

## Some Tips from Over Five Years into this Journey

### STEP ONE:

Pretty much every Ocular Melanoma website has the same basic information on the options available to all of us for treatment of our primary eye tumor once we receive our diagnosis.

*NOTE:* It is important to be confident of the accuracy of the diagnosis, either because our eye doctor or a retina specialist refers us to an Ocular Melanoma specialist or whomever makes the diagnosis is or consults directly with one.

There are (outdated but give a first step for finding a specialist) lists of Ocular Melanoma specialists on multiple websites and seriously, **if the person you consider for treating your primary tumor is not on one of these lists, you really should consider either making sure they trained under one of them or give serious thought to getting a second opinion.**

[www.ocularmelanoma.org/doctorfinder.htm](http://www.ocularmelanoma.org/doctorfinder.htm)

[www.melanoma.org/sites/default/files/u13882/PrimaryOMPhysicianList\\_0.pdf](http://www.melanoma.org/sites/default/files/u13882/PrimaryOMPhysicianList_0.pdf)

### STEP TWO:

It is also critical that as soon as the primary tumor is treated, or in between diagnosis and primary tumor treatment if there is time, you get a referral to a Medical Oncologist who is qualified to monitor your surveillance.

You need baseline scans to both see what \*your normal\* looks like and make sure the cancer has not already metastasized.

*NOTE:* Most of our OM specialists agree on the following surveillance methods: **an abdominal or liver MRI with and without contrast, a chest x-ray or CAT Scan, and basic bloodwork to check for your overall health and liver function, done ASAP.**

Then once the status of the primary tumor is assessed, either based on size or various genetic testing/classification, an annual surveillance schedule is established.

### **NOT ALL ONCOLOGISTS ARE QUALIFIED TO MONITOR PATIENTS WITH OCULAR MELANOMA OR IN THE TREATMENT OF METs**

An oncologist who specializes in skin melanoma MAY NOT be up to speed on the latest treatments for OM if it metastasizes. If they are not on the lists above or the link below, then they should at least be in regular consultation with the leaders in the field. They should for example, have published articles with the "big names" or refer their patients to them on a regular basis.

[www.melanoma.org/sites/default/files/u13882/SystemicOMPhysicianList.pdf](http://www.melanoma.org/sites/default/files/u13882/SystemicOMPhysicianList.pdf)

The most important advice I can give is that you not give over your care to anyone without **doing your homework** and remember, every decision is your decision; the doctors are your partner in treating this cancer. Ask questions including on data and statistics to support any recommendations the doctor gives.

### STEP THREE:

So now your primary tumor is treated. You had your scans and hopefully there is no evidence of disease elsewhere in the body. Now you may wonder whether there is anything else you can do to lessen the possibility of METs.

Unfortunately, as of this publication date [2018 Feb 21] "***no systemic adjuvant therapy has been shown to reduce the risk of metastasis or improve OS (overall survival).***"

[www.ncbi.nlm.nih.gov/pmc/articles/PMC5824910](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC5824910)

But many brave people at this stage try experimental treatments called **Clinical Trials**. Technically, these are not "treatments" per se, but instead, you are a volunteer and they are testing out potential treatments on you. **This is a very valuable step in the process of bringing new drugs and treatments to market. The CURE will be found through this process. The people who try clinical studies are HEROs who are responsible for saving lives!** Learn more: [www.ocularmelanoma.org/trials.htm](http://www.ocularmelanoma.org/trials.htm)

**Lists of Clinical Trials are found here:**

[clinicaltrials.gov/ct2/results?term=uveal+melanoma&recr=Open&sel\\_rss=mod14](http://clinicaltrials.gov/ct2/results?term=uveal+melanoma&recr=Open&sel_rss=mod14)

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### Personal Thoughts and "My Story"

*But what if your doctor is making suggestions which don't seem to be the common ones as you review all the basics on the OM websites? That is why I originally wrote this article as a post on the Ocular Melanoma Support Facebook Group. There are patients getting inappropriate advice from less than qualified doctors.*

I keep seeing people say their doctor did this test or that, or this surveillance schedule or that, or drugs or procedures which do not appear as the normal path established by those true Ocular Melanoma experts.

I was watching the TV show "The Resident" and part of the story line was a cancer doctor who is over prescribing or prescribing inappropriate drugs for her patients and a nurse becomes suspicious. As the article above states "There is no FDA-approved standard of care for metastatic uveal melanoma."

So, when your doctor suggests something, make sure you know WHERE their recommendations come from! Their own practice of treating METs in OM? Then ask them to support their recommendation with data. Does the recommendation come from data from another expert? If so, would that doctor be more qualified to provide you care or will your doctor be consultation with them while you undergo treatment? Does your doctor regularly consult with experts like Dr Sato in Philly when their patients get METs, for example?

As a person who almost died two months ago from immunotherapy, I can honestly say **I was made aware in advance, immunotherapy can be very toxic. The potential benefit was only 5-15%**. My doctor and I discussed at length, all of my options at this point, as well as what future options would be available to me as someone who was currently dealing with two liver tumors and completely normal bloodwork. I chose systemic treatment knowing liver directed treatments are still an option for me later.

## **THIS PART IS REALLY IMPORTANT BECAUSE *I DISMISSED AND EXCUSED SIDE EFFECTS!***

I was informed of the possible side effects, but I didn't actually realize **I was supposed to inform my doctor as soon as I got any of them.** I assumed since they were possible, I was just supposed to be prepared to experience them. I misunderstood and thought I was supposed to tell them of any *unexpected side effects*, not let them know if I got any side effects at all! But I also was in denial. I dismissed everything that was happening because I wanted to continue treatment so badly. I blamed my rash on soap, winter, even needing a new humidifier; until the rash was so itchy and red and (to use my doctors own words when I eventually showed him) "quite impressive". I finally called and described the rash, and was prescribed a cream.

**But they NEEDED to *know* I was experiencing this side effect. Fortunately, *you don't die from a rash.***

The week I was scheduled to receive my second ipi/nivo infusion I had new aches and pains. I could barely sit unassisted because my stomach and back were so weak. I had to pull myself up the stairs with the railing my thighs ached so much. If I didn't balance my head directly over my neck I could not hold my head up and my neck throbbed. I had double vision. But I blamed everything on lifting boxes at work, squatting in a weird position while I packed the boxes, and staying up late to wait for my daughter to arrive from the west coast. I blamed my husband for taking a bad photo of me when I saw my "bad eye" was practically closed in a photo he took of me at dinner!

It was four days before I finally accepted that I was having side effects. I was too dizzy to drive to work myself. When I got there realized I could not sit unassisted, could not see well enough to work on the computer, and most alarming – my good eye was not focusing properly. A co-worker pointed out my bad eye looked slightly droopy. I went home and called my Medical Oncologist. The eye symptoms alarmed him the most, so he got me in for a full exam with my Ocular Oncologist the next day.

I pretty much convinced my Ocular Oncologist that *my droopy eye was from crying all the time and being over tired. It wasn't.* But my eyes and the eye tumor were all normal!

The next day was my second scheduled infusion. My liver enzymes were elevated so it was postponed a week, but I went over my physical symptoms at great length and with lots of drama (finally)! My doctor felt like something was not making sense about how good I *looked* (his opinion - not mine!) but how bad I *\*said\** I felt. After I left, he called the lab to run a test for CK, an enzyme which shows up in the blood when the muscles are breaking down. Normal is 0-170. When he woke up at midnight to check labs, *mine was 8400.* He saved my life by calling me at 1am and saying he was too alarmed to wait until the morning, get to the ER! By the time I got to the ER it was 8900 and my Troponin (similar enzyme but heart muscle) was elevated and rising too. *I was at risk for renal failure and cardiac arrest.*

If I posted my symptoms on Facebook and didn't tell my doctor, and my doctor was not a *specialist* in the treatment of melanoma with immunotherapy - I'd be dead. I spent 8 days in the hospital. It took about 50 doctors from multiple specialties to diagnose that my immune system attacked my skeletal muscles, I lost 15 pounds (mostly muscle) from Myositis and Rhabdomyolysis and I was left with the autoimmune disease, Myasthenia Gravis.

So basically, Facebook groups are so wonderful for emotional support and finding really critical tips for how to deal with this disease, but symptoms and making critical decisions about treatment options REALLY need to be addressed with a doctor that you have researched to make sure is QUALIFIED to be your partner, a member of your team, in treating this RARE cancer! – - Susan Sawhill Apito