

Prepared for Teresa's site on January 17, 2019.

Journal

Wednesday, August 23, 2017

Amanda Grabler, August 25, 2017

Teresa had an appointment with her FNP, Sally Blackburn.

She'd been losing weight everywhere except her stomach, which had become very hard. Amanda read that this could mean there were ovarian cysts or other things, and told T to get an appointment as soon as possible.

After Sally examined her, she managed to get T in at the Bristol Regional Medical Center, in Bristol, TN, for two emergency ultrasounds (pelvic, abdominal), and a CT scan.

Sally also ordered bloodwork. She told us we could call the next day for results, and speak with Dr. Andrews and his nurse, since she'd be out-of-town.

That evening, however, Sally called us after speaking with the radiologist.

The scans showed a large mass where her uterus used to be, and enlarged ovaries. The uterus wasn't visible at all. They suspect uterine carcinosarcoma.

She told us we would be getting a referral to Dr. Kramer, a gynecologic-oncologist in Kingsport, TN. Everyone has said he's the best *in the area*. Of course, we want more for T than just the best in this area.

But, we waited for the referral, seeing him as at least a good starting point, and then we would see about a second opinion.

Thursday, August 24, 2017

Amanda Grabler, August 25, 2017

We waited for hours, but no call came.

We finally called and spoke to someone at the clinic, and learned they were still trying to get the referral (they'd faxed Kramer but had not received a reply) and that the bloodwork wasn't back yet.

At 7pm, Dr. Andrews called. He told us her hemoglobin, which should be around 12 or higher, was at 7.7 and we needed to go to the ER of our choice and get her an emergency blood transfusion. He also told us the mass was 35cm (12-15"), and had spread to her ovaries. He didn't say it had spread anywhere else. They'd done a thyroid panel and liver panel. He didn't mention them.

We made some calls, packed up some things, and headed back to Bristol.

We were taken to triage just after 8:30pm. They took blood for labs, and did a Doppler ultrasound to check for clots in her right leg, which is much more swollen than her left, although the left has swelling too. They didn't see any clots.

At 12:58am, we were finally admitted and in a room. Her blood transfusion finished shortly after that, and they started her on IV fluids.

We are scheduled to see the oncologist in the morning.

Friday, August 25, 2017 9:00AM

Amanda Grabler, August 25, 2017

Dr. Green, a general surgeon with years of gynecology experience, will be removing Teresa's 30lb mass around noon today. The surgery should take about 1 - 1 1/2 hours.

He won't know until he is in there how much of a hysterectomy and oophorectomy needs to happen. We won't know until after if it is benign or not. He said at her age, it's not likely to be benign, but not impossible.

He thinks it's better to operate now, rather than continuing to wait for a referral to Kramer. I asked about a referral to Sloan Kettering. He has done it for other patients, but it can take 2-3 weeks. Would be smarter for follow-up care so she can get this out.

Comments

Teresa,

I know that you are in good hands with Dr. Green . Have heard many good reports. Dear friend , I will be thinking and praying for you. Let me know what I can do to help. My thoughts and prayers

—Ellie Novak-Scofield, August 25, 2017

You are both in our thoughts and prayers. Aunt Anne & Uncle Frank

—frank wagner, August 25, 2017

Friday, August 25, 2017 12:19PM

Amanda Grabler, August 25, 2017

Teresa was taken down to surgery right on schedule. The nurse who came to get her said what everyone else is saying, that Green is amazing, so trying hard to stay hopeful and positive.

After surgery, she goes to PACU (post anesthesia care unit) to recover and wake up. Then she should go back to her room, and is probably staying for the weekend at least.

Probably at least 6 weeks recovery.

Friday, August 25, 2017 1:35PM

Amanda Grabler, August 25, 2017

Pager message received:

Dr. Green has started. Teresa doing well.

Comments

Thankful that she is doing well. Love and Prayers

—Ellie Novak-Scofield, August 25, 2017

Friday, August 25, 2017 5:45PM

Amanda Grabler, August 25, 2017

Teresa is out of surgery and stable.

She is in recovery, waiting to go to ICU, as soon as a bed is available. Once that happens, I can go see her.

The mass was about the size of 1-2 watermelons. It weighed 32 pounds. She also had a gallon of fluid, so they removed a total of 40lbs.

My understanding is the incision is rib cage to pelvis.

It took three surgeons to pull it out.

Her protein is very low, which contributed to the fluid build-up. She is malnourished.

Pathology is gone for the day, so Monday is the earliest they can start, but Dr. Green thinks it is malignant. He said there's a chance it is benign, but it is very small.

The right ovary looked normal, but our understanding is he took it out. They never saw the left one; it was lost in the mass. He doesn't know if it started in the uterus or the ovary.

There is a possibility it has been growing for at least a year, but he will know more once pathology examines the cells.

He took 90% of the uterus and 95% of the tumor.

He left parts of the uterus so she wouldn't bleed out, because of how large the blood vessels to the tumor were, and the 5% of the tumor so as to not damage the other nearby organs.

He believes the last 5% can be fully treated with chemo or radiation, and that would be followed with a pelvic clean out in a follow-up surgery.

She lost 2500cc of blood in surgery. They gave her two units, and I believe they are giving more as her hemoglobin dropped to 6. (It should be above 12.)

She has a breathing tube, and I think one for food.

She is in ICU overnight because of a remote chance of bleeding. The ICU nurses are better equipped to respond

if that happens.

She will be discharged when she is eating well, has good urine output, and they know her bowels are working properly.

They expect that to be Monday or Tuesday.

Dr. Green said follow-up at MSK is a good idea. He is very good, this MSK has so many more options and technology.

She is awake, and very tender. Very large incision. She is on a pump for painkillers, but I don't know what. She did have some morphine before surgery, which she said helped.

I will post more as soon as I can.

Comments

Sending lots of hugs. I am glad all went good

—*Patricia Coffman, August 25, 2017*

Oh Amanda please tell Teresa that we are thinking about her and wishing her well. What an ordeal.

—*Christine Daly, August 25, 2017*

Thoughts and Prayers to both of you
Hans and Ingrid

—*JOHN GROSSMANN, August 25, 2017*

What an ordeal. We are thinking of her and you. Stay strong.
Aunt Anne

—*frank wagner, August 25, 2017*

Sending healing thoughts and prayers.

—*Gia Koehler, August 25, 2017*

Love, healing energy and strength to you both.

—*Monica Spath, August 26, 2017*

Saturday, August 26, 2017: Morning

Amanda Grabler, August 26, 2017

Sara stayed with Teresa in ICU last night so that after I saw her with my own eyes, I could go home and get a regular meal (couldn't eat in the cafeteria because ... gluten), better sleep, check on our cats, etc., and pick up some things to bring back to the hospital.

I texted Sara this morning to find out how she was doing and to hear if the doctors/residents had rounded yet. Mom and I will be heading back to the hospital soon.

The doctors have been by. They're going to try to get Teresa up later and move her around. She's doing great! Supposedly may take the tube out (in her nose) tomorrow, so we guess she'll be in ICU another night. As long as the tube is in, she cannot eat (NPO), but Sara is wetting her mouth with the sponge-on-a-stick as needed.

T is in some pain, but is far more coherent than yesterday (she's on Dilaudid), but still drifting in and out. Sara said she's not as doped up, so I'm thinking T is not administering as much as yesterday. (She has a self-administering pump for pain medicine.)

She got her color back. Asked about me and my parents; lost some time (not much) but knows where she is. Good urine output. Asked how much time she'd lost: She remembers us being there after she got to ICU, but couldn't figure out where I was this morning (we told her last night where we were going), so Sara explained it again. She understood. Getting some sleep but the nurses are in doing stuff about every hour.

Sara also said she's asking for her tablet, which is definitely a good sign. I made sure to charge all our tablets, phones, etc last night. Until we're in a regular room, outlets are going to be hard to come by.

Once I'm back down there and know more, I'll post again.

She can't really have visitors besides us until she's out of ICU, but would love to have them once she is and is more aware. I decided not to post room-specific information on the site, so please email me at amanda.grabler@gmail.com if you want that information once I have it.

Comments

This is good news. Terese will be stronger each day. Please tell her that we are thinking and praying for her.
Aunt Anne

—frank wagner, August 26, 2017

Thank you for keeping us updated. We are praying all goes well and she's strong enough to go home soon. Give her our love and prayers.

—Karen Grabler, August 26, 2017

Sending love and hugs. Wishing her a fast recovery xoxo

—Maureen Lauria, August 26, 2017

Saturday, August 26, Afternoon

Amanda Grabler, August 26, 2017

Sitting with Teresa now. She's doing well. **Much** more lucid. They've started her on breathing exercises.

She still has the tube in, so no food. We use a sponge to wet her lips as needed, and give her a little moistness for her mouth.

Comments

Tell Teresa I say hey !

—Linda Call, August 26, 2017

Saturday, August 26, 2017: Afternoon-Evening

Amanda Grabler, August 26, 2017

She's still doing well!

The surgeons still want her NPO, and as of now, they won't have her getting up. Maybe tomorrow. She did move her legs some and was able to shift herself up and off of the bed earlier. Got into a different position.

Vitals are still good.

A woman from oncology came by, just to introduce herself and ask T a few questions, even though she said we may not even need her (which I hope is the case!). Like us, she won't know anything until pathology is back next week. She did say they're usually pretty prompt.

Night nurses are on now, so new people to learn! Everyone is still super friendly.

Sara is on her way back and will stay overnight. I will probably go back to the apartment tomorrow afternoon to get some stuff for T, and have another regular meal or two. We make sure there's always at least one of us in the room with her at all times.

Comments

Glad that she is doing well.

—Gia Koehler, August 26, 2017

You are both in my thoughts.

—Bridget Gallagher, August 26, 2017

I hope that's the last time you see anyone from b any oncology anything.
Thank you for updating

—*Maria Yakkey, August 27, 2017*

I think that is a good idea to have at least one person with her. Thank you for the update. I asked during mass last night for prayers for Tesesa.

—*Monica Spath, August 27, 2017*

Sunday, August 27, 2017: Morning

Amanda Grabler, August 27, 2017

My Dad got me a room at the nearby Fairfield Inn. He and Mom are there too. He has already gone to the hospital this morning. This is what he sent my Mom when she asked.

"Looks good. Even more alert than yesterday. Moved her up in the bed a half foot so she could sit up better. Getting potassium. Physical therapy later today. Hemoglobin up from 7.4 to 8.1 with her making it*. Bandages have been changed. Wound looks good. Bowel sounds a little less today, but Mandy the nurse is not worried about that at this point."

*Significant as up until now, she's required transfusions. I believe since Thursday night, she had 4.

I believe she was also coherent enough last night to watch some Star Trek on her tablet.

Comments

Thinking of you all, especially Teresa.

—*Heidi Baird, August 27, 2017*

Sunday, August 27: Evening

Amanda Grabler, August 27, 2017

A lot happened today!

Everyone who has an account here to follow Teresa's progress should have received email from me tonight with how to contact and/or visit her. If you didn't and would like a copy, please leave a comment here. I check the comments multiple times a day. I'll get it to you ASAP.

This morning, her bandage was changed and incision inspected. It's looking good. Healing well. The skin around it looks normal. I wasn't there for the morning change, but I was for the evening one. Her skin also feels normal temperature-wise.

Her color is even better today.

PT visited her and got her up and walking, with a walker. She walked around her bed, out the door, into the main ICU area and back. She was able to sit down by herself but need help getting into the proper position to lay down.

Besides helping her heal, checking her mobility allowed them to determine if she could get her catheter out (and then there were three options depending on how much she could handle moving). They did remove it, and then there was a 6-8 hour timeframe to see if she could go on her own without pain. She proved that almost immediately.

Since the incision was looking good, and she had mobility, and they'd been able to take her off of oxygen, they were able to move her to a private room.

She is still NPO, and still just on IVF fluids, but we're hoping that the more she moves around, the faster her bowels will wake up. When that happens, it is my understanding that they will remove her NG tube and start her on clear fluids.

Will write more tomorrow.

Comments

Teresa,

It was great to be able to talk with you yesterday. I hope today brings you more strength and good news. Have a great day. My thoughts and prayers.

Ellie

—*Ellie Novak-Scofield, August 28, 2017*

Progress!!!!

—*Heidi Baird, August 28, 2017*

Sounds like Teresa's strength and confidence are bringing her back to health quickly! I'm very impressed.

way to go, Teresa.

—*Lee Ware, August 28, 2017*

I'm glad that they are starting to remove some things...(Catheter, O2). These are all good signs! Make sure they give you an incentive spirometer for your lungs. You don't need pneumonia. Glad they moved you too. I hope you continue to improve. I'll be thinking about you! Let me know if I can do anything. ?

—*petra oconnor, August 28, 2017*

Teresa & Amanda

Thank you for including me in this news feed!

My prayers will certainly be with you both!

—*Carol Shuler, August 28, 2017*

Teresa, I'm praying for a speedy and complete recovery. Amanda will be there for you.

—*jim bier, August 28, 2017*

Monday, August 28, 2017: All Day

Amanda Grabler, August 28, 2017

T has had a very busy day!

After being up and down all night (losing more of the built up fluids!), she had her NG tube taken out!!

She is mostly still NPO, but has ice chips now. This is getting her used to sort of eating again, and not putting her in the possible position of having to have a bowel movement early in the morning when she isn't quite awake, especially since that will take more muscle use.

She's been very good at, as she put it, training the nurses! Teresa is running her own version of the Help Desk from her bed! Very assertive. It's great to watch. I called her from the apartment earlier today, and she sounded just like she does at work!

We thought PT was coming today to get her up and into a chair, but they never showed. Later, a nurse told Dad that T had declined, and we concluded there'd been a misunderstanding. We think someone mentioned Rehab, meaning PT, but T thought they meant a Rehab *facility*, which she doesn't want. One of the night nurses told her just to tell her nurse in the morning that she does want the in-house PT.

Pathology: The latest word is that we get the results on Wednesday. We have no idea what time of day, or if Wednesday is an estimate or an actual date.

Discharge: Still unknown. And I really want to be sure she can handle solid foods before they release her.

Breathing Exercises: She is working on this as best as she can as her muscles heal. (It's a vertical incision from just under her rib cage to her pelvis. If you ask, she will be happy to have me email you a photo of it. It was taken between bandage changes, so it also shows how well her skin is healing, and that there's no redness.)

Comments

Teresa you are a STAR!!!
You are lookin' good and it's good getting
the updates from Mandy Lou.
You're in our thoughts at all times and all
good thoughts are flying your way!!!!

—Terry Werick, August 28, 2017

Continued good progress I am happy to know! Thinking of you all the time.

—Heidi Baird, August 29, 2017

Each day is a blessing that you are getting better. Have a good day. Talk with you later

—Ellie Novak-Scofield, August 29, 2017

I think it's a good idea to wait until she can handle solid food before she is discharged. Also to wait until she has

a good bowel movement too.

—*Monica Spath, August 29, 2017*

Tuesday, August 29, 2017: All Day

Amanda Grabler, August 29, 2017

Lots happened today!

Food:

This morning, Teresa was able to get clear liquids for breakfast! Outside of the IV bags, it was the first nutrition she'd had since Thursday afternoon. The only thing she had Thursday was one container of banana baby food.

For lunch, she also had clear fluids.

For dinner, they let her use her judgment on if she could handle a full liquid diet.

Clear liquids mean things like broth, juice, jello, Italian ice, and various drinks. At breakfast, this included coffee. She said it's so bad, that it makes McDonald's taste good.

She ordered two clear liquids plus potato soup and cream of wheat for dinner. She said they sat well, but the cream of wheat doesn't taste like what she remembered, and the soup was pretty salty.

Visitors:

She also got visitors today! Kristen Miller and Jacob Dinger (both of whom we know from KVAT/Food City), came by for quite awhile! It was very nice to see them both, and Teresa was in very good spirits!

Sara also came by for a few hours, which was great!

IVs:

Teresa is almost IV-free!

The only one left is just in place in case of an emergency, so they wouldn't have to try to restick her in a hurry.

Mobility:

When I arrived this morning, I found Teresa sitting in a recliner. She told me she also was able to walk, with her walker, to the window at the end of her hallway. It's an impressive distance!

Coughing:

It is still very painful for her to cough, and she's been trying to avoid it as much as possible. I got her some cough drops at the hospital Walgreens tonight, but eventually she did end up coughing up a lot of phlegm tonight. Luckily, a PCT (Patient Care Tech) had just come in to help her walk to the bathroom. When she had a second coughing spell, and it was just the two of us, it was less scary.

As of now, she's watching TV and playing on her tablet to keep her mind off of coughing.

I am staying in her room tonight. Dr. Greene comes by before I can ever get to the hospital, even though the hotel is super close by. I'm hoping to be awake enough to ask him some questions in the morning! :-)

Comments

Way to go, Teresa! You're healing fast!

—*Jody Werick, August 29, 2017*

Pretty good?! It must feel brutal to cough with the stitches and incision but they like you to keep everything loose - no developing pneumonia!

Take care. Well check in again tomorrow

—*Terry Werick, August 29, 2017*

Sounds like good news!

—*jim bier, August 30, 2017*

I'm glad we were able to come visit. I wish it had been under better circumstances, but it will get better and we'll be hiking in no time.

—*Kristen Miller, August 30, 2017*

Wednesday, August 30, 2017: Morning

Amanda Grabler, August 30, 2017

I stayed with Teresa last night. One, to be with her. Two, so I could catch Dr. Greene in the morning. (He comes by early!)

We may get pathology today, but it could be tomorrow now.

Her hemoglobin is up to 9.1!

Although path isn't back, Greene said she'll need some kind of therapy, chemo or otherwise, to help melt the last bits of tumor he couldn't safely get out. (He didn't want her to bleed out, and he didn't want to risk damage to her other organs.)

So far, it's not a radical hysterectomy. He did remove ovaries and most of the uterus, but not her cervix. This doesn't mean that further surgery won't be necessary down the road.

He will have an order put in to move her from full liquid diet to regular diet!

She can bathe/shower now. We decided a nurse should do it first, and then I can learn from that experience, so I can do that for her going forward.

He will need to have at least one follow-up appointment, in about a week, to take her staples out and see how she's doing.

She must continue the breathing exercises at least 2-3 days. It's a challenge, so may be more.

She can be discharged tomorrow if she feels ready, but Friday seems more likely at this point as the earliest. Walking is still very difficult.

Comments

Thanks for keeping me update..

—Linda Call, August 30, 2017

Teresa, this all sounds good. I hope that your discharge will be Friday. You need to get more strength. I also

think that being Labor Day week-end that Dr. Green would keep you till Monday for safety reasons being a holiday. Have a good day.

—*Ellie Novak-Scofield, August 30, 2017*

Great news! Thanks for the update. Love to both of you. Aunt Anne

—*frank wagner, August 30, 2017*

Amazing progress, Teresa. I hope very much that the test results are good!
Lee Ware

—*Lee Ware, August 30, 2017*

Great news! Thanks for the update.

—*Donna Ackley, August 30, 2017*

Thanks for the updates!

—*Bridget Gall, August 30, 2017*

Wednesday, August 30, 2017: Afternoon

Amanda Grabler, August 30, 2017

With my Mom and I helping, Teresa was able to take her first shower today. There's a chair in the shower, so she could sit down the whole time. She also got a new bed (hers kept locking up), and new sheets. We have a clean gown and clean socks for her too. It should help her feel a lot better!

She is partial to Pantene, but it makes me break out. Once she's out of the hospital, she's willing to try my shampoo and conditioner. Mom is helping her get her toenails trimmed too, since T can't bend over to do them.

We got her hairbrush washed before the shower too, so it would be nice and clean post-shower.

(Hospital gowns are confusing when they're completely unhooked!)

Dr. Greene played her taking our regular antihistamine, and it seems to be helping some.

Despite feeling tired from the shower, Teresa is feeling good and refreshed!

Comments

So good that talk to you today

—*Maura Fischer, August 30, 2017*

That's great to hear the process Teresa is making. Lots of love and healing blessings.

—*Monica Spath, August 31, 2017*

Is it too soon to ask when she will go home? Sending hugs.

—*Heidi Baird, August 31, 2017*

Thursday, August 31, 2017: Morning

Amanda Grabler, August 31, 2017

Just a quick note. Will write more later.

News from my Mom (she stayed with T last night):

Teresa has asked for discharge, either today or tomorrow. Dr. Vance said he pass word along. When Dr. Greene came in later, he told her he'd get ball rolling for today. But sometimes the orders don't go in quickly, so we shall see! We want to her her out and settled before all the holiday traffic starts up.

She is asleep right now.

As soon as I know more, I will let you all know. And once she's actually discharged and settled, I'll let you know how/where to contact/visit.

Comments

Address?

—Linda Call, August 31, 2017

Great news!

—Karen Grabler, August 31, 2017

Thursday, August 31, 2017: Evening

Amanda Grabler, August 31, 2017

Teresa was discharged today.

My Mom is with us.

We we will stay at our apartment tonight, and then the plan is to head to Roanoke tomorrow.

I will send out an email with contact information once we are in Roanoke.

Comments

Great news!!!

—Maureen Lauria, August 31, 2017

Great news! Happy to hear!

—Karen Grabler, August 31, 2017

This is good!

—jim bier, September 1, 2017

Thursday, August 31 - Friday, September 1, 2017

Amanda Grabler, September 1, 2017

Since I didn't have time to leave a detailed entry on Thursday or Friday, now that we're more settled, I thought I would share information for both days.

My Mom spent the night with Teresa on Wednesday into Thursday. Thursday morning she told me that T was doing well. They both got several hours of sleep in between the nurses and PCTs checking in. T coughed way less. For her breakfast, she ordered Cheerios (which she never ended up eating), bacon, toast, and grape juice.

Dr. Vance came by around 6:15am. He said he would pass the word on that she was ready to be discharged and would like to get on the road before holiday traffic, either early Thursday or early Friday. He told them that pathology planned to send off some of her slides for someone else to look at. I was glad to hear this because I hoped to get a second opinion.

Her potassium went up to 3.4. Normal is 3.5, so they gave her some pills instead of a drip, but she only had to take it once. No more magnesium drip - that's all done.

Her hemoglobin was 8.8; a little lower than yesterday, but we figure it fluctuates (especially since they keep taking samples for testing 1-2 times a day!).

Thursday morning she was able to pull herself up to go to the bathroom without any help, including washing her hands instead of just using one of the hospital wipes. (And now we know why the hospital sink is so high up! The lower sinks at home are more painful to use.) She did her breathing exercise but couldn't get it past 1000.

One of the nurses said T had a pleural effusion (about 2 soda cans worth) and that this could be making it difficult to do the breathing exercise. T is not having shortness of breath otherwise, though. Also, Angie (nurse) said that if she gets up to do her walking, it should completely, or mostly, reabsorb on its own so that she won't need it taken out with a needle. (Pretty sure T has had enough needles for awhile, so that would be great!)

PT visited her that afternoon, and she walked 2 hallways, and did 24 stairs. PT was pretty impressed from what I heard!

While some of this was going on, my Mom and I went up to Abingdon to pickup the cats. I'd been able to secure emergency boarding for them at our vet. They'll be there for about a week (give or take). We will be bringing them up to Roanoke, but I had

figured that we'd probably be in the apartment at least one night, and we couldn't risk them jumping on T's abdomen!

We got them settled at the vet, took care of a few other errands, and headed back to the hospital.

Jeremy Perkins and Sally Blackburn got a chance to visit before she left the hospital, which was great! Really appreciated!

T did get her discharge papers for Thursday, and we got her all packed up in pretty record time.

We went to our apartment in Abingdon, VA. This was me, Teresa, and my Mom. My Dad had already gone back to Roanoke.

Mom and I got everything unpacked from the car and inside (much easier without having to worry about tripping over the kitties!) and into the living room so I could sort it that evening. We got Teresa settled and we all had dinner.

T cannot eat a lot yet, but she is having good food each meal time.

We knew there was a lot of rain coming the next day, so T and I (especially T) monitored the forecast carefully to make the best decision on when to leave.

Early Friday, I ran some errands in town to get a few things we needed. Came back, had breakfast, and then started repacking the car. We were very glad that I'd packed up most everything the night before, as Teresa had determined by this point that we had about an hour to get packed and on the road in order to stay ahead of the rain.

We missed it by a little bit, but did eventually drive out of it. Most of the trip was pretty clear, and we only ran into heavy traffic 3 miles from our exit! We got to my parents' house about 4:30p.

Everything T needs is set-up and ready to go at my parents' house. Dad made steak and baked potatoes. We'll be working on not only getting her protein levels up, but also working on getting her foods to help her hemoglobin go back up.

Her color still looks good, and Teresa said she looks normal/like herself when she looks in the mirror!

Although we have a walker on hand, which we would take if Teresa decided she really needs a day out of the house, she does NOT need to use it in the house. Sometimes she needs me to help her get up. Sometimes she does it on her own.

Tonight, Teresa was able to get the incentive spirometer up to 1250! She also feels like she understands how it works better now too, which has made it easier. (They taught her how to use it while she was still on dilaudid!)

She can't stand up straight all of the time from the pain, some of which she thinks may be from the staples (she counted 46!), but she is able to stand up straight for short periods. This, of course, will help her heal better. She will get her staples out soon. She has an appointment tentatively scheduled for this coming Wednesday, but Dr. Greene could decide to wait a few more days.

Everyone who is currently following Teresa's journey through this site will be receiving an e-mail from me (amanda.grabler@gmail.com) on how to contact and/or visit her now that we're at my parents' house.*

Thank you so much to those of you who have already sent cards. If you've sent one within the last 1-2 days, she'll probably get it when we go down for her staple removal appointment. A good friend is taking in our mail for us.

* This will be sent out sometime on Saturday 9/2 after I've had some sleep! :-)

Comments

Again Amanda thank you for the updates-I truly appreciate them. Also hugs & love to Teresa.

—*christine Daly, September 1, 2017*

Wonderful progress still! Will visit when it suits.

—*Heidi Baird, September 2, 2017*

That's great the process T is making. I'm continuing to send love and blessings to you both.

—*Monica Spath, September 2, 2017*

So glad at how well she is doing. Prayers continue.

—*Brenda Boyer Smith, September 2, 2017*

Thanks for keeping us posted! Sending good thoughts your way.

—*Laurie Abeel, September 3, 2017*

Praying she has a good week, this week.

—*Michelle Kellogg, September 4, 2017*

I hope everything is going well and you both had a good weekend to recover.

—*Kristen Miller, September 4, 2017*

Tuesday, September 5 - Wednesday, September 6, 2017

Amanda Grabler, September 5, 2017

Just a brief update to let you know where we are on everything.

We're heading back to Abingdon later today.

Tomorrow morning, T has her first follow-up appointment with Dr. Greene. This is, hopefully, to get her staples out. They're really bothering her (she has 46!).

We also hope to finally hear about the pathology. It's still an unknown, and right now, not knowing is worse.

Depending on how it goes, how the weather is on Wednesday, and how a situation with one of our cats goes, we *should* be back in Roanoke by Wednesday evening. But once I know more what's going on, I'll post again.

Sent from CaringBridge iPhone app

Comments

Prayers all goes well with the follow up

—Karen Grabler, September 5, 2017

Glad you are home . Is Faden sick? Or Marble? Or Flash?

—Beverly Keener, September 5, 2017

Still reading these posts. You're in my thoughts!

—Bridget Gall, September 5, 2017

Wednesday, September 6 - Friday, September 8, 2017

Amanda Grabler, September 8, 2017

Teresa had her first follow-up with Dr. Greene on 9/6. This was the first day he tentatively thought he could take Teresa's staples (46 of them!) out, but he said it could be too early. This was because she went into surgery malnourished.

Teresa, however, heals really well! And fast, apparently. The staples came out! The incision flattened out and looks good. It's still weeping a little (mostly clear fluid, some fresh blood) but Dr. Greene said this was normal and not to worry about it. It's not infected or anything.

We have another appointment with him on 9/20.

I asked if he would do follow-up blood work (CBC), so we could see where her hemoglobin is, and he wrote us an order to take down to the lab. One of his 'henchmen' (his words!) checked her lungs and said they sounded good. (She'd had a pleural effusion, but Greene said this wasn't unexpected due to all the fluid buildup in her abdomen, and how the tumor had pushed her organs out of the way.) He also wrote an order for radiology to do an x-ray of her chest to see how it was clearing up.

She's not having any shortness of breath, however, which is a good sign. We were told that if she does the breathing exercises, and gets up and moves around, this would help it resolve on its own. (The alternative, I think, is a thoracotomy to drain the fluid with a needle.)

We did receive the pathology report.

The tumor was malignant. It is called Uterine Myxoid Leiomyosarcoma. It is a rare cancer. It is not a good prognosis.

HOWEVER.

Teresa has a good, positive, strong attitude. She is doing well. She is healing well. She has her appetite. She is strong and fighting.

To help her recuperate, my Mom is preparing meals for Teresa from Dr. Joel's Furhman's books; particularly those aimed at super immunity and anti-cancer. For example, she's making sure Teresa gets Greens, Beans, Onions, Mushrooms, Berries, and Seeds, every day. Nuts as well. These foods in particular help fight cancer because, for a basic explanation, they help destroy tumor cells.*

Also, no processed sugar.**

Our current understanding from pathology (pathology reports are NOT easy to read) is that is stage IIB, which isn't great, but it's a lot better than it could be, especially given the size of the tumor.

It is possible that oncology may restage her -- whether this will be better or worse, there is no way for us to know at this time. Dr. Greene was going to get us an appointment with an oncologist at BRMC, but told me to go ahead and try to get her in at Memorial Sloan Kettering in NY. Chemo usually starts 3-6 weeks post-surgery, which gives her a little more time to heal from her large operation.

She will have to have another operation to remove her cervix. She was too anemic for Dr. Greene to do any more

surgery the first time around.

Our understanding right now is that it hasn't metastasized, but we'll know more after we get to talk to oncology, of course. Pathology did find the left ovary, and it was normal. It got swallowed by the tumor (which definitely started in the uterus as a fibroid), but it did not metastasize into the ovary.

Her other reports so far (heart, lungs, liver, spleen, gallbladder, pancreas, kidneys, bladder, etc), all seem to be good based on my understanding of the reports we've received. Her heart is not enlarged!

We realize that this information is going to make people sad, upset. Possibly feeling physically ill. We understand. We've had those feelings. We're still having those feelings. But, Teresa is doing her best to stay cheerful and positive. On top of a good diet, these two things, plus genuine laughter, will help her heal. Will help her fight.

*So, we know it is hard. But we ask you, please, please, have these feelings *before* you call and/or visit. If you cry when you visit, if you cry on the phone, she will cry too. (Not that we don't expect that she will never cry. It's tough news! But the less, the better.)*

We want to stay as hopeful as possible, so that Teresa can have the best possible outcome from this diagnosis.

Again, if you're planning to visit, please call and/or e-mail first to make sure it's a good time. Unless we suddenly get an appointment at Memorial Sloan Kettering, we will be in Roanoke until 9/19, at which point we'll go back to Abingdon for her morning appointment on 9/20 with Dr. Greene.

She really does enjoy receiving calls, and would love to have more visitors!

* Here is the diet information if you're interested in what we're doing: [The Healthiest Anti-Cancer Foods](#)

** I know when some of you asked, prior to us receiving the pathology, what treats she likes, we told you bagels and maple things. Ideally, it would be better if she didn't eat those now, and if treats were not food items. We're in the process of working out fun things she can have which are still healthy, but right now, I really wouldn't know what to tell you food-wise!

I read all your comments to Teresa, and tell her who is leaving the hearts on each post. I cannot reply directly to comments, however, so, if you have questions, please send them to me at Amanda.Grabler@gmail.com, and I will respond as soon as I am able.

We both appreciate those of you who have asked after our sick kitties, but if you'd like to know what's going on there, please write me privately.

At this time, we are still not posting anything publicly on Facebook. Teresa may decide at some point to share there, for anyone we may have accidentally left out of the loop, but we're not there yet. Thank you for understanding.

Comments

It is good hearing from you. I am busy at work trying to stay sane. Watching the weather in Florida where my sister is. So far she is safe. It is getting chilling in the mornings. I know that you will have a lot to go through on this journey. But you are both fighters and have good spirit. My thoughts and prayers. Have a good week-end!

—*Ellie Novak-Scofield, September 8, 2017*

Hugs from Texas!

—*Michelle Kellogg, September 8, 2017*

Ladies,

I am thinking of you and hope you both are resting when you can because the stress of all of this needs to be pushed away as you both work together to kick cancer's butt.

—*Cindy Ford, September 8, 2017*

I am sad! And mad at life! You two will handle this in the best way possible. And there is always hope.

—*Heidi Baird, September 10, 2017*

Amanda, The two of you are in my heart and prayers. I hope the oncologists can come up with a good plan. Nutrition is so important so I am glad your Mom is able to get a jump start on that.

Lots of love

Maura

—*Maura Fischer, September 12, 2017*

Monday, September 11, 2017

Amanda Grabler, September 11, 2017

After going around in numerous circles with BRMC and Quest (lab) in Greensboro, NC, I finally got results of Teresa's CBC and chest x-rays from 9/6.

The pleural effusion is still visible but it hasn't gotten any worse. Dr. Greene's Medical Assistant, Ashley, confirmed that if she keeps up with her breathing exercises as well as light exercise (ex: walking laps around the

first floor where she can make a complete circle), the effusion can go away on its own!

Her hemoglobin was up to 10.6! They consider normal 11.7, so she's getting close! This also tells us she's making **and keeping** her blood now! That test did not check her potassium (which she was prescribed prior to leaving the hospital), but Ashley said we can go to a local urgent care and ask them to do that test. If we do that, I'll also have them do another CBC so we can keep a good eye on her hemoglobin.

Also, as I've mentioned before, part of Teresa's healing is keeping her positive, and laughter is a good way to do that. She has healed enough that laughing is not as painful on her abdomen. She still has to be very careful (we don't want her to get an incisional hernia!) but laughing is good for her.

To help her in this (the quest for more laughing), I've created 2 forms that I hope you all will take a moment to fill out for us. You may have recommendations for funny things that we haven't thought of yet.

You can find the forms here (they're in my Google drive, so the links are safe). Please leave your comments about the movies/books on the polls, not as comments on this site. With the forms, I can export the answers to excel and easily take them with us to the store. :-)

[Funny Movie Poll](#)

[Funny Book/Comics Poll](#)

Comments

Sounds like things are getting better! Great!!!! Teresa , daily I say to myself "Ellie keep your old body moving" So Teresa you have a young body and it sounds like your moving and getting stronger. Once you have a plan in place all will be fine. Have a good day!

—Ellie Novak-Scofield, September 12, 2017

Memorial Sloan Kettering

Amanda Grabler, September 13, 2017



We have secured an appointment at Memorial Sloan Kettering Cancer Center (NYC) for Teresa on September 25. She will be seen by Dr. Nadeem Abu-Rustum. You can learn more about him here: <https://www.mskcc.org/cancer-care/doctors/nadeem-abu-rustum> (And you can watch a short video of him speaking as well.)

He has wonderful reviews. He is smart and innovative. This story about a life saving surgery he performed on a pregnant woman with cervical cancer is amazing: <http://nymag.com/health/bestdoctors/2010/66460/>

(Not that pregnancy was ever a concern for us, but knowing that he was able to do that really helps us feel we're in the very best possible hands at MSKCC.)

He is a gynecologic oncologist, and also holds the following positions: Chief, Gynecology Service; Vice Chair for Technology Development, Department of Surgery; Avon Chair in Gynecologic Oncology

We are working with a wonderful Patient Care Advisor who is helping us get everything going. We've already had her records sent from BRMC.

If any of you are fans of Grey's Anatomy, from what we've learned so far, Abu-Rustum seems to have the very best qualities of Chief Webber, Dr. Derek Shepherd, and Dr. George O'Malley.

That said, she does have another follow-up with Dr. Greene at BRMC on 9/20 (we'll head to Abingdon on 9/19) in the morning. And that same day, in the late afternoon, she'll meet with (we believe) Dr. Tamara Musgrave, an oncologist. We think she's the oncologist who introduced herself to us while T was still in ICU, but we met so many people, we're not sure.

At this time, we don't know if all of T's treatment will be done at MSKCC, or if at some point, we'll have them refer treatment back to BRMC, so that we don't have to drive as far for treatment. But BRMC in that case, would be strictly following the protocols and procedures as directed by MSKCC.

We will leave for NY on Saturday, 9/23.

If you want to visit before we leave, please send me an email so we can work out the best day. We do ask that if you're feeling under the weather (or have an immediate family member who is) that you do not visit at this time. And we really appreciate those of you who planned to visit but let us know you needed to wait because you might be getting sick. Thank you!

Teresa wants to thank those of you who have sent her cards. She's really enjoying getting them in the mail. Really cheers her up! She was especially amused by the *18* cute kittens received in the mail on cards from my brother and sister-in-law's family (Brian & Donna), and her friend Maura. Even better, they arrived on the same day! :-)

As you can see by the photo I'm including, great minds think alike!

Comments

That's great you were able to get a great doctor to take Teresa's case. Also having one with a great reputation is also a plus too. That's great news.

—*Monica Spath, September 14, 2017*

Teresa,

This sounds great . I read about the doctor and it sounds like you have the best. I have been thinking about all that you have gone through and how quickly things happen and got done. I feel that things will turn around and treatment will help. You are young and strong and when you have that behind you , all is well. Looking forward to seeing you and Amanda.

—*Ellie Novak-Scofield, September 14, 2017*

MSKCC Is a great hospital. If I do not talk to you before you go, travel safely. Glad you enjoyed the card?

—Maura Fischer, September 15, 2017

Second Post-Op Visit, Bristol Oncologist, & Traveling to NY

Amanda Grabler, September 23, 2017

On Wednesday, September 20, Teresa had her second post-op visit with Dr. Greene.

While I cannot remember what he said verbatim when he walked in the room and saw her (in the outfit she's wearing in her new CB profile photo), I *can* tell you that what he essentially said was, "Why, aren't you the picture of a cure!"

She can do gentle exercises. She can try some abdominal exercises (ex: she can test out playing golf on the Wii to see if her muscles can handle the motions of swinging a virtual golf club), but nothing too strenuous (no sit-ups/crunches or similar yet). She's not cleared to lift anything greater than 2-3lbs.

She can drive some, but she cannot open / shut doors. (I'm glad for the driving part because I wasn't quite prepared to drive in NYC just yet! My Mom is staying at a hotel in the city, and we're dropping her off there.)

Before we left Greene's office, I requested another CBC and a Metabolic Panel. She'd been prescribed potassium on discharge, and had taken the last pill the 19th. At discharge, she'd just been slightly low on potassium (3.4, with the range being 3.5 - 5.3). She is now at 4.4. (And, in fact, everything they check for in the metabolic panel is now considered in range!)

Her hemoglobin was 10.6 on 9/6 (range 11.7 - 15.5). As of 9/20 she was at 11.2!

Her anemia is nearly gone, but since her body still has a lot of healing to do, she still gets tired easily.

That afternoon, we also met with Dr. Tamara Musgrave. Her specialties are oncology and hematology. If we transfer Teresa's treatment back to BRMC, she would be T's medical oncologist. She told us what the 2017 drug regimen for the cancer Teresa has is, and told us that the first place it usually metastasizes to is the lungs. Because I was worried about the pleural effusion, I asked for a chest x-ray to be done on 9/6. Based on that, Dr. Musgrave says it is not in her lungs.

T also says that it has become easier and non-painful for her to take deep breaths, so it sounds like the effusion is going away!

Musgrave also told us that T will probably get a Mediport for the chemo. This would mean she wouldn't have to

go through getting an IV at every appointment. Her arm is finally nearly bruise-free from all of her hospital IVs (and even from the arterial IV), so we can certainly see the benefit of this.

You can read about mediports here: <https://www.mskcc.org/cancer-care/patient-education/your-implanted-port>

Today (9/23), we will leave for NY, and hopefully get in while it's still light out to make it easier to get Mom to the hotel she'll be staying in, before we head to T's Mom's house.

Monday (9/25) we have our first appointment at Memorial Sloan Kettering Cancer Center, with her surgical oncologist, [Dr. Nadeem Abu-Rustum](#). That appointment is estimated to last 1 1/2 hours. If he decides she needs another surgery soon (re: removal of the rest of her cervix, which Greene says is very small -- about 2 x 2 1/2 cm square), she can opt to either schedule pre-surgery tests, or to go ahead and get them taken care of on Monday.

Musgrave expects that the 2 chemo drugs Teresa will/could be taking are Gemzar (Gemcitabine) and Docetaxel (Docefrez, Taxotere). I think Docetaxel is the preferred one. It would be 4-6 cycles, two weeks on, one week off. And a shot, I think on day 9, to keep white count up. You can read about them here:

<http://chemocare.com/chemotherapy/drug-info/docetaxel.aspx>

<http://www.cancercenter.com/cancer-drugs/gemcitabine/>

With these drugs, she said to most likely expect flu-like symptoms, mild - moderate nausea, possibly some edema, and hair loss (possible within 2 weeks). Considering Teresa's very positive response following such a major surgery (and everything related to it), we're hopeful that this will continue through any treatment plan, be it chemo and/or otherwise.

Musgrave is open to any protocol MSKCC decides to do instead of, or alongside of, what her plan is. We appreciate this as MSKCC seems to have a number of very innovative ways of taking care of their cancer patients!

Once we know more, we can call the Bristol Cancer Center and let them know what's happening, or MSKCC can do so (which seems less complicated in the long run - and more likely to get all the details firmly and correctly in place).

I will be keeping an eye on my e-mail as much as possible (amanda.grabler@gmail.com). If you're on FB, you can message me there as well. I will keep an eye out for messages from non-FB friends too. You're much more likely to get a response if you e-mail or message me than you are if you contact Teresa (and this is a general statement; it has nothing to do with what's going on right now! :-)).

I will post again here once I know more.

Comments

I'm getting my chemo port out 10/16!. Soon. It was very useful. They still have to pierce the skin every time they want to use it, which wasn't nearly so bad as having them fish around for a vein (which then gets trashed), but if it really bothers you, there's a numbing cream you can use before you get to the hospital. Sounds like real progress being made. Thanks for the update.

—Margaret Frey, September 23, 2017

Appointment with Dr. Nadeem Abu-Rustum on 9/25/17

Amanda Grabler, September 25, 2017

Teresa, her Mom, my Mom, and I went to her appointment. (They tell you to bring a support person or team!)

Dr. Abu-Rustum is great! We can really see why so many people have written so many great reviews of him.

He is kind, gentle, and knowledgeable. Before we left, he stood up, hugged Teresa, and told her to stay strong.

No more abdominal/Gynecology surgery needed.
He's **very** impressed with her healing.

He did a gynecology exam to check her cervix, and the NP, Karen, did a breast exam. She didn't find any problems!

Teresa will start chemo at home, using the drugs I wrote about in my last post. He consulted with the medical oncologist at MSKCC who specializes in uterine sarcoma, and she recommended the same drugs our local oncologist did.

This alone made the trip to Memorial Sloan Kettering Cancer Center worth it. Even if it's not all covered by insurance, knowing one of the best Gynecology Oncologists, at one of the best hospitals, would do the same treatment which our local oncologist recommended, is extremely comforting.

She will need CT scans of chest, abdominal area, and pelvis immediately when we get home to have as a baseline, and then again every three months for next two years. If everything stays quiet, she is considered in the clear.

If the scans show activity anywhere down the line, surgery to remove it, plus the cervix will be reconsidered. And he said we can come back anytime and work with their medical oncologist. If clinical trials start for her type of cancer, we can consider them.

I'm calling her doctors in Bristol tomorrow/Tuesday to setup appointments. These will be to get the mediport put in (minor surgery, likely near the collarbone from what I've read), and the first chemo.

As of now, our understanding is that Greene could put in the mediport.

We're leaving NY on Saturday morning since that is when my Mom's hotel reservation ends. We've made some plans for the week, but if you're in the area and would like to get together, even briefly, please send me an email and we will see what we can work out! (We drove up so we are fairly mobile.)

Comments

The best news!

—*Heidi Baird, September 26, 2017*

Love you !!?
Doing happy dance !

—*Linda Call, September 26, 2017*

It sounds like you had a great visit. I am happy that things are going well. I know the road ahead is long but the outcome is sounding better each time. Your picture Teresa looks great. I hope you will be back home in Abingdon soon. Miss you both. Take care and enjoy New York.

—*Ellie Novak-Scofield, September 26, 2017*

Way to go, Teresa, Mandy and two moms! This is very good news. Thank you so much for sharing. So nice to know that each member of the medical team is in agreement as to treatments so far and those yet to come when y'all get back home. Looking forward to hearing about more progress and successful outcomes as the process moves forward. It must be especially comforting to feel such strong confidence in Dr. Abu-Rustum. With Love and Caring ... Uncle Roger and Aunt Patti

—*Roger & Patti Ackley, September 26, 2017*

Treatment Update

Amanda Grabler, October 3, 2017

I've waited to update until I had more than a line of information to give you all.

Today (10-3) we drove back home from Roanoke so we could go to a consult with Dr. Greene. Although she doesn't need any more gynecologic surgery at this time, she does need to have a minor operation to get her mediport. So we met with him and got that scheduled. He said that it absolutely makes it better (especially for your veins!) and that if he should ever get cancer, the very first thing he'd do is get a mediport.

He told us that there is a 1% chance that a collapsed lung can happen with this procedure, but that it's not serious, not fatal, and is more of an annoyance (but a fixable one). Which they'd fix right away, of course. He likened it to the policy many stores have: "you break it, you buy it", except for them, it's, "we break it, we fix it". And, that he hasn't had this happen in 5+ years.

Tomorrow morning, we go down to the hospital for pre-op lab work. This includes a CBC, Metabolic panel, an x-ray (I believe), and an EKG.

Sometime on Thursday afternoon, we'll get a call telling us what time to be at the hospital on Friday morning for the surgery. There's a chance she could get prepped 1-2 hours before the surgery even starts, although since she's supposed to be one of the first operations, that is unlikely.

Also on Friday, we'll go to an imaging center, which is in the Wellmont network, to get her baseline CT. Dr. Abu-Rustum told us that, of course, they'll see a little bit of tumor left from before, but it shouldn't be any more than there was immediately post-op, and not to worry. This is her starting point CT which they'll compare the next 8 to (every 3 months for 2 years).

We check in at 2PM for the CT, and it should be started by 2:30PM. Her operation has to be done and she has to be clear to start drinking her contrast drink by 12:30PM. Dr. Greene said an advantage to having the port done first is that he can leave the access point open, and they can inject the medicine for the CT through the port rather than having to stick her. (Right now, her arms are *completely* healed from all the bruising she sustained in the ER, ICU, and her regular room in August).

Barring any complications with the above, she will start her chemo way too early on Tuesday morning (10/10). Originally, they wanted us to come in at ten to eight, and I begged for a later start date. That we'd have a hard time telling if she was feeling ill from the chemo or just because it was way too early in the day for us. So they bumped us up an hour. (Better than nothing!) :-)

As a reminder, she'll be getting gemzar and docetaxel. Dr. Musgrave told us she'd have chemo on Day 1, Day 8, then a week off, then start over. Day 9 may include a shot to keep her white blood cell count up. I've read from a lot of people that this is an expensive, painful (bone-painful) shot. I've also read an account from a woman who has the same type of cancer (in remission since 2014) who only had to have the shot once, and then was able to keep her WBC count up with diet and exercise. So, that's our goal!

For a clear explanation of Day 1, 8, etc, from what we've been told, our understanding is that the first cycle would be 10/10, 10/17, off. 10/31 would start the second cycle.

What we don't know yet is how many **cycles** of chemo Teresa will be having.

Before chemo starts on Tuesday, T will have blood work done, and we will have chemo education. We were told that if we can work it out, we can have the education done before Tuesday. An idea which I like, because that will give us time to think of questions to ask on the actual day, instead of thinking of questions after we leave from having the chemo done. So, we'll try to do that (earlier education) if possible.

As soon as I learn more about duration of the chemo, I will let you all know.

For local-to-Abingdon friends, we will be in town until the chemo is done on 10/10. Then, as long as everything goes well, we will go back to my parents' house in Roanoke. So, if you want to get together, come by the apartment, etc, to see Teresa, please let us know, either in email or on Facebook *private* messaging.

If you have a cold, or anything else contagious, though, we ask you to catch-up via telephone instead. We don't want to risk having to delay the start of the chemo. If you don't have our home number, please let me know and I'll send it to you privately.

Comments

A very caring and articulate Teresa update, Mandy! You are doing a wonderful job of leading her recovery process. Thank you so much for keeping us so well informed. Please know that you both are in our prayers. Love, Uncle Roger and Aunt Patti

—Roger & Patti Ackley, October 4, 2017

Mediport & CT Scan

Amanda Grabler, October 5, 2017

We'll go down to BRMC in the morning for Teresa to get her mediport put in. The entire time frame from check-in to finish is about 4 hours, but the procedure itself should only take about 20-30 minutes. Once she has woken up in Recovery, and they make sure everything is okay, she'll be good to go. This is an outpatient procedure, with, we believe, general anesthesia. (I've read some people get it with local, but from what we've seen in her chart updates, this will be under general.)

Since the surgery is happening later than we expected, we worked with a CT Tech to get her CT pushed to early Monday afternoon. We're also getting the chemo education session on Monday (after the CT) instead of the morning of chemo. We like this plan better, because it gives us more time to process all of the information and come up with questions ahead of time (instead of minutes before the treatment starts).

We're hoping to find out on Monday how many cycles of chemo she'll be having. I will share that when we know.

I will also let you all know how the mediport surgery goes tomorrow. (Some sections of the hospital have great internet and others have no service at all, so I may not be able to update right away.)

Comments

Teresa,
My thoughts and prayers all goes well today.

—Ellie Novak-Scofield, October 6, 2017

In our thoughts and prayers.

—frank wagner, October 6, 2017

Trusting all went beautifully...looking forward to positive update.

—andi treon, October 6, 2017

Port Surgery Follow-Up

Amanda Grabler, October 6, 2017

We checked in 10 minutes early this morning (at 10:20). We were taken back into Short Stay pretty quickly. We were told yesterday that she'd be taken back for surgery at 12:30. I was able to stay with her until they took her at 12:09. Getting to wait with her minimized both her boredom and my stress.

The **actual** surgery started about 2:30 and they paged me to go to the consult room to talk to Dr. Greene at 2:42.

He said everything went fine. They put the needle in with guides (x-ray and fluoroscopy, I believe). They took her to X-ray to make sure she didn't have a collapsed lung (nope!).

The dressing can come off tomorrow and she can shower tomorrow without covering it. Discharge paperwork suggests covering it so it doesn't rub against her shirt, at least for the next 10-14 days. It is on her right side. This is what she wanted since between the two of us, she usually drives, and this way it won't be in her primary driving arm, or under the driver side seat belt.

She had dilaudid prior to surgery, and, from my understanding, twilight sleep anesthesia, but she only remembers part of pre-op. She woke-up quickly (which is an upside of twilight sleep vs full sleep) and was wide awake when Sara and I went back to see her.

I was told I'd be able to get her CBC and X-ray results from 10/6. This involved going to Medical Records. One of the few places we haven't had nice people to deal with. The main woman wasn't friendly to start with and became distinctly more so when I said Teresa is my wife. (We haven't had *any* problems otherwise.)

Eventually I did get them. Her hemoglobin is still just over 11. Just about every CBC I get displays the results differently though, so I need to compare this one to others to have a better idea, but overall, I think her numbers are improving.

As for the X-ray, "Significant improvement with near complete resolution of bibasilar infiltrates and pleural effusions"! We were pretty sure though that the X-rays would show an improvement, because she can take deep breaths without any pain now. And on the incentive spirometer, she is regularly hitting between 1700 and 2500, and usually closer to 2200 for the bottom number. (2500 is as high as it goes.)

She did not get any pain medicine after and they did not prescribe a pain medicine. She had 3 200mg ibuprofen about 2 hours ago, but that's it. She's sore where the port is (and surrounding area) but doing well and is in good spirits.

Comments

Hi Mandy - Really appreciate your very thorough and caring descriptions of Teresa's progress. Seems like this latest process was very successful. Please tell Teresa we're pulling for her and you both remain in our prayers. Love, Uncle Roger and Aunt Patti

—Roger & Patti Ackley, October 6, 2017

Thank you for these updates!

—Heidi Baird, October 7, 2017

Teresa,
The very best today for your treatment.

—Ellie Novak-Scofield, October 10, 2017

Sounds like good news. Thank you for the detailed update.

—jim bier, October 11, 2017

Cycle 1, Day 1 (Chemo)

Amanda Grabler, October 14, 2017

I apologize for not updating sooner. It's always a lot to take in and I want to be sure I have everything organized in my head so I can share it properly with you all.

CHEMOTHERAPY, SESSION ONE:

As you know, she had her port surgery last Friday. On Monday, we had chemo education, which was very helpful. With the research I've done, I knew almost everything we were told, but hearing it from a chemo nurse was certainly reassuring. We also learned a few totally new things.

While we do not have a precise number of chemo cycles nailed down, we do have a better idea. Dr. Musgrave wants to do several cycles and then reevaluate. Teresa will be having CT scans every 3 months, and this is part of the way she'll be able to decide what direction to go in, how many cycles to have, and so forth. And, of course, blood work is done at every session.

Unless something changes, Teresa will probably have about 6 cycles, but since she goes for treatment twice during a cycle, it will feel like 12 for us.

She will have Gemcitabine (gemzar) on day 1 every 21 days.
She will have Gemcitabine **and** Taxotere (docetaxel) on day 8, every 21 days.
She will have Neulasta on day 9 of every cycle (21 days).

Gemzar and docetaxel are the actual chemotherapy drugs. Neulasta is a shot given to stimulate bone marrow production, since gemzar and docetaxel, especially the latter, are likely to drop Teresa's WBC.

We do not have to have a second office visit in each second week to get the shot, however. Teresa will have a thick patch (it looks like a box of dental floss on top of a patch) applied at the end of day 8. 27 hours later, it will administer a sub-q shot over 45 minutes, and then the patch can be removed. (They've sent us a Sharps container for this.) You can read about Neulasta and the Onpro Body Injector [here](#).

Neulasta has some unpleasant side effects, but our nurse tells us the only one she has *ever* seen is the bone pain. But that one can be pretty bad on its own. From what I've read, it sounds like quick onset temporary arthritis. But having your WBC too low could be worse (ex: an infection that might be little trouble to us could quickly become septic for Teresa).

She did really well with the gemzar (and her pre-chemo drug cocktail). So far, she has not needed any of the prescribed anti-nausea medicine. Gemzar is supposed to be really low down the list for nausea.

Docetaxel is also low but is higher than gemzar. Docetaxel has a higher chance of (allergic) reaction, fluid retention, etc, so on Monday, Tuesday, and Wednesday of the second week of the cycle, she'll be taking Dexamethasone (steroid) twice daily.

Docetaxel is also the one more likely to cause hair loss. But, like all side effects, it doesn't happen for everyone, but we have been given a lot of really helpful info (both from the cancer center and friends/family) for if it does.

The third week of her cycle, she will not take any medicines except for Claritin and Zantac, which will help fight any bone pain she gets from the Neulasta.

Nadir = low point. In chemo, this is used to refer to the time when WBC and platelets are at their lowest point after treatment. For taxotere, this is 5-9 days (with an onset of 4-7 days); gemzar has no noted onset and happens within 10-14 days. You can read more about nadir here: [What is Nadir?](#)

BASELINE CT:

This is the CT that was done on Monday, October 9.

Thorax:

Thyroid, unremarkable.

Lymph nodes, No axillary, hilar, or mediastinal lymphadenopathy.

Heart/vascular, No cardiomegaly. No pericardial effusion. Unremarkable great vessels.

Mediastinum, No other significant abnormality.

Airway, unremarkable.

Lungs, small right pleural effusion is present.*

Abdomen:

Liver, unremarkable.
Spleen, unremarkable.
Adrenal glands, unremarkable.
Kidneys, unremarkable.
Pancreas, unremarkable.
Gallbladder, unremarkable.
Vascular, no significant vascular abnormality.
No enlarged lymph nodes, free fluid, or free air.
Stomach and small bowel are unremarkable.

Pelvis:

Bladder, unremarkable
Bowel, [colonic diverticula](#) are present with no significant abnormality.
Appendix, unremarkable

No significant osseous** abnormality.

* Same pleural effusion as before, but the scan results we've been receiving have continued to indicate that it is diminishing. This was the first CT we've had done at the Imaging Center in Bristol, TN.

** Relates to bones.

VISITORS:

Can Teresa still have visitors? Yes**.

But, we do have to be careful. If you feel at all sick, even if you are already on the road, please do not come. Please send us a message and let us know. We'll be VERY understanding and reschedule with you for a better time!

Teresa may wear a face mask when you come, even if you're feeling fine. Please do not be offended by this. It is for her safety. This will be especially true depending on what point of the cycle she's in, and possibly, what your job is. Or if you have young children. If you've recently had a vaccine, especially a live one (includes oral and nasal), please do not visit for a minimum of 6 weeks. Risk time for vaccines vary from vaccine to vaccine. To play it safe, we're going to set it at a minimum of 6 weeks for all of them unless we learn something different from her oncologist or nurse.

If you visit, and after the fact feel like you might be getting sick, or discover someone you saw before visiting Teresa is now sick, etc., please let me know immediately so that we can let Teresa's oncologist know right away. This is very important!

Teresa may have to cancel on you, even if you're already on the road. Please know that it absolutely doesn't mean she doesn't want to see you. But if she starts getting super fatigued, starts having nausea, or other hard to manage symptoms, she may simply not be up for company, and please know that this could happen very suddenly. Remember, we're learning as we go as well!

Also, please do not do surprise visits for obvious reasons! (She may not be up for visitors or we may have returned to Bristol for the next session, or may not have returned from Bristol yet.)

All that said, visitors are awesome. If you want to visit, but you have questions and/or concerns, if you want to bring something but you're not sure what, or anything else, please e-mail me at amanda.grabler@gmail.com so we can work things out for you ahead of time, and I will do whatever I can to make it a good visit for you and for Teresa. :-)

COSTS:

Some of you have asked about costs with all the treatments. When I posted briefly about this before, I said that we'd only seen a few bills thus far and they hadn't been bad. That was, of course, pre chemo, and... pre a lot of other things.

We've met one insurance deductible, so we're not paying for things like office visit co-pays, as long as they're in network, but we have a second in-network out of pocket deductible we still have yet to meet -- by about \$3600. So for anything that falls under that benefit, we're paying 10%, insurance pays 90%. For example, for the required CT scans, the cost to us is about \$114/scan.

The Neulasta, per shot, is billed at \$16,000. Yes, you read that right. Sixteen thousand. Per shot. Without any insurance, 6 of them will be more than what I had in graduate loans before I qualified to have them discharged. Medical care, especially for cancer, is utterly ridiculous.

We **did** get a letter from BCBS that they approved the Neulasta, but we will not know until November 3 how much they will actually pick-up of that 16K.

On Tuesday, we worked with a financial aid counselor. We filled out two forms -- one of which was **just** for the Neulasta! She quoted us \$948 as the cost per session (for all the drugs including the shot in the second week of each cycle). She said it is one of the lower quotes they've given people. But once the billing processes through (Nov 3), it could be less... but it could also be more.

Once we meet that \$5000 deductible, then insurance pays 100%. Until the insurance calendar year resets. Then we're back at zero.

So, until Tuesday, we'd been waffling on setting up a Go Fund Me account, but, sadly, now, don't be surprised if we post a link to one sooner than later. Some of the billing offices we're working with are marking

bills as "outstanding" within 24-48 hours. We don't want to have bills go to Collection, and at the same time, we need to be sure we can pay our regular bills too!

So, that's everything I can think of now. I will probably post again next Wednesday or Thursday. We are staying at home in Abingdon for the night before and night of each treatment. (If she does have a reaction that needs to be treated on site, I'd much rather only have to drive her 20-25 minutes than 2 1/2 hours!)

** If you need the Roanoke address to send cards or to visit, please [send me an e-mail](#). If you want a phone number so you can call Teresa, please [send me an e-mail](#). I will not be posting either of those on CaringBridge.

I do read all of your comments to Teresa, but she would really love to hear from her family and friends directly. We understand that it may not be possible for some of you to visit during the school year, but please don't hesitate to ask for a phone number and call! :-)

Comments

Thank you for such complete info, Amanda. You two have so much ahead of you. Many of us are with you in spirit!

—Heidi Baird, October 16, 2017

Vaccine Update

Amanda Grabler, October 22, 2017

As a follow-up to my last post, we were told by the on-call oncologist RN that not all vaccines are created equal, so to speak. If you've had ANY live vaccine recently, you cannot be around Teresa*. If you get the shingles or chicken pox vaccine, both live, and (later) develop blisters as a side effect, you cannot be around Teresa until they heal and go away. If you visited and then develop blisters, please let us know right away.

If you have the LIVE flu vaccine, you cannot be around Teresa (I believe this is the nasal spray). If you have the injection, it should be acellular, and therefore safe. But please note that it takes 14 days before you will start building up antibodies, so even if you get the injection, please wait 2 weeks before you come to visit her.

The nurse also told us the pneumonia vaccine should be safe.

I'm currently waiting to hear if it is safe for us to get the DTaP booster. It's recommended to get this one every 10 years. I've only had 1 booster as an adult and it was more than 10 years ago. I *hate* needles, but when my niece was born, a doctor had told me that it's possible for a healthy person to carry pertussis (whooping cough) without being sick, but still have the ability to pass it on -- generally to a child who isn't old enough to be vaccinated or to the elderly. And, of course, anyone with a compromised immune system is also at risk.

So, I got the vaccine so that I wouldn't be a risk to her. Her safety was worth a little discomfort on my end, and Teresa's is too. I know I'm overdue for that one, so I sent a message to Dr. Musgrave's office via the Wellmont app, and am waiting to hear back on that.

If I don't hear back (some doctors / offices do a lot with the apps, others, not so much), I will ask when we return for her next cycle. I will also find out if there's any other vaccines which should be avoided, or ones which are recommended to have to protect Teresa. I will let you know what we learn.

*We will verify for sure how long after a live vaccine you need to wait before you can visit.

Cycle 1, Day 8 (Chemo)

Amanda Grabler, October 23, 2017

On Tuesday, October 17th, Teresa had her second chemo appointment.

This time she received the Taxotere (docetaxel) first, and then received Gemcitabine (Gemzar) for the second time.

Before the infusion can start, blood must be drawn for labs, and we had an office visit with Dr. Musgrave. This lets us review any side effects of the previous chemo with her, and see if we need to make any changes.

In an apparent reaction to the Gemzar, Teresa developed an itchy, measles-like rash on 10/15. It started on her chest, around her port, and across the top of her back, and then slowly moved down to include her entire body, minus her neck and face. (Her face was slightly splotchy but not like the rest of her body.) At the recommendation of the on-call oncology nurse, I went out at midnight to get her Benadryl around midnight. It didn't do anything as far as we could tell.

We were told that if she started having trouble breathing or swallowing, go to the ER immediately. This did not happen. Gradually, a few days later, the rash started to go away, in the order it appeared. Her legs were the last place to lose the rash and the itching. We'll see if it comes back again this time. The Gemzar is vital, so Dr. Musgrave is hoping that if the rash does return, it will not become severe. Although itchy, Teresa can probably handle it if it returns at the level it was before.

I know several of you have thought that the chemo appointments are super-long; that start times are delayed even worse than your typical doctor appointment, and so forth. It's not a time management issue on their part. Maybe a little, but not overall.

They cannot start anything until they test her blood and review the results. Then, if it's safe to proceed, they put in the order for **her** chemo. So, even though she's receiving 2 standard drugs, each of them must be mixed based on her dose, which is based on her age, weight, treatment plan, type of cancer, and so forth.

That can take time. *A lot* of time! Especially since there is usually a full house in the treatment room.

Once the lab work comes back, if she's cleared for chemo, we go to the treatment room and get set-up in one of the cubicles. Then they start her on the pre-chemo cocktail drips (and may flush the port, even if it was just flushed for the lab work): saline, Zofran (nausea), Decadron (dexamethasone; steroid), and Zantac (anti-histamine).

Once those are done, it's a waiting game for the actual chemo infusion.

This week, she received both drugs. Taxotere is the one Teresa pre-and-post-medicated for by taking two dexamethasone twice a day on Monday, Tuesday, and Wednesday (day before, day of, day after). The nurse set-up her laptop station in between Teresa's cubicle and the cubicle next to us so that she could keep an eye on both. She wasn't expecting a reaction, but as this was the stronger chemo, she wanted to be close by just in case.

There was no reaction.

Then, Teresa got her gemzar drip.

After that was done and Teresa was unhooked, her nurse applied the Neulasta OnPro body patch. You can see what it looks like [here](#).

Taxotere is 1 hour. Gemzar is 1/2 an hour. Each of the pre-med drips take about 20 minutes each.

We arrived at the center at 11am. We left at 4:50pm.

As with last week, we stayed home that evening so that if there was a more immediate reaction, we'd be close to both the center and BRMC.

We left the next afternoon so that Teresa would be settled in Roanoke before the Neulasta patch activated. It delivers the medication 27 hours after chemo ends. It gives you a warning before it starts delivering the dose, and the delivery takes about 45 minutes. Then it can be removed and placed in the Sharps container we received.

Approximately 24 hours after that, the bone and joint pain kicked in. So far, on a scale of 0-10, Teresa says it's mostly been a 6-7. And the pain is everywhere since the point is to stimulate bone marrow to keep her WBC up.

Ibuprofen has helped some. She's holding off on taking anything more potent unless the pain becomes unmanageable.

As of today (10/23), only mild achiness remains, but she no longer feels like she has the flu. A flu-like feeling is typical for Neulasta. Teresa says now it just feels like the aches you get on a cold, damp day. Too bad there's a lot of actual cold, damp days coming.

She also seems to be experiencing CRF - [Cancer Related Fatigue](#). A variety of things can lead to this, and it varies

from person to person as to how long it lasts.

The Neulasta shot strengthens Teresa's chance of **not** getting an infection, of **not** getting neutropenia, but it can still happen. This doesn't mean she can't go out in public; this doesn't mean she can't have visitors, when she has the energy. It just means we must be super careful, particularly during the point in her cycle where there is the largest chance of her WBC being low. You may see her with a mask and gloves in public. You may see her in a mask and gloves if you visit.

Teresa's next cycle starts on Halloween. Her nurse told us we could dress up, so we're exploring options (the center tends to be VERY chilly!). I will post photos if we do go in costume!

This is Teresa's off-week. We're in Roanoke, and won't go home until the 30th, unless Teresa has a bad reaction, or the Gemzar rash returns but is worse. In that case, we would return early for an immediate office visit with Dr. Musgrave.

Comments

You two are very courageous. Wow. So proud to be your friend.

—Heidi Baird, October 23, 2017

I really hope you beat it. I wish I could do something to help you from NY. Keep fighting .

—Michael Butcher, October 25, 2017

You all will be in my thoughts and prayers. Take care!

—Debbie Foster, October 25, 2017

Thank you, Mandy, This reminds me of my experience with chronic Leukemia chemo treatments. After 3 months, I thought it was a breeze & that I was finished.

But my white blood count was very low and I was to stay home. The next month I was in the hospital with infection. They gave me neulasta shots to help my white cells grow. It took a long time. Another problem was extreme constipation from a drug that was supposed to prevent stomach upset & vomiting. Do ask the doctor about this. I wish you both the best! love, Lee

—Lee Ware, October 26, 2017

Cycle 2, Day 1 (Chemo)

Amanda Grabler, November 1, 2017



Yesterday, Teresa started her second chemo cycle and received her third dose of gemzar (gemcitabine).

It was Halloween, so we dressed up. T wore her Top Gun jacket and kept her sunglasses (aviator style) on. I wore my Gryffindor robe (which kept me almost warm enough this time!). You can see us in a photo at the end of this post. You should be able to click on it to make it larger.

T's doctor dressed up as Dolly Parton, but by the time we had our office visit, she'd gotten too hot and changed, so we only got to see a photo of her. Most of the staff were wearing something – either a fun hat or a full costume. A drug rep came by in full costume. It was a jovial atmosphere!

Usually all the premedications are in the drip bags, but yesterday, each one had to be slowly fed via syringe. The bags they use come from Puerto Rico, which currently cannot produce them, much less ship, so they're under a shortage. Only her gemzar was in a bag.

She did not develop a rash from the gemzar in Cycle 1, Day 8, but it could have been all the dexamethasone she took for the taxotere. If it's coming back, we'll probably know by this Sunday evening. One of the nurses told us though that it *could* just be an initial reaction to the toxicity of the chemo, and that it won't repeat. She told us that this happens to a lot of people. No more rash would be great!

She is still not having any nausea. And, in fact, wasn't even sure she'd know what nausea felt like, so one of the nurses described variations of nausea. Nope, not having that!

Hair Loss

Either shortly before or shortly after the gemzar infusion began, I noticed that Teresa was shedding more than normal. And a lot.

She was given an estimate of 2 weeks from Cycle 1, Day 8, for hair loss to begin. Yesterday was 2 weeks.

It is not coming out in clumps or anything, but you can see many loose strands; can even see them slip out at times. She is having some itchiness of her scalp, but it's not severe. A gentle shampoo is recommended (although it's also recommended you don't wash your hair too often once it starts coming out, so that you don't lose it faster than necessary), so I picked her up some Johnson & Johnson Baby Magic shampoo today.

Today we visited a nice wig store in Roanoke, VA. The owner fitted her for a wig Teresa really likes. She was also going to call Blue Cross Blue Shield to find out what they will specifically need to cover either most or all the wig cost (\$425). She will call us tomorrow to let us know, and then we can call the Cancer Center to get a prescription faxed in for the wig. Although shorter, it looks a lot like her regular hair style and color. This first wig comes with a set style, which seems like a good starting point for getting used to having a wig. If she gets a second one, we'll probably consider the synthetic ones which are heat-safe and can be styled. That way, Teresa could get one that *really* matches her current hair!

Iron Deficiency:

At Teresa's last chemo session, she had blood drawn for several iron panels. The only one they didn't do, which I'd specifically asked about was B12, so we'll have that done next week.

Teresa has iron deficiency anemia, and has started taking ferrous sulfate once a day. The dietician also gave us a list of iron-rich foods. Several we were already familiar with, but there were some new

ones too. They will check her again next week. If her hemoglobin is still going down (it's down to 9.2), she will get IV iron.

Her platelets are still within normal range.

White Blood Cell count:

Teresa's WBC is currently at 20.2. This is normal after Neulasta treatment, and is what we should expect with that medicine. The standard range is 3.5 – 11.0 K/uL. The upshot in layman's terms is that if you're wanting to visit Teresa, this is a good time to do it.

Metabolic Panel:

Except for her bilirubin, everything in this category is in range. Also, her bilirubin has been steadily coming down over the last month, and is now only .2 above the highest end of the normal range.

Vaccines and Other:

She is having occasional dry eye; I got her some Refresh Tears today.

A few weeks ago, she started experiencing the side effects of surgically-induced menopause.

As some people have said online about their own experience there, she won the menopause lottery: hot flashes *and* night sweats. ? **Not** the lottery you want to win!

My sister-in-law, Donna, recommended the book *The Wisdom of Menopause (Revised Edition): Creating Physical and Emotional Health During the Change*. She also gave me some good tips to pass along to Teresa, such as paying attention and seeing if what she eats coincides with the hot flashes/night sweats, and then eliminate trigger foods.

Both symptoms have eased off some, but there's no way to know if they'll come back around again or not.

If anyone has any other suggestions, for these symptoms, or others which may come later, we're open to hearing them.

Dr. Musgrave said that if anyone has a live vaccine, there needs to be a minimum of a week in

between the vaccine and visiting with Teresa. We'd be okay with more in case you develop a reaction to it (ex: blisters often happen with chicken pox and shingles vaccinations).

I asked if it was safe for me to get the DTaP vaccine booster, which is a good one to have if you're going to be around people who either can't be vaccinated or have a compromised immune system. She said it is (safe).

She has her next treatment (Cycle 2, Day 8) on November 7. We have to be there at 7:45am. ?

Comments

??????

—Karen Grabler, November 1, 2017

Glad Teresa is having no nausea and sorry she's having hot flashes and night sweats! Hot drinks can bring on hot flashes, I've learned that having both flashes and night sweats myself. Iced drinks help -- and for the night sweats, it helps to keep one of those giant towels laid out in your bed to sleep on. Very absorbent and comforting in the middle of the night!

—Jody Werick, November 1, 2017

Thanks for posting this update and hugs to both if you. I will be following this site. Caring Bridge is a wonderful way to update everyone at once. I'm so glad you two are with your parents for added support.

—Sue Harris, November 2, 2017

Good to keep up with all you are doing. It sounds like it is going very, very well!

—Heidi Baird, November 2, 2017

Great picture of the two of you. Love and healing to Teresa. Love and peace to you both.

—Monica Spath, November 2, 2017

Your reports are excellent, Mandy. I have dry eyes, and I use a thicker gel lubricant with polyethylene glycol. I use warm compresses daily. I'll send you

my 7-page collection of eye treatments, to Mandy's email. Dry eyes are worse in winter= more dry air. It can be damaging if ignored too long.

Teresa, you have a wonderful can-do attitude. I admire you.
hugs, Lee Ware

—Lee Ware, November 7, 2017

Cycle 2, Day 8 & 9 (Chemo)

Amanda Grabler, November 20, 2017

My apologies for taking so long to post this.

Teresa had asked me to wait a few days so we could see if she would have any side effects from this double round, and then my own health issues restricted my typing this up.

The treatment went well (November 7).

After getting the CBC back for this day, we noticed that her glucose was high, despite that she hadn't eaten. Then we looked at past labs and noticed it was low on both Day 1s and high on both Day 8s. We suspect the extra steroid she is taking. This Tuesday is Day 1 of Cycle 3 and we're going to test that by her fasting again (appointment starts at 8am so fasting isn't so awful) before the labs are drawn, and see if her glucose is normal again.

Although she gets dexamethasone as a pre-chemo drip for each treatment, it's only for Day 8 that she has to take 2 twice daily the day before, of, and after treatment.

She is having some nausea now, but we are pretty sure it is the ferrous sulfate (iron supplement), not a delayed reaction to chemo. I read a post about the unpredictable nausea caused by taking iron, and that even the brand you get can make a difference. It's not prescription, so we can investigate other brands and see if that makes a difference. On a scale of 0-10, she considers this nausea about a 1-2. The zofran she was prescribed for chemo nausea works for iron-nausea, even if she doesn't take it until she feels it.

Depending on her hemoglobin levels, looking for a new brand may be a moot point. If they're still low, she may get IV iron instead, either tomorrow or next week.

So far, she still has not needed the zofran or the compazine for the actual chemo.

She did have the bone pain following the neulasta shot. That one's sort of a catch-22. The pain is pretty bad, but when she feels it, she knows it's doing what it's supposed to -- stimulating fast production of white blood cells, which is what she needs, especially following Day 8!

I've seen some people say it hits them everywhere all at once, but T's experience is that it moves around. Her ankles may hurt, but then later, it's her knees, or her eye sockets, or her thigh. It comes on within about 24 hours of the neulasta injection and slowly eases off a few days or so later.

Wig:

We have the wig now and it looks lovely on her. Very cute! It *really* looks like her regular hair. She's worn it out once, and although her own hair was still visible in the back, if you didn't know it, you'd never be able to tell what was her own hair and what was the wig. It's really awesome.

Health & Spirits:

Except for needing to nap more, she's still feeling pretty good, all things considered, and is still definitely interested in having visitors. Really cheers her up. Drop me an e-mail at amanda.grabler@gmail.com if you want to arrange a visit.

If you're wanting to visit but aren't sure what to say to her when you come, or anything like that, let me know! Don't let a worry that there may be awkward silences, or that you might say the wrong thing (or something you think may be the wrong thing) keep you away.

If traveling to T isn't possible right now (I know it's getting into snow season for some of you!), but you'd like to talk on the phone with T, send me an e-mail so I can give you the best number to use.

Cycle 3, Day 1 starts at 8am on Tuesday, 11/21. We're still not morning people, but are hoping we'll be able to be back on the road by early/mid afternoon and avoid any early holiday traffic. So we took the early spot. :-)) I will try to get a follow-up post to that appointment MUCH sooner!

~0~0~0~0~

Science & Medical Friends & Family:

I've been reading research that scientists/researchers (ex: CalTech is one I believe) have been working on a portable device for checking WBC at home, similar to a glucose monitor for diabetics. Have any of you come across anything like that? Already on the market or available in trial? Would love to have a way for her to keep up with what her WBC is, especially after Day 8 where we have to wait 2 weeks before she has more labs done.

Cycle 3, Day 1 (Chemo)

Amanda Grabler, November 23, 2017

Teresa started her third chemo cycle on Tuesday, November 21.

Day 1 is always a short day (give or take, if things start on time), so we only took snacks with us.

It wasn't a short day.

We got started right on time, and went back to the office visit much faster than usual. This time we met with FNP Kelley Mayden (she's awesome) instead of T's oncologist.

We got a lot of good questions answered (ex: her tumor is not estrogen or progesterone receptive so she shouldn't need any aromatase inhibitors (AI) for it).

T told her that the iron supplement made her a little nauseated, so we were told that now that they could tell T's insurance that T had "tried and failed" with the supplement, she should be able to get approved for IV iron. They could probably set that up for either same-day or the following Tuesday, depending on how T's bloodwork came back.

It wasn't good. When T was severely anemic, pre-surgery, her hemoglobin was 7.7. Tuesday it was 7.2. We were sent to the ER that night in August for an emergency blood transfusion, where they gave her 1 unit.

After chemo, which they rushed through as fast as possible, given that the drip times can't be changed, we went down to BRMC's infusion center, so Teresa could have a full blood transfusion instead of just IV iron.

She received 2 units. It took about 3 1/2 hours.

We'd been planning to return to Roanoke on Tuesday, but everything ran so late, we waited until Wednesday so we wouldn't get caught in rush hour traffic.

Her hematocrit was also very low. And her RBC was low. However, most of the numbers on her metabolic panel were good.

We'll find out with next week's bloodwork if she needs another transfusion or if she can just have IV iron.

Her nurse on Tuesday told us that anemia is one of the most common and long-term effects of chemo. It kills

off RBC and WBC. She receives the neulasta shot to stimulate WBC, which is working well.

Besides transfusions, we don't know yet what they'll do to keep her RBC, hemoglobin, etc, levels up where they should be.

Her next CT scan will be December 5, and hopefully we'll get the results from that ASAP. This is the scan which will tell us how well the chemo regimen is working. We're thinking good thoughts for the very best result possible!

So, schedule:

Cycle 3, Day 8 (chemo) will fall on 11/28.

CT scan, 12/5

Cycle 4, Day 1 (chemo) - 12/12*

Cycle 4, Day 8 (chemo) - 12/19

Week off - 12/26 - 1/2 (So, hopefully, no holiday travel!)

* Assuming the CT results do not change anything.

Also, if you all remember from several posts ago, we were told that the Neulasta generally bills at (before insurance) \$16,000. That was apparently a low estimate. Or maybe it's for the shot and not the OnPro body injector. Either way, the Neulasta she gets bills at \$21,634.00. For ONE injection. And that doesn't count the actual device. That's another \$148.

Docetaxel comes in at just under \$7500. Gemcitabine at \$2021. That doesn't include the cost of administering them.

IV Zantac costs a lot more than the pill form! Sodium Chloride solution is pretty pricey too, given how many they've used so far.

And that's just for October's treatments.

Still waiting on the "your part owed" bill, which hasn't show up in our Wellmont app or in the mail yet.

All this aside, Teresa is feeling good enough to cook our Thanksgiving dinner (with breaks, of course!). :-)

Comments

Happy Thanksgiving !!?

—Linda Call, November 23, 2017

Both of you are in my prayers. I hope Thanksgiving goes well too.

—Monica Spath, November 23, 2017

Thinking and praying for you. Love and Hugs from Uncle Frank and Aunt Anne

—frank wagner, November 23, 2017

What a process! I'm glad Teresa is feeling pretty well through it all. Happy thanksgiving to you two with love from Jody.

—Jody Werick, November 23, 2017

Thank you for the update Amanda

Happy Thanksgiving to your family, Teresa and you. You should post pictures of the food. Teresa had told me about the menu and it sounded awesome. I hope it is all delicious. Enjoy the rest of the weekend

—Maura Fischer, November 23, 2017

Mandy and Teresa, this is such a difficult time for you! I'm sure your parents (both of yours) are great support. But the money - I hope the insurance covers a high percentage of the charges. And I hope the results of the scan Dec. 5 are good, of course. Thanks for your caring bridge postings, I follow and save them. Keep me posted, I'm thinking of you always..
love, Lee

—Lee Ware, November 28, 2017

Cycle 3, Day 8

Amanda Grabler, December 1, 2017

Teresa had her gem/tax combo on November 28th.

The earliest we could get in was 1pm, because they're solidly booked after holidays. We were told many people skip their appointment if it falls during the week of Thanksgiving. And they were closed the 23rd and 24th.

(Teresa's first appointment in this cycle did fall in the week of Thanksgiving, but she went to it.)

She didn't start receiving the actual chemo until after 3pm, and we were the last ones to leave the building (besides the nurses), somewhere between 5:30pm - 6:00pm!

We knew it was going to be a late appointment (and we didn't know if she was going to receive IV iron this time), so we'd already planned to leave Abingdon sometime on Wednesday. Due to various reasons, we ended up leaving (on Wednesday) a little after 5:00pm.

Kelley Mayden, the FNP we saw on Day 1 of this cycle, ordered another iron panel. Her numbers are definitely improved over the last iron panel*, although Teresa's Vitamin B12 is still extremely high, and her hemoglobin is up from last week.

Before the blood transfusion (2 units) she was at 7.2. Tuesday, she was at 9.6. The lowest good number is 11.7, so she's still low, but not considered critical. This may put her back in eligibility to receive IV iron. I've read numerous posts from people in various cancer forums saying that they (or their loved ones) experienced an immediate energy boost.

I'm going to call tomorrow/later today and find out if she would be able to receive the first round of IV iron next week.

**Improved to the best of my limited knowledge in reading iron panel blood results. Anyone want to help me out?*

We'll head back home sometime this coming Monday so that we won't have a long drive Tuesday. She has her first mid-chemo CT scan on 12/5. Fingers (and toes) crossed that we'll hear that the chemo is working. We received the baseline CT results fast, but don't know if we'll have to wait until her appointment on 12/12 for these results (good or bad), when we can discuss them with Kelley Mayden.

But I will let you all know as soon as we know something.

The CT results will also give us a better idea about what the future holds. For example, will 6 cycles be all she needs? Does she need a new chemo regimen? Should she take a break to allow her immune system to come back and have the second surgery?

We are still looking at starting a YouCaring (similar to GoFundMe, except the person gets to keep more of the money raised than what they'd get via GFM), but decided it makes more sense to wait until we have more

information to go on.

Late Wednesday evening, the sub-q Neulasta patch activated. This time, she started feeling some bone pain sooner than usual, but the worst of it didn't really hit until yesterday (11/30) evening.

While her fatigue is getting worse each time, thankfully, the Neulasta pain isn't. Hopefully that will remain constant.

When we came up Tuesday night, we had plans to have garlic soup. We love it, and garlic is good for you, so it seemed like a good plan.

During the drive up, Teresa thought she might already be losing her sense of taste. She confirmed this while having the garlic soup. Mom and I loved it, but T thought it tasted bad. (Sweet foods are the most pleasant for her right now. While she is still generally trying to eat healthy foods, during the bad-taste week, we feel that eating something is better than eating nothing, even if nutritionally it leaves a lot to be desired.)

Unfortunately, the garlic soup didn't just taste bad to her. It made her sick.

While the chemo in and of itself is not making her nauseated, certain foods are.

- Potato chips
- Fries
- Garlic

We thought at first it was grease, but garlic isn't greasy. Also, Buffalo wings? Not a problem.

So, that was disappointing!

The next morning, however, she discovered that the wet cat food smelled *delicious!*

.
. .
. .
. .
. .

Don't worry. She didn't eat it. ;-)

That's all I can think of for now.

Comments

Happy December 1st. Have a good week-end!
Ellie

—*Ellie Novak-Scofield, December 1, 2017*

Today - Quick Update (CT Scan & Fatigue)

Amanda Grabler, December 5, 2017

Teresa has her first mid-chemo CT scan today. She has to start drinking the contrast at 11am. We check-in to Radiology at BRMC at 1pm and the CT is at 1:30pm. Fingers and toes crossed for good news!

She also, as of yesterday morning, has an appointment for blood work and an appointment with Dr. Musgrave, tomorrow after the CT scan. She has been *very* tired/fatigued, and we were hoping she could get IV iron. That had been the original plan before she was sent for the 2 units of blood a few weeks ago. But her iron is just high enough to make her ineligible for IV iron. :-)

When Teresa received the 2 units of blood, her hemoglobin was 7.2. The lowest normal is 11.7 (this may vary slightly by hospital system, but that is what they look for here). The 2 units brought her up to 9.6 but it really didn't do much for her energy levels.

So we're going to see what her blood work says later today, and see what Dr. Musgrave has to say about the situation. This is most likely still chemotherapy-induced anemia, based on what we've been told so far. Hopefully they can do something to help her feel more like herself and help her have energy to actually get things she needs to do done, and get to do things she enjoys (like puzzles, painting ceramics, etc).

If anyone reading this has any general insight, or if you've had a similar experience, we'd appreciate hearing from you. She *does* try to eat iron rich foods when she can. The week or so after the taxotere is always hard though, because it screws up her sense of taste.

As far as the CT goes, again, I don't know how soon we'll know something. I'm hoping that since we have the appointment with Dr. Musgrave afterwards, that they can rush the results (they have before) so we don't have to wait a week to find out. I will update here about that as soon as I can.

Comments

Hope all goes well! Hugs! ?

—Sara Poston, December 4, 2017

Thank you for keeping us informed Amanda. I hope you and Teresa get good news as well.

—Monica Spath, December 5, 2017

Hope everything goes well
Love you T

—Jim Constantinides, December 5, 2017

I'm sorry to hear that Teresa is feeling so wiped. That's a very annoying feeling. Makes you want to lie down and take a nap all the time. Hope she's getting ample nap time and good sleep at night! Too bad she can't have the IV iron! Thinking of you all every day and sending lots of love your way, of course. Love, Jody

—Jody Werick, December 5, 2017

Mid-treatment Medical/Chemo Update

Amanda Grabler, December 10, 2017

Heads up: This is a long one.

On Tuesday, December 5, Teresa had her first mid-chemo CT. (She's finished 3 cycles.)

We'd become concerned about her level of fatigue, and tried to get her an iron transfusion, but her previous blood transfusion had increased her iron levels enough to make her ineligible. But she was still very fatigued and feeling signs which she has come to associate with her anemia being worse.

So we scheduled an appointment with Dr. Musgrave, and the Cancer Center also then scheduled her for labwork to occur 15 minutes prior to the appointment. On the way down from Roanoke, T pointed out that it would probably be better to have the blood drawn before the IV contrast for the CT was done.

The CC said it was fine if we did the bloodwork early. So we dropped our stuff at home, and headed down to Bristol. We got delayed here, by the receptionist thinking we'd been taken back when we hadn't. But they called over to CT, told them what was going on, and they said it was no problem. And since her port was already

going to be accessed, they really didn't need her there 30 minutes ahead of time anyway.

So we go over to CT, and that's done pretty fast (once she goes back). And I ask before we leave if the results can be rushed to Dr. Musgrave so we don't have to wait until (this coming) Tuesday. We're told the scans are already available, the dictation will just take 1-2 days. (Or, as it turned out later, that day.)

So we go eat lunch, and when we're close to being done, I have voicemail from Dr. Musgrave's nurse telling us Teresa needs blood (no surprise) and we need to go to the hospital RIGHT NOW, and we don't have to see Dr. Musgrave after all. Call if you have any questions.

I called right away because we'd specifically wanted to ask Dr. Musgrave a lot of questions. We guess her nurse didn't realize that we'd requested the time with Dr. Musgrave.

They tell us we can see her the next day (Wednesday) at 2:40. We agree and we go to the hospital.

But when they drew her labs, they didn't cross & match her. This will take an hour, it's late, and they can't do that *and* the transfusion, can we come back in the morning for the transfusion part if they do the cross and match now?

We say sure and they schedule her for 11:30a on 12/6. They call the CC back and get our 3p appointment with Dr. Musgrave back. They cross and match her and we go back to the CC. (Thankfully, these places are just minutes apart!)

At the CC we get a copy of the CT, and find this, "The uterus appears to be massive. It measures up to 17.9cm in cephalocaudad dimension x 10.6 cm in AP dimension and 17.3 cm transverse dimension."

SO.....

Given that you cannot regrow your uterus...

- A.) The tumor has grown a fair bit and they mistook it for her uterus.
- B.) They are referring to the cervix and it's enlarged.
- C.) It's all fluid (Dr. Musgrave thought this may be the case).
- D.) Something else altogether.

But I also have noted that the CT says that her pericardial effusion has increased since her last CT. Her last CT states, "no pericardial effusion". So is this an increase from 0? New person reading the CT? Chest portion of CT got mixed up with someone else who has a port-a-cath (it's noted on the CT).

If any of you can provide some insight here, we'd be profoundly grateful. I can easily cover her personal information and take photos of the CT to share. (It hasn't come through the app yet so we only have a paper copy.)

We really didn't get any clarity on if the chemo is working or not, but we did leave with various not good other impressions. And tests.

(The pericardial effusion led to T only receiving 1 unit of blood, even though with her hemoglobin being down to 7.3, she really needed 2 again. So she's been doing as little as possible to conserve her strength.)

Dr. Musgrave had more labs done. In addition to the pericardial effusion, her pleural (lung) effusion has increased slightly. Dr. Musgrave didn't think the pericardial effusion would be too much because she could hear Teresa's heart very strongly with her stethoscope.

She said that some or all of the fluid could be caused by thyroid issues. I have read that a number of women have thyroid issues in menopause. Especially, it seems, those with surgically-induced menopause. So she ran a thyroid panel. She also ran another LDH panel, and another reticulocyte count. There may be others, but those are the ones I remember.

There is concern that Teresa is developing Hemolytic-Uremic Syndrome.

Based on the results of previous bloodwork, I've been suspecting that Teresa had hemolytic anemia, not (just) iron deficiency anemia and/or chemo-induced anemia.

Some of you know we became very familiar with hemolytic anemia, when our cat, Faden, was diagnosed with it. His treatment was a long course (on/off as he went into and out of remission) of prednisone. For Faden, this caused him to eventually develop chronic pancreatitis and diabetes.

Dr. Musgrave said they do not treat it in people the same way as they do in cats, which Teresa was glad to hear. She doesn't want to have to take prednisone for anything unless she absolutely has no other choice.

Hemolytic anemia is when red blood cells are destroyed and removed from the bloodstream before their normal lifespan is over.

HUS is a disease characterized by a triad of hemolytic anemia, acute kidney failure (uremia), and a low platelet count (thrombocytopenia). It is USUALLY caused by e-coli, but can show up as a rare (and dangerous) side effect of Gemcitabine/Gemzar.

We know she has a severely low platelet count. Standard range is 150-400. Hers are less than 70. This can result in severe bleeding if the body loses the ability to clot.

We know she likely has hemolytic anemia.

We know that on her last CMP (complete metabolic panel), her creatinine was elevated. Standard range is 0.50 to 1.20 and hers is 1.22. Her eGFR (glomerular filtration rate) is 52. This test measures kidney function and

tells your doctor your stage of kidney disease.

This is the first time that her creatinine has been out of range and the first time her eGFR has been an issue. I went back and looked at her previous CMP panels, and it was consistently >90, which is where it should be.

I've read several case reports about patients who developed HUS in reaction to Gemzar. It can easily be fatal. The majority of the ones who were able to be stabilized had most of their issues reversed, but had to remain on dialysis - permanently. I've only found one so far who was completely cured of HUS.

We're hoping that if she is starting to have HUS, that it was caught in time.

But what does this mean if it **is** HUS?

A.) She'd have to stop taking Gemzar, which was the key chemo drug, from our understanding, of the Gem/Tax protocol. Dr. Musgrave said she'll probably need to consult with MSKCC. (I've also discovered that a number of places offer online opinions -- such as Hopkins, MD Anderson, Dana Farber Cancer Institute, etc., so if this is a route that is taken, I'm going to suggest we get at least one additional opinion while she consults MSKCC.)

B.) Teresa is more or less immediately switched to a new chemo regimen - yet to be determined.

C.) Teresa stops chemo altogether. Gets a month or so to heal and bring her numbers back to where they should be (especially the ability to clot!) and has her second surgery. This would be to remove the remaining tumor and complete her hysterectomy (i.e. remove the cervix). Then after another 4-6 weeks, she would probably begin (adjuvant) chemo to reduce the risk of recurrence or metastasis.

Since Teresa receives gemzar on Day 1 and Day 8, she's had it 6 times. She's due for her next round this coming Tuesday -- the start of Cycle 4. We both feel that until we know for certain, that it seems like a bad idea to keep taking it and potentially make things worse. She really doesn't want kidney failure on top of everything else!

Here are a few of the questions I plan to ask on Tuesday:

[?](#)Can we get approved (i.e. for insurance reasons) to have T's tumor tested for specific mutations, to see if she's a candidate for targeted drug therapy?

We've read from a sarcoma specialist that radiation is recommended for tumors larger than 2". Reduces risk of recurrence. Why isn't T having radiation?

I told T I was going to be one of those potentially annoying people that ask the doctor EVERYTHING. No chances taken with Teresa on this. I'm getting ALL the information I can possibly get and learn as much as I can, so that we leave no stone unturned.

On Thursday, Dec 7th, Teresa had an abdominal ultrasound and an echocardiogram. We have not yet received either of those results. We're hoping it will shed light on the fluid situation, and hopefully about the tumor. The same woman who did her first abdominal ultrasound did this one too, and she told us that they all found it peculiar that the CT read, "massive uterus" since T had a hysterectomy.

Hopefully we'll have a solid direction to go in after Tuesday morning. I'll update as soon as I can. Please feel free to ask if you have any questions.

Comments

Following and holding you both in my heart, thoughts and prayers. <3 <3 <3

—*Melissa Fields, December 10, 2017*

Thank you for keeping us informed on Teresa. Love, prayers and blessings to you both.

—*Monica Spath, December 10, 2017*

Be as annoying as you have to be. It sounds like some mistakes may have been made, maybe not major, but if you don't follow up on it, don't expect them to. This is based on 16 months of experience trying to get medical care for my son. I'm hoping for the best possible outcome.

—*P.C. Durbin-Westby, December 10, 2017*

There is so much going on with Teresa at this time. There needs to be questions that should be answered. You should ask for a repeat of the CT scan and question why they saw a mass that was not there????? Then make sure the DOCTOR is answering your questions. I would not leave until I had a clear answer to what is happening and what is next. My thoughts and prayers. REMEMBER annoy them and get answers. Ellie

—*Ellie Novak-Scofield, December 11, 2017*

All I can say is I am thinking of you and hoping for good news and a good protocol. So much to deal with.

—*Heidi Baird, December 11, 2017*

Amanda, you are doing all the right stuff. Everyone needs an informed advocate and you are bringing your considerable intellect and love to bear on Teresa's whole being. Good job.

—*Sally Treanor, December 11, 2017*

I have been praying for you since I read the news. My advise to you is to keep standing your ground, leave no stone unturned. Follow your gut, ask for second opinions, as for repeated test, be aware, be knowledgeable about anything and everything. My heart hurts for you both, and I will continue to pray for God's healing grace.

—*KELLY TERRY, December 11, 2017*

I'm sorry about the mystifying CT written summary report and disturbing threat of kidney involvement. I commend Amanda for comprehending as much as she does and encourage her to keep asking questions until she's satisfied with understanding as much as the doctor. I hope Teresa is feeling stronger soon!

—*jim bier, December 12, 2017*

Test Results & Chemo Protocol Changes

Amanda Grabler, December 12, 2017

We now have the results of the abdominal ultrasound and the echo.

The **good news** is that her echo (the test they did on her heart) is good - based on my understanding of reading the dictation and from what Musgrave said this morning. The pericardial effusion is minimal and nothing they're worried about.

ECG summary for any cardio folks reading this:

Normal left ventricular cavity size.

Normal left ventricular systolic function.

Ejection Fraction = 55% (55 and up is considered normal).

The right ventricle is normal in size and function.

Mildly dilated left atrium.

Right ventricular systolic pressure is 30-35 mm Hg.*

Normal diastolic function.

Trivial to small predominantly posterior pericardial effusion of no apparent adverse hemodynamic effect.

Large left pleural effusion. (Lungs)

* She is dealing with some high blood pressure, but Dr. Musgrave said it's not at a point where she's worried about it yet, and she doesn't want to add in any other drugs at this point which may alter Teresa's kidney values. This is also why she does not want to start Teresa on HCTZ or Lasix (yet).

The bad news:

The chemo didn't work. At all.

The tumor is growing.

After surgery but before chemo, the tumor was 11cm by 5.6cm by ? (not sure what the 3rd number was, aka 4.3" x 2.2"). As of today, it is about 16.3 cm x 8.1cm by 16.4cm (aka 6.4" x 3.18" x 6.45"). THIS is what the CT called "massive".

The pleural effusion is large, and Teresa is going to have an ultrasound-guided thoracentesis (pleural tap) to see if she has malignant ascites or if the fluid (which is in other places too) is just buildup from the Gemzar, or maybe something Thyroid related. (We didn't have time to discuss the TSH panel, and Dr. Musgrave ordered numerous tests today. She wanted Teresa to get over to the hospital to get another unit of blood ASAP.)

Thoracentesis: using a needle to remove fluid from the pleural space for testing

[Malignant ascites](#) is bad news. It is a grave prognostic sign. Possibly worse than the prognosis for the leiomyosarcoma.

I don't know if we'll know anything about the results until next Tuesday when she has her next appointment with Dr. Musgrave.

If Teresa has malignant ascites, she will no longer be a candidate for surgery -- mostly. Dr. Musgrave said they may be able to do palliative surgery, but there will be no way to cure/put her in remission with surgery in this situation.

So really, really, really, really hoping that this is a test we will receive good news for. She will have this procedure done around 7:30am this coming Thursday.

These are the other things that were ordered today, in addition to the thoracentesis:

Bilirubin, Direct

CBC Oncology (standard test ordered)

Cell Count and Diff, Pleural Fluid

CMP with Estimated GFR (standard test ordered)

CSF Culture with Gram Stain and Sensitivity (Don't know when/where this is being done.)

Direct Antiglobulin Test (DAT)

Glucose

Haptoglobin

Lactate Dehydrogenase (LDH) * 2

Non-Gynecologic Cytology (Can anyone define this one? Tried to research, just got lab codes back.)

Dr. Musgrave did mention again that the gemzar may be causing HUS (see previous post for info) and that at this point, especially with Teresa's creatinine continuing to go up, and her kidney function number continuing to go down, it would not be smart to let her have any further Gemzar.

She'll use this and next week's labs to see if there are continued signs of hemolysis so she can decide what to do about that.

The next regimen she is proposing for Teresa is [Doxorubicin](#) + [Olaratumab](#). I've provided links to both so that you can check them out if you want to do so.

Doxorubicin can have severe cardiac side effects. It can cause dilated cardiomyopathy which can lead to congestive heart failure. If she does this, it is likely she will have many ECGs to monitor her heart. Due to this, and other side effects, and because the chemo itself is apparently red, it has been nicknamed, "red devil" and "red death".

It also puts you at risk, even up to years later, of developing blood cancers such as leukemia.

And the risks go on.

Both drugs are more likely to cause pain (muscle and skeletal), low WBC and RBC values, nausea, vomiting, hair loss.

These are clearly both MUCH stronger than Gem/Tax.

Dr. Musgrave told she has a patient on it now who had a very large abdominal tumor and after a few treatments was able to clearly see it was decreasing in size.

If it works, hopefully unlike gemzar, the benefits will outweigh the risks.

IF she ends up on this regimen. Her current kidney issues may make it a no go from a few things I've read about these two drugs.

Dr. Musgrave is going to consult with Memorial Sloan Kettering first. I don't know for certain, but it sort of sounded like if Teresa CAN have another surgery, that she might be sent to MSKCC for the operation. The doctor she first saw would be great -- he's the Chief of the Gynecology Service, a surgical oncologist, and, as I mentioned many posts ago when we first went, clearly an intelligent and innovative doctor. And he showed us that he's very caring and personable.

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She's also, at my request, going to ask them to send a slide to be tested for generic mutations to see if there's any targeted drug therapy which will work for Teresa.

Summary:

- Heart Good
- Lungs - lots of fluid, will be tapped on Thursday morning to see if it's malignant (cancerous) or not -- hope, hope, hope it's not.
- Chemo - didn't work and caused additional problems.
- Tumor - got bigger.
- Surgery - depends on fluid tap.
- New chemo - we have potential regimen but will depend on consultation with MSKCC. And in the meantime, I'm going to see if I can get another opinion from another hospital.

Comments

So sorry to hear the chemo wasn't working. Here's hoping that this new combo will be a go and will work. As to your question about the Non-Gynecologic Cytology - definition will depend on where they take a sample from and what type. This has a pretty good rundown. Having had both parents with cancer recently, I have a lot of things bookmarked. https://www.cytopathology.org/wp-content/dynamic_uploads/54.pdf

—*Becky Galambos, December 12, 2017*

Praying for you T! Love you! You will beat this!
Love you Amanda! Prayers for you too!

—*Jim Constantinides, December 12, 2017*

I'm hoping for the best possible outcomes. Let me know if there is anything I can do.

—*Kristen Miller, December 12, 2017*

Ignore the non-gynecologic part, it's just specifying that this isn't coming from a gyn exam/procedure (I'm sure you get the cytology part, there are lots and lots of routine gynecologic cytologies sent as part of regular pap smears, etc.). Fingers crossed for better news. I think looking for targeted therapy options is a great idea.

—*Alison Wilkins, December 12, 2017*

Praying for you T. Love you always. Thank you Amanda for all of the updates . I wish the news was better.cancer has lots of ups and downs. Hopefully good news will call me out of the next tests

—*Maura Fischer, December 12, 2017*

Thinking of both of you and hope the new meds will work much better.

—*Pernille Brandt, December 12, 2017*

Prayers and Hugs!!

—*Sue Harris, December 12, 2017*

We are holding you and Teresa in the light.

—*Lana Whited, December 12, 2017*

I am so sad. Hugs and love.

—*Heidi Baird, December 13, 2017*

This is very upsetting. Thank you for keeping us informed, and I can only hope that Teresa can pull out of this terrible situation.

love, Lee

—*Lee Ware, December 13, 2017*

You both continue to be in my prayers.

—*jim bier, December 13, 2017*

I am so sorry to hear this. You both continue to be in my thoughts.

—*Bridget Gall, December 13, 2017*

Thoracentesis Follow-Up

Amanda Grabler, December 19, 2017

Teresa's thoracentesis procedure on 12/14 went smoothly.

The radiologist removed 1.3 liters (about 5.5 cups) of fluid from around Teresa's right lung. She recommended that Teresa have the other one done soon (they can't do both same-day). She will have the second procedure tomorrow (Wednesday, 12/20) morning. Although all of the tests have come back from the first one, they will repeat the testing on the second draw, just to be safe.

There were some pains as her lung re-expanded into the space it was supposed to have been in, and some

muscle spasms where the needle and catheter went in. But, the pains went away in about 2 days, which was the estimate I found on multiple sites. The needle/catheter hole is VERY small.

With both sides done, T should be able to breathe MUCH better. (And even with only 1 side drained, she was still able to reach 1500 on her incentive spirometer! Dr. Musgrave was impressed.)

All of the lab results were auto-released to the app *except* the cytology. We didn't find out the answer to whether the fluid was benign or malignant until today.

Dr. Musgrave told us there were NO cancer cells seen in the fluid! (Many happy tears here!)

And it was a day of good news, because prior to that, we learned from her lab work that almost all of her numbers have improved. While many values are still low (and a few high), they are working their way back to normal. Her kidney function test is on it's way back up to where it should be. Her creatinine is completely back in the normal range.

We're hoping that this all indicates that the worst of the problems with her labs were truly induced by the chemo, and not from the cancer, or some other unknown problem. (Anemia aside, since it presented prior to chemo, although we're told some is definitely chemo-induced.) Dr. Musgrave is still watching for hemolysis (destruction of red blood cells - which has been happening prematurely) but says that has improved as well. It needs to resolve before Teresa can start a new chemo regimen.

She did try to get in touch with Dr. Nadeem Abu-Rustum at Memorial Sloan Kettering, but he is out until January 2nd. She wants to see if he agrees with starting doxorubicin/olaratumab or if he (and Hensley - the medical oncologist/sarcoma specialist there) would go with another plan. T also really wants to get that second surgery done and is hoping it can happen prior to starting a new chemo track. She would definitely feel a lot better without the tumor there (it is causing abdominal tenderness, and some pain - especially when coughing).

Before any chemo starts, I would like to be given a clear answer on if it is the next chemo in line, or is it truly the best chemo for T's situation? I don't want her to just go down the line of chemo with one bad result after another, if there's a way to know a specific one would work best.

It definitely sounds like the surgery would happen at MSKCC in NYC. We just don't know when.

Dr. Musgrave also gave us a CBC order that we can have done in Roanoke next week so we don't have to travel just to have her blood checked. If her hemoglobin is at least 8, she said that T can wait on a transfusion until the following week. If it's less than 8, we either need to find a place that can do a transfusion in Roanoke, or come back down to have it done in Bristol.

T has her next appointment with Dr. Musgrave on January 3, 2018.

Please let us know if you have any questions.

Comments

Thank God! ?

—*Bridget Gall, December 19, 2017*

Prayers and hugs from Texas

—*Michelle Kellogg, December 19, 2017*

We really appreciate your detailed account of how T is doing. You had a lot of good news in this report. We'll be keeping both of you in our prayers as T continues on to a full recovery. Love to you both from both of us ... and Merry Christmas!!

—*Roger & Patti Ackley, December 19, 2017*

Thinking of you both daily! Prayers ? and love ??

—*Jim Constantinides, December 19, 2017*

I am glad to her you have good news. Do we know when Teresa may be able to come back to work yet?

—*Michael Justus, December 19, 2017*

Congratulations on Teresa's good news! Mandy, you're doing a great job! Love, Jody

—*Jody Werick, December 19, 2017*

All good news. I'm amazed at your ability to sort through the information and pass it on on an understandable way. T and you are unbeatable. All my best wishes and prayers.

—*Sally Treanor, December 19, 2017*

So much better! A Christmas present for you both!!!!!!!!!!

—*Mickey Werick, December 20, 2017*

We are grateful for all the good news and hope the second thoracentesis goes smoothly and brings more relief. The date of the next appointment, Jan. 3, is Brandon G-W's birthday: clearly a favorable omen! Teresa's resilience and your persistence are both inspiring.

—*Lana Whited, December 20, 2017*

Thank you, dear Mandy
Lee

—Lee Ware, December 20, 2017

We love happy tears! Am filled with joy at the news!

—andi treon, December 20, 2017

So relieved from e both of you. You can now have a very Mery Christmas. I wish you both a happy and healthy new year.

Thank you again for all of the updates

—Maura Fischer, December 20, 2017

It's great to see some good news! Praying for more.

—jim bier, December 23, 2017

Clarification of Last Post (Re: Thoracentesis)

Amanda Grabler, December 21, 2017

Due to some apparent confusion / misunderstandings and questions we've received, we decided I needed to post a clarification.

When I shared that the fluid was cancer free / no signs of cancer cells, all we meant was that the pleural effusion (fluid) that **surrounded her right lung** did not have cancer in it. The cancer had not metastasized to the pleural cavity.

It IS **very good news**. However, this does **not** meant that Teresa is in remission. It does **not** mean she will be able to go back to work any time soon.

Teresa still has a very large, painful tumor in her abdominal area. At the very least, it is attached to her cervix. There "is a small nodular density" in or near the posterior of the cervix but there is no clear word on if they are related to the tumor or are something benign.

The chemotherapy Teresa was on **did not work and the tumor has grown significantly**.

Dr. Musgrave is waiting to hear back from Dr. Nadeem Abu-Rustum from Memorial Sloan Kettering Cancer Center (NYC). She will follow his (and probably Dr. Hensley's) guidelines on what to do next. He is out for the holidays until January 2nd. Our next appointment with Dr. Musgrave is January 3rd - but it may be too early for her to have heard back from him.

Teresa's options:

- Chemo then surgery.
- Surgery then chemo.

Teresa would prefer surgery first. It will most likely happen at MSKCC.

The chemo will likely be the protocol I mentioned before (doxorubicin and olaratumab) but it's not confirmed yet.

We are currently waiting to find out if the pleural fluid that surrounded her **left lung** is also benign. (There was less on that side; about half of the amount that was around the right lung.) They will hopefully call and let us know so we don't have to wait until January 3rd.

Comments

This is all so tenuous. Teresa and you are so lucky to be together in facing this hardship. Thinking about you always, wishing I could lend you some of the strength you need.

—Sally Treanor, December 21, 2017

Thank you for your posts Amanda! Thoughts and prayers with you both everyday ???

—Jim Constantinides, December 22, 2017

Thinking of you and hoping.

—Heidi Baird, December 22, 2017

Thank you for the update Amanda. Continued prayers and blessings to you both

—Monica Spath, December 23, 2017

I'm so sorry that this is so difficult and heart rending. Mandy, please take good care of yourself too - this is very important.

love, Lee

—*Lee Ware, December 23, 2017*

Been thinking about you often since reading this. Stay strong Teresa. Be the warrior princess I know you are. My prayers are with you both.

—*Eva Horvath, January 7, 2018*