave me

one for January 6. *Nineteen days later.* Fortunately, the PA, upset about the delay, had put in her own call and gotten me two appointments: one for the next day and one for the following Monday at the same location. Why two? Because the imaging center couldn’t do both the mammogram (which takes 10 minutes) and the ultrasound (maybe 15 minutes) on the same day.

Now, maybe a few days doesn’t seem like a long time, but in this case it was. Six months prior I’d had a clean mammogram, but the lump in my breast was now large enough to feel in a self-exam. This thing was growing fast.

So on December 23rd I called the recommended surgeon to remove the

lump that the mammogram and ultrasound had red-flagged. But the first available appointment was January 12th. Here we go again — 20 days with “highly suspicious of malignancy” hanging over my head. I tried to emphasize the “ASAP” and the “highly suspicious” but to no avail. January 12th was it. No budging; no concern. Not even a half-hearted “sorry.” I said I’d have to get another surgeon referral. She said “Okay.”

By then it was nearly 5 pm on December 23rd. I knew my chances of getting an appointment in the next few days were slim. My frantic calls to my primary care physician’s office for another referral went unanswered.

I left a message with a human, with a machine and with an “exchange” (something between human and machine which only doctors employ. Seriously, does anyone else have an “exchange”?). I repeated that routine the following morning, Christmas Eve.

My doctor called around noon with my appointment with a surgeon on December 30th. I didn’t want to know how far down the list of recommended surgeons they’d had to go. I just wanted to see a doctor and know how highly suspicious things were. I should note here that I have insurance. I have a PPO. I could choose whatever doctor I wanted. Locally, there just weren’t any available to choose from.

On Christmas Eve afternoon, I hurried over to the imaging center to pick up my records. Since they are physical and not electronic, they couldn’t be sent via email to the surgeon’s office, and the long holiday weekend was looming.

This was when the thought first occurred to me that because I’m single, childless and self-employed I could give myself the time off to shuttle my paperwork from one office to another. I could also sit at my desk during the work day (the only hours you can reach a doctor’s office) to make the incredible number of phone calls necessary to obtain care.

What if I was an employee? Had kids to care for? How many people can devote this kind of time and effort without serious repercussions? Not that this wasn’t costing me pay — when I’m not working, I’m not earning; it’s the joy of the solo law practice — but at least I had this choice. And I could and did work weekends to catch up.

The Corona surgeon’s visit was another eye-opener. While the surgeon seemed kind,

knowledgeable and competent, what she told me was shocking. Not the fact that I may have cancer, but the timeline that was ahead of me. Since there are few if any comprehensive breast cancer care center in the Inland Empire, each test and procedure would be handled separately.

She offered up this timeline: biopsy appointment (two to three weeks out); obtain results (another week); if it’s cancer, an MRI (two to three weeks for that appointment); once those results were obtained and reviewed (a few days), we could schedule the appropriate surgery, which would again be two to three weeks out, maybe longer. All tolled, if it’s cancer, it’d be hanging out in my body for another two to three months.

I asked if we couldn’t just schedule all of those things now to at least let me be “in line” for the procedures and shave off a few weeks of waiting time. The answer was no. One step at a time. Half of my brain was screaming “COMPLETELY UNACCEPTABLE” while the other half, the half controlling my mouth at the time, was saying “Please make these appointments as soon as possible.”

The surgeon did say she’d try to expedite anything she could. She also pointed out that with my insurance I could go to a breast care center and this timeline would be greatly compressed. In hindsight, I believe that she was sympathetically trying to convey to me that I should “get out of Dodge.” I was a little slow receiving that message. I’m not an Inland Empire or Riverside basher. I’ve lived here for more than 20 years. By choice. I like it here. And I didn’t want to believe I couldn’t get appropriate healthcare here.

Again, I had to take my own records over to a different imaging center for the radiologist to review and schedule my biopsy. The surgeon has a scheduler, we’ll call her Bambi, who was supposed to coordinate with the radiologist’s scheduler, but after numerous phone calls that day and the next to Bambi (including one where I informed *her* that the radiologist’s scheduler was on maternity leave and perhaps she was going to have to call someone else), I can only assume Bambi had spectacular New Year’s Eve plans and that was all she could handle.

I did finally learn from someone at the radiologist’s office, that the first available appointment for my biopsy was January 16th. Thus it would be almost one full month from the time I first went to my doctor complaining of a lump in my breast to the day of the biopsy to determine

**Loma Linda  
University Cancer  
Center and  
Eisenhower Lucy  
Curci Cancer  
Center in Rancho  
Mirage offer  
comprehensive  
cancer treatment  
in Inland SoCal.**





**The University of California, Riverside expects the shortfall of doctors in the Inland Empire to be as much as 1,140 physicians by 2015.**

whether or not it was cancer.

Luckily, on January 6th I had lunch with a friend whom a Riverside physician had misdiagnosed with ovarian cancer earlier in 2008. She went to UCLA for a second opinion and learned she had an ovarian cyst, not cancer. My friend was thus kindly, but stridently, insisting I get out of town for a second opinion. She e-mailed her UCLA physician. Let me say that again. *E-mailed*. Her doctor! By 2pm her doctor had emailed back with a referral and the fact that the referred UCLA doctor had an appointment available at 2pm on January 8th. Two days away? Email? Communication directly from a doctor? You may as well have told me they'd found a cure for cancer, so elated was I.

On January 8th I drove to the UCLA Medical Center and met with the good and great and kindly and skilled Dr. Amer Karam. He reviewed my reports and tests and films and went downstairs to see if he could get me in for a biopsy *that afternoon*. He returned in about 20 minutes with the biopsy scheduled

get it done immediately.

In the space of the time it took my father and boyfriend to go get a cup of coffee and a snack, I had chest x-rays, blood tests, and an EKG. And I did it all carrying a few sheets of paper and riding an elevator. By the end of January 15, I had the biopsy, the diagnosis, the MRI, surgery scheduled and the pre-op tests completed.

In Riverside, I would have still been a day away from having the biopsy done. I did have to return to my Riverside primary care physician for a surgery clearance where I waited in the lobby 50 minutes past my appointment time (and there was only one other person in the lobby).

I wonder, what is the usual time line? Was "big city" UCLA exceptionally fast due to the size and nature of their facility or was this an anomaly? Was Riverside's timeline average? Is that acceptable? The fault cannot lie with the insurance company — my insurance was the same in Riverside as UCLA. I realize that my

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for the following morning and apologies that it couldn't be sooner. He was looking at the same test results everyone else was looking at, and he, too, knew it was most likely cancer.

On January 9th I returned to UCLA for the biopsy, where Dr. Karam also scheduled my MRI for January 12 and the pre-surgical meeting on January 15. The appointments were made before my biopsy was over.

Dr. Karam called on January 12 and gave me the cancer diagnosis. Then, together with my boyfriend and my father, I met with Dr. Karam on January 15 to discuss the recommended course of action: a lumpectomy and sentinel node biopsy to see if the cancer had spread.

We picked January 28th for the surgery based on both of our schedules (it could have been sooner) and I signed the necessary consent forms. I handled all the paperwork and insurance with a billing person right down the hall from Dr. Karam. Much to my surprise, she also gave me all the paperwork for the pre-op work up and told me I could head downstairs and

diagnosis came over the holidays, but that can't possibly be an excuse. If Starbucks and Target can remain open and serving their customers, surely our health care providers can as well. Unfortunately, since my diagnosis I've talked to enough other breast cancer patients to come to the conclusion that what I experienced was the norm for both Riverside and UCLA. What I experienced appears to be the pervasive culture in both.

I have a friend who underwent treatment locally for breast cancer in late 2007. She told me that when she heard I was going to UCLA for treatment her first thought was that I was going to have to do a lot of driving and would probably regret my decision. She later said that after reading my experiences on my blog, she's convinced she spent a lot more time driving around to various appointments than I did.

I've also talked to a local physician with cancer who left town for treatment. And another breast cancer patient who was told both by a USC and a UCLA physician that the results of one test she underwent were misinterpreted by her local physician and that she was over-treat-

**In April President Obama announced the Joint Virtual Lifetime Electronic Record for military personnel. It ensures that health care providers have all the information they need to deliver high-quality health care while reducing medical errors. It will serve as a model for the nation.**

ed with chemotherapy. Although I've asked, I have yet to talk to a breast cancer patient who stayed locally for treatment in the last few years and was wholly satisfied with the standard of care.

Interestingly, I have talked to breast cancer survivors who were treated locally 15 to 20 years ago who were quite satisfied with their care and their doctors. Several told me how their doctors called frequently, sent flowers, and stayed in touch for a long time after their treatment. Ah, the good ol' days.

While the local physicians (as opposed to their staff in many cases) were kind, I never got the impression they were at all bothered by the timeline or the standards for care locally. No one ever directly said "You'll get better and faster care for this if you leave town." Why not say that? If the physicians have too many patients, if the wait is too long to obtain the requisite testing, if we just don't have the facilities locally, isn't it incumbent on the physicians to send the patient elsewhere?

Perhaps this is where the insurance issue comes in. Are our physicians compelled to accept patients they know they can't ade-

quately serve just to keep their numbers up? Is this acceptable to them? Is it acceptable to us, the patients?

quately serve just to keep their numbers up? Is this acceptable to them? Is it acceptable to us, the patients? I realize now, more than ever, that there are not enough physicians in the Inland Empire. I'm sure our physicians would have even greater difficulty seeing patients if they gave out their cell phone numbers (However, I think email should be an option.). The quantity of care providers is clearly a problem. I can't help but feel that quality is as well.

There seems a pervasive culture that says the delays, the apathy, the lack of urgency or concern for the patient, and even troublesome diagnoses, are the acceptable standard of care. No one that I encountered locally, save perhaps the surgeon in Corona, seemed to feel there was a problem with how things were done. There was no striving for excellence. There was malaise.

Struck by the fact that every person I encountered at UCLA — every receptionist, nurse, doctor, billing person, and even the parking lot attendants — seemed entirely focused on helping me, I asked Dr. Karam if UCLA actually teaches this philosophy. If it's engrained in

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quately serve just to keep their numbers up? Is this acceptable to them? Is it acceptable to us, the patients?

My surgery was successful (clean margins, nothing spread to the lymph nodes) but the cancer was determined to be highly invasive and aggressive. Time mattered. Dr. Karam continues to be available to me to answer questions, reassure me and follow-up by email, cell phone or regular work phone whenever I need him. I never talked to a "scheduler" to see him. And I never waited more than 20 minutes past my appointment time with him.

I'm in chemotherapy now, and, because of the nature of this treatment, I took the UCLA oncologist's recommendation and went to a facility in Rancho Cucamonga. I've seen the doctor twice: at the initial consultation, and at my third treatment. I speak to the nurses during regular office hours only, which excludes lunch. I asked the doctor if I could email her with questions or concerns. She

UCLA employees like it is in Nordstrom employees. Here's what he told me:

*"I did not get any specific training about patient-centered care but my goal is to try and make every patient feel like they are at the center of our team and to try and serve as their best advocate. Patients get easily lost in the system and it takes an insider to get things going. When the ancillary help and assistants see how much the docs are invested in the patients they follow suit."*

Maybe local doctors are all right with the culture here. Or maybe they aren't, but they don't have any other options. Maybe the doctors are as outraged as I am. Maybe that's why more of them don't practice in the Inland Empire.

A month after I finish chemotherapy I will need to undergo daily radiation for five weeks. Because I need to maintain my law practice during this time, I will have to be treated locally. I'm worried about this. You might say, I'm "highly suspicious of a malignancy" in the local health care culture. ❏