

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

## Journal

### To Operate or Not To Operate: That is the Question

*Amanda Grabler, January 9, 2018*

Even before Teresa started chemo in October, she wanted the rest of the tumor, and her cervix, out.

Before chemo seemed the best opportunity -- the tumor was very small. The cervix wasn't enlarged and was about the same size as the piece of left behind tumor per our understanding, and her labs (CBC and CMP) showed significant improvement over her pre-surgery labs.

But the doctor we saw at Sloan Kettering declined surgery, saying essentially it was small and chemo would take care of it, and so forth.

From things we've read online, we now feel a lot of this may have been more so that she would have a "chemo baseline" with the drug regimen that's supposed to have the best outcome.

If it works.

It didn't work. And, as you all know, her tumor grew alarmingly fast. It's at least half of the original size of 30cm.

**The gold standard in treatment for LMS cancer is surgery with clean margins.** It is treatment-resistant, so your best chance is to get absolutely as much out as possible and then do chemo if there's any left that surgery cannot get.

Teresa never stopped wanting the second surgery, and when we learned that the chemo didn't work and the tumor was bigger, something which was extremely obvious, we pushed for surgery again.

Dr. Musgrave got all the information she needed from us to speak with Dr. Abu-Rustum. As a reminder, he is a surgical oncologist, and one of the reasons we picked him is we read a very good article about him performing a very high-risk surgery (I shared a link to it last Fall).

He has declined to perform the surgery, saying it is too high risk and he thinks Teresa should try at least one more chemo regimen, if not two different ones. That will take **weeks**; especially considering one cycle is often 21 days!

Of course, if he feels it is too high risk, we really don't want him performing the surgery in the first place!

Monday night, I discovered he's not a sarcoma surgeon. I happened across the page of MSKCC sarcoma surgeons and he is not listed. He has vast experience with gynecological cancers, but he is not a sarcoma surgeon.

Dr. Musgrave advised that we see if we can find another doctor at MSKCC, who **is** a sarcoma specialist and oncology surgeon, to perform the operation instead. In the meantime, she will set everything in motion for T to start a new chemo regimen (doxorubicin/olaratumab) to make sure Teresa's insurance will cover everything.

So, next Tuesday, she is scheduled to have another echo and another ultrasound.

On Wednesday, she'll have her regular labs drawn, and we'll have chemo education on the new medicines. If the plan goes through insurance, she may start chemo as early as next Wednesday -- which would likely put a snag into the surgery plan. (You really want your fast growing cells for healing to be operational if you're going to have surgery!)

So, I'm going to get back in touch with our patient adviser at MSKCC. But I'm also going to see about an appointment at Roswell Park, in Buffalo, NY, providing they're familiar with leiomyosarcoma specifically. And I'll be asking people in the leiomyosarcoma group I am in to recommend surgical oncologists with experience specifically with the uterine variety of LMS.

(We just wish this wouldn't mean a potential long drive in winter to NY!)

Dr. Musgrave said Teresa's lungs sound pretty clear, which is awesome.

What's not awesome is Teresa has been having a fair bit of abdominal pain. We have no way to know if it's the tumor, pulled muscles - since she's lost a lot of muscle tone - or a combination thereof. Dr. Musgrave said any of that is possible. So now Teresa has started palliative care for pain management (she'll officially see the Palliative care person on January 23, but in the meantime, she has medicine to take to help with the pain, and it's already made a wonderful difference).

Last week, Teresa's hemoglobin was above the critically low range for the first time since November 21! It's still low (8.9) but she didn't need a blood transfusion. This week, it was still 8.9. Her RBC is coming up slowly but steadily too, and her kidney function (eGFR), which should be between 90 and 120, is nearly back to normal, coming in this week at 88!

Sorry for taking so long to share any new information, but up until this week, we just had little bits and pieces. I really wanted to have a more comprehensive picture to share with you before I posted.

Please let me know if you have any questions.

## Comments

I hate that she has to go through this but thank god you are there with her. Never lose faith in god he will find a way to bring her out of this. I will be praying for her will you tell her that for me?

—*Deanna Hall, January 10, 2018*

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—*Deanna Hall, January 10, 2018*

Have you considered Brigham or Dana farber in Boston? Do you need help driving in winter weather?

—*Maria Yakkey, January 10, 2018*

I'm with you, Teresa and Mandy. Thanks for sharing so much. My thoughts are with you.

love, Lee

—*Lee Ware, January 10, 2018*

Thoughts and prayers with you both. I pray every day. If you travel to NY please let me know so I can visit.  
7186145747  
Jimmy

—*Jim Constantinides, January 10, 2018*

Thanks for the update!! I've been thinking about both of you. Praying too!

—*Sue Harris, January 10, 2018*

Thinking of you both.

—*Christine Daly, January 10, 2018*

Please never apologize for all the information you're providing here. Unfortunately, many of us have to face decisions about cancer treatment options for ourselves or our loved ones, so you never know whom you're helping. (I know just writing down this record must be of enormous benefit to you as well.)

We are glad to hear every bit of good news, no matter how small. And I wish we could offer to be of more help.

—*Lana Whited, January 11, 2018*

## How To Save a Life

*Amanda Grabler, January 17, 2018*

Hopefully with this next type of chemo!

Yes, as you all know, Teresa really wanted to have surgery next. And Dr. Abu-Rustum refused, saying she was too high risk.

**He decided that over the phone. He hasn't laid eyes on her since September 2017.**

Of course, as we said before, if he thinks she's too high risk, we don't want him doing the surgery. But it's still infuriating.

A number of people in a LMS support group I'm in recommended Dr. Samuel Singer (also at MSKCC). But Teresa is no longer a new patient at that hospital, so I cannot just ask for an appointment this time. It has to be a referral, likely through Abu-Rustum.

Dr. Musgrave is going to try to get her in, but even if it goes down fast, it could still take 1-2 weeks to get everything arranged, and get up there -- if no more snow comes which would make travel difficult at best.

T was scheduled to start chemo next week, but after reviewing the ultrasound from yesterday, Dr. Musgrave said she cannot wait. The tumor has grown significantly since early December.

So she's starting chemo tomorrow, **Thursday, January 18**. She could have done it today, but today was already scheduled as chemo education day, so we went with tomorrow. So she had a blood transfusion today.

Her hemoglobin dropped -- still over 8 (8.3) but this unit of blood will help mitigate the effects of tomorrow's chemo.

It is a 21-day cycle, just like last time.

The chemo I mentioned a few posts ago is definitely what she will be on:

[Adriamycin \(Doxorubicin\)](#) and [Lartruvo \(Olaratumab\)](#)

She will receive the Lartruvo on days 1 and 8, and the Adriamycin on Day 1.

Doxorubicin is an anti-cancer (antineoplastic or cytotoxic) chemo drug. It is classified as an anthracycline antibiotic.

This chemo is more likely to bring on nausea/vomiting. She has the same anti-nausea meds as last time -- zofran and compazine. She's also taking the steroid dexamethasone again, but this time, it's because it boosts the effects of the nausea meds. (Last time it was to help minimize the side effects of the taxotere.)

Doxorubicin is also likely to drop her WBC count, possibly severely. This time, she will not be given neulasta unless she "proves she needs it". This is an insurance thing. ?

This means she may be at much more risk of infection. We won't know until next week at the earliest if it will drop her WBC count. It may also have a cumulative effect.

This drug is one of the chemos more likely to cause heart damage -- which can even show up years after stopping it. Therefore, there is a lifetime limit on how much a person can take. This is why Teresa had an echo yesterday, and why Dr. Musgrave will carefully monitor her heart throughout this chemo regimen.

We did get some really good news from yesterday's echo: **There is NO SIGN of the pericardial effusion!!!!**

A new medicine this time around is called [allopurinol](#). If you've ever known anyone with gout, you may have heard of it. It stops the body from making any, or as much, uric acid.

When doxorubicin works, it can result in [tumor lysis syndrome](#). In basic terms, as it kills off the cancer, the kidneys help flush out the dead cells. But if it works really fast and/or there's a lot of tumor, it can overload the kidneys, and they can fail.

Teresa has a lot of tumor.

The allopurinol will help mitigate that side effect. They will also give her extra fluids during chemo on Day 1. And she must increase her water/fluid intake to help flush out her system.

If tumor lysis syndrome happens, it usually occurs within 24-48 hours of therapy.

"Lartruvo is a prescription medicine used with doxorubicin to treat adult patients with soft tissue sarcoma (STS) for whom doxorubicin is appropriate and who cannot be cured with radiation or surgery\*."

Radiation is generally used on STS larger than 2", but since her tumor is so large, Dr. Musgrave said the side effects that radiation causes would outweigh the benefit.

\*Teresa may still be able to have surgery. But at this time, we do not have surgeon for Teresa, and Dr. Musgrave is having good results with this chemo combo with another patient in the same situation as Teresa (including where gem/tax didn't work). So she is hopeful T will respond as well. She said if Dr. Singer is willing to see her and says he can operate, they can do "sandwich therapy": Chemo/Surgery/Chemo.

Doxorubicin is pushed with a syringe in about 10 minutes. Olaratumab is delivered through a drip over about an hour. Pre-medications can take about an hour.

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Many of you have asked how you can help. There are 2 immediate answers we can give at this time.

1. Call. We've stressed before how having visitors helps Teresa feel normal, and how it keeps her spirits up. But we don't know how safe visiting will be with this new chemo. Once we have a better idea of her body responds to it, we will feel safer in having visitors again. Right now, we'd like to ask that if you work with the public or children (or both) or have children, particularly young children who are more likely to catch everything going around at school, that you refrain from visiting at this time.

If you work with the public and are able to take appropriate precautions, that may be different. Please send me an email if this is you and you're wanting to come by.

2. We feel a little weird asking for financial help, but it's come down to that point, unfortunately. If Teresa gets through all 3 cycles of Dox/Olara, with no break in between for surgery, she will be having chemo through March 8. Her short term disability through work ends on February 23. She can take 2 90-day periods after that, but it will be unpaid. She can keep her insurance if she can pay the full cost, up front, out of pocket. And then there are all the other bills like rent, utilities, medical bills insurance doesn't cover, and so forth.

With this in mind, we have set-up an account with [YouCaring](#). Like any site where you use a credit card, there is a credit card processing fee, which is minimal, but they do not charge a platform fee, meaning recipients get almost the entire donation. (This is not true of all fundraising sites.)

**FROM TERESA:**

I have a site now at <http://teresa.grableronline.com>. For those of you with PayPal accounts, you can donate directly through PayPal too. It is explained on my page called Help Me. I have some good resources on that site that aren't on here. Right now, I don't know how often I will make personal posts. Amanda will still be updating CaringBridge after each of my appointments. My personal site is not going to be a replacement for CaringBridge.

**Amanda and I understand that not everyone can help financially. We ask that if helping that way isn't in your budget, that you please share my fundraiser within your community to get the word out to as many people as possible.**

**The fundraiser on YouCaring, and my personal site are both publicly shareable. (Do not share this post to share my fundraiser. Only people with a CaringBridge account will be able to access it. We'd like to keep these posts accessible to friends and family only.) Also, sometime tomorrow or the next day, we will both share the fundraiser on Facebook. They will be public posts. If you are not tech savvy, and it is**

easier for you to share the links from there rather than the individual sites, that is fine.

Thank you.

## Comments

Thanks for your thorough update. Your ability to wade through the complexities of Teresa's illness/treatment is astonishing. Thanks also for your bravery in asking for help. You've answered a question I've had about how to go about it. Stay strong for each other.

—*Sally Treanor, January 18, 2018*

Thinking of you both--oh, so weary, but strong and fierce!!

—*Susan Mead, January 18, 2018*

With you in spirit! Sending love.

—*Heidi Baird, January 18, 2018*

I have made a donation. Please do not thank me. I want to help. Spend your time and energy on your life. Love you!

—*Heidi Baird, January 18, 2018*

I love you guys! You will beat this T! I have never known you to lose at anything! I am hopeful and pray every day! ?

—*Jim Constantinides, January 18, 2018*

As always Amanda thank you for your up-dates. Teresa it was good to see you post something. We think of you often and we're hoping this next round of treatment is the one. Its been a rough couple of months for both of you. Many hugs coming your way!

—*Christine Daly, January 18, 2018*

## On the Road, Again

*Amanda Grabler, February 2, 2018*

We received really good news on T's last labs (1/25/18).

While she's still anemic, her hemoglobin is 9.5. That is the highest it has been in MONTHS! She did receive a unit of blood the week before that, but up until now, 1 unit would just sustain her to the next week, and then her hemoglobin would be back where it was, or lower.

This time, it stayed up!

Her kidney function is also back where it's supposed to be!

With the first chemo (gem/tax), she took her at-home nausea medicine (Zofran) maybe 3-4 times over an entire 9 weeks.

With the second chemo (dox/olara), she was immediately nauseated the day of chemo. And while mild, it's been pretty much on-going, along with some not-so-fun heartburn.

The nausea was worse the week she received both (Day 1) as opposed to the week following Day 8 where she received just the olaratumab. And that's with the fact that on Day 1, she was given a powerful pre-chemo anti-nausea medication, Aloxi + Emend, which is supposed to work 3-5 days, and prevent immediate and delayed nausea.

The heartburn has been worse since Day 8.

We're really hoping the nausea doesn't get worse after Day 1 of Cycle 2 (February 8)!

Thankfully, Zofran works pretty well for her. She's been prescribed compazine too, but hasn't needed it yet. (And, as many of you know, her favorite drink, milk, is an excellent heartburn treatment for her!)

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As I mentioned in the last post, Dr. Musgrave is trying to get an internal referral to Dr. Singer at MSKCC, but it's *s l o w* going. And I'm not keen on waiting around for anything about T's health, so I applied for an appointment at another NY hospital with a sarcoma center: [Roswell Park Comprehensive Cancer Center](#) in Buffalo, NY. (T's insurance says they're in-network, and I sent a copy of the insurance card in for them to verify. They told me they always check to make sure the patient doesn't get a surprise.)

She is scheduled for February 23, 2018. I'm just waiting on the chemo flowsheets from Dr. Musgrave/Dr. Musgrave's nurse (spreadsheets which list dates and dosages of all chemo) to send up; I've already sent the Pathology reports, and they have all other documents. They should be getting slides and/or paraffin blocks of



the tumor soon too, now that they have the Pathology reports.

I've read in so many places that doctors really need a patient to have at least 2 chemo cycles completed to tell if the chemo is working. By waiting until the week of the 18th, she will have finished her 2nd cycle of dox/olara. The week of the 18th is her next off week.

So everyone keep your fingers crossed for no lake effect/otherwise heavy snow that week or the next! :-)

Right now, the surgeon she will see is also saying no to surgery, but as in, "not at this time". He wants to see the tumor shrink more first (this would definitely make surgery safer), and from what we've been told, because of the way the first surgery was done (completely different than they'd do for sarcoma), it's made it harder to get clean margins. So they really need the tumor to shrink first to have the best possible surgery.

(Of course, back in August, it was suspected to be carcinoma. No one knew it was sarcoma, much less leiomyosarcoma, and Teresa likely wouldn't have survived long enough for a second opinion. So now, we just need to get things on the best track possible for going forward.)

But, the surgeon is still going to meet with us! We'll be seeing [Dr. John Kane, III](#) (surgeon), and [Dr. Anne Grand'Maison](#) (medical oncologist).

Dr. Musgrave is a medical oncologist, so I had initially questioned why they wanted us to see theirs, but Dr. Grand'Maison is sarcoma specialist (as is the surgeon), which makes a big difference.

We may also be meeting with a radiologist and pathologist.

At Roswell, they present patient cases to the tumor board to come up with the most optimal treatment plan for the person. Patients treated at sarcoma centers, or who have their treatment directed by a sarcoma center, are said to have **much** better outcomes than those who go a cancer center that doesn't see many cases like theirs. Read more here: <http://sarcomahelp.org/sarcoma-centers.html>

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**From Teresa:**

I want to thank all of you who have donated and/or shared the link to my fundraiser. It really helps a lot. We're just a little under \$1000 from reaching the halfway point of my first goal!

I do want to clarify a few things based on some questions we've received, so I've added an explanation on my website about having a fundraiser vs applying for assistance, exactly **why** I could lose my insurance after February 23, and so forth. Some people also wanted to donate via Google Wallet, so Amanda looked into that for me. That info is on this page too. You can find it here: <http://teresa.grableronline.com/help-me/>

Also, if you go to <http://teresa.grableronline.com/> you can read posts from me as I'm able to write them, see my

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timeline, and more. My first post about how I'm actually doing is now available. You can find it under "Recent Posts" and/or on the Blog page - access this by using the site's menu. The post title is today's date (Feb 2).

## Comments

Zantac helped me a lot with the acid chemo stomach. It knocked the reflux way back, and when I did throw up, it was no big deal, as opposed to before the Zantac (they had me on Pepcid before and it was worse than useless), when I threw up and it felt like the bile was eating through my throat. Good job on the hemoglobin.

—Margaret Frey, February 1, 2018

Sounds like things are moving forward and you're doing well. Good to hear! Continued good luck! I head to Pittsburgh tomorrow, first treatment Wednesday.

—Michele Dillon, February 1, 2018

As the saying states "slow and steady wins the race". Love and healing to you both.

—Monica Spath, February 1, 2018

Good to hear that progress is being made on many levels. Continued prayers for healing!! Hugs to both of you!!?

—Sue Harris, February 2, 2018

Thanks so much for the update, and gentle hugs to both of you! Praying for kind weather in Buffalo. Bring warm clothes!

Do keep in touch. Hugs. ?

—Marcia Horn, February 2, 2018

Thank you for the detailed updates! You're both in my thoughts.

—Bridget Gall, February 4, 2018

## Cycle 2, Day 1: Chemo a No-Go

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*Amanda Grabler, February 8, 2018*

Teresa was scheduled to start her second cycle of doxorubicin and olaratumab today. Unfortunately, her WBC and Absolute Neutrophils were too low for this to happen.

So, today was just labs and an office visit with Dr. Musgrave, who is going to file with Teresa's insurance to get the Neulasta shot approved. (It was approved immediately for Gem/Tax, but as most of you know, it's a very expensive drug - 21K+ per treatment, so this time, insurance said she has to prove she needs it.)

Dr. Musgrave sounded confident that this wouldn't be a problem, and next week, on the 15th, Teresa would be able to receive doxorubicin, olaratumab, **and** the Neulasta on-pro body patch. So 2/15 will be the new Cycle 2, Day 1.

Then we will be in Buffalo, NY. Her appointment with Roswell Complete Cancer Institute's Sarcoma Clinic is on 2/23, and then sometime the following week, she'll have Cycle 2, Day 8 (olaratumab).

On the upside, her lungs and heart sound good. Her hemoglobin went up again (now it's 10.2!), and her RBC went up (they're still low, but getting closer -- lowest minimum is 3.79 and she's at 3.61). Her platelets, which should be between 150 - 400 K/uL jumped from 328 to 525.

Her low WBC and low ABS neutrophils means she has to be extremely careful right now. She cannot be around anyone who is sick or getting over anything (even a cold). Even more hand-washing by her and everyone around her. Monitoring for fevers. She cannot have any raw fruits/veggies for the time being. And so forth.

Dr. Musgrave is hopeful that an extra off-week will give her WBC/neutrophils a chance to come back up so that it will be safe to do her treatment, and then also hopefully have the Neulasta approved so that her numbers don't drop off again.

Please let me know if you have any questions.

Don't forget about Teresa's site where she has several posts up (ex: supporting a loved one with cancer, info about visiting when it's safe, her most recent post from February 2nd, and lots of helpful resources)!

<http://teresa.grableronline.com>

## Comments

Dear Mandy and Teresa, K.C. suggested that Teresa get and wear a mask. Sound like a good idea? Love, Jody

*—Jody Werick, February 8, 2018*

Thank you for the update. Mask sounds like a good idea. I heard that a person is most contagious the day before they become symptomatic! So if there are others around at all, even masks on everyone may be a good idea.

Prayer continue.

—*jim bier, February 9, 2018*

Hugs and continued strength to you both!

—*Marcia Horn, February 9, 2018*

We should get masks too

—*Terry Werick, February 15, 2018*

## Cycle 2, Day 1: Houston, we have lift-off!

*Amanda Grabler, February 15, 2018*

So, round 2 of Cycle 2, Day 1, was a success!

Teresa got her labs done quickly. We were initially told that we wouldn't see Dr. Musgrave today, because she'd called in with a possibly fractured rib. :-)

But later, while we were waiting to see if T's numbers were good enough for chemo, Dr. Musgrave's nurse Cathy came and sat with us, and told us that Dr. Musgrave was going to try to come in, and she'd come talk to us while we were in the infusion cubicle. (Which is what happened. This resulted in us finishing chemo approximately 40 minutes early!)

A FNP went over T's blood work and cleared her for chemo. For the most part, it was a fairly boring day for me, because T was sound asleep pretty soon after she got the Benadryl! And then slept for several hours after we got home. I caught up on my reading. :-)

Many of you on Facebook already know that her numbers had significant improvement. For those of you who haven't seen my post, here is the info:

Her WBC is up to 7.5 (from 3.1) and her neutrophils are up to 5.2 (from 1.3, with ABS neutrophils at 69.3 from 42.5)! They are all in normal range.

Her RBC is at 3.62 (from 3.61) and her hemoglobin is 10.4 (from 10.2). Both are still low, but they are still increasing on their own! (The low number for RBC is 3.79 and for hemoglobin, 11.7, so she isn't *too* far out of

normal range for either.)

Her platelets are high at 555 (they were high last week too, 525). Normal range is 150-400. Hers have gone up and down throughout treatment. When asked, Dr. Musgrave said it is most likely reactive and may be due to an ongoing iron deficiency. So she ordered an iron panel for Teresa - which we'll probably see the results of over the next week as they trickle into the app.

The first time she took an iron supplement, it was short-lived as it made her sick. I've found another OTC type at Food City, which has Vitamin C added in to help with iron absorption. If Dr. Musgrave says she needs to try iron again, we may try that one. (You can get IV iron too if you can't tolerate it as a supplement, but last time it was in question, T's numbers were just a little too high for IV iron.)

Teresa was approved to have the Neulasta On-Pro Body patch again, which is applied after chemo is complete. It should activate (i.e. start dispensing) around 5:30pm tomorrow. If she reacts like she did when she took Neulasta for gem/tax, she can expect about 3 days of bone pain. (But this is much better than being at increased risk of infection!)

On Tuesday, we will head up to Buffalo, NY. Her appointment is on Friday (2/23). Hopefully we will have good weather (or, at least, no snow) for our trip! Then barring any changes in our schedule (i.e. Roswell wants to meet with her more, or, it snows), we will return to our Cancer Center\* for Cycle 2, Day 8 (olaratumab only) on February 27th.

Teresa and I both want to extend our deepest gratitude to those of you who have donated, and / or shared her fundraiser information. We've even started receiving donations from people we don't know at all, but who are friends/family of yours, and we are overwhelmed by the kindness and generosity.

We know that some of you prefer sending checks rather than donating online, and we respect that. The "[Help Me](#)" page of Teresa's site has been updated to include some information about what to do if you want to send a check in the mail, including who it needs to be made out to.

For those of you who have Facebook, I've set-up Teresa's site to allow commenting via your Facebook account. For those that don't, there is a commenting system called Disqus (free to sign-up), which is pretty user-friendly in my experience.

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\*In the past, I've sometimes referred to it by name - Wellmont. Our hospital system merged with Mountain States, unfortunately, so they are now Ballad Health. So if I call the Cancer Center, or Hospital, Ballad something --- same place, different name.

## Comments

Daily prayers? Happy for good news! I know it will keep getting better! You are so strong T! Love you both! ??

—*Jim Constantinides, February 15, 2018*

Love you both! ?

—*Bridget Gall, February 15, 2018*

So happy to hear Teresa's numbers are up! I am right there with her on Benedryl. Is she taking Claritin for bone pain? I take the 24 hour one. I would still feel achy, but not the extreme pain. Prayers and good mojo for the chemo to be working!

—*Michele Dillon, February 16, 2018*

You chronicle the progress so well -- it's very encouraging to DO something and then see a positive result. Keeps us all going. Safe journey and hope to see you in Buffalo.

—*Sally Treanor, February 16, 2018*

## Roswell Park Follow-Up

*Amanda Grabler, February 26, 2018*

We apologize for the delay in posting. We know you have all been very curious as to what we learned from the sarcoma specialists we saw in Buffalo, NY. We received a LOT of information. The appointment was both physically and mentally exhausting. We're still overwhelmed by it. I really had to sit and think about how to best share what we've learned. It was definitely worth going to this appointment. We learned more than we have from any other doctor to date.

But it is not happy news.

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[Roswell Park Comprehensive Cancer Center](#) doctors, PAs, and nurses are all *very* thorough.

Our appointment started on time. First with a nurse, then with a PA, then another person - we weren't sure if she was a nurse, PA, fellow, or another position.

Then Dr. Grand'Maison, and then Dr. Kane, and Dr. Kane's fellow.

Altogether, it ran 4 hours.

**Medical Oncologist:**

Dr. Grand'Maison said she would have started with the same chemo Dr. Musgrave had, and then moved to the chemo she is on now. She said T's reaction to gemcitabine/gemzar is rare but it happens, and had gemzar added as an allergy in T's file. She can never have that again.

There are other chemos to try if dox/olara doesn't work, such as trabectedin. There's also some which can be done inpatient. Since there was no CT done prior to starting dox/olara, she is recommending to Dr. Musgrave that a CT happen ASAP for as close to possible as a baseline. Then at least 2 more cycles, and then another CT.

Without the initial baseline, it's harder to tell if it's working and that's why she wants T to have several cycles, as long as there is no toxic reaction, to know for certain.

*A basic explanation given:*

Imagine that in December's CT, the tumor was size 12, and then a month later, it became a size 16, but there was no January CT to compare it with. Then chemo started late January, and started to shrink\* the tumor. After 2 cycles of chemo, a new CT is taken, and now the tumor is size 14. If we compare this to the CT in December, it looks like the tumor grew, but in reality, it shrank.

Since there was no January CT, even if it looks like the tumor isn't responding in her next CT, Dr. Grand'Maison wants her to continue on the dox/olara for at least 2 more cycles, so that a more accurate CT comparison can be done.

\* We are not saying that the chemo is or isn't working. This is just to give you the best visual explanation of what's going on (it was drawn for us on a whiteboard).

I also asked about zinecard (it was suggested in a LMS group I'm in) which is designed to protect the heart against the cardiotoxicity of doxorubicin. Dr. Grand'Maison seemed surprised T wasn't already on it, and said she could send that as a recommendation as well. Zinecard is a chemoprotectant (but could still have unpleasant side effects).

She also said that clinical trials and various new procedures are good to keep in mind, but we need to do things with known results right now. She was glad to hear we asked Dr. Musgrave to send samples to Foundation Medicine, but for the sake of reality to keep in mind that there's about an 8% chance it will come back with something helpful.

Dr. Grand'Maison pointed out that while sarcomas are rare, and leiomyosarcomas are a rare type of sarcoma,

uLMS rarer still, and uterine myxoid lms, even more so, to remember that 30-40% of the patients she sees are LMS patients, so for her, it is a common cancer. This is exactly the type of specialist we needed.

### **Surgical Oncologist:**

Dr. Kane sat down with us and went through Teresa's CTs and explained what different parts were and what they meant. This was the first time this was done. It was very helpful. It will give us a better chance of understanding future ones -- not perfect by any means, but now it won't be quite so mysterious.

He also explained why he won't operate. (I did ask if he means no surgery, ever, or no surgery now. He said he never says never.)

If we'd known it was any kind of sarcoma to start with (which would have been difficult), and it hadn't been found so last minute -- i.e. at a point where surgery HAD to happen, the surgery could have been done differently. And better. But we didn't know and there wasn't time.

The tumor didn't come out intact. Which we knew to a point because they weren't able to get all of it. But what they did get, Dr. Kane says, did not come out intact. It came out in two pieces. LMS has a fragile covering, so when it broke, [it created spillage](#).

For a visual, Dr. Kane said it's like when you blow a dandelion puff and the seeds go everywhere and implant. That's what happened with the surgery T had in August. Little tumor bits went forth and (possibly) prospered.

Although we don't know for certain, it's possible that although the gem/tax didn't work on the left behind pieces of tumor in small size (or as it regrew) that it possibly did something to any circulating tumor bits, because as of her last scans (CT in December, Ultrasound in January), there is still no evidence of metastasis to the best of their knowledge.

Another surgery right now, however, would create the same risk. And he doesn't want to do that.

(There is a blob of something next to the liver. The density is too thick to be regular fluid, and he said if it's blood from the first surgery it should have gone away by now, but there's a chance it could still be blood. It also hasn't changed size over 2 CTs, so it just needs to be monitored.)

In addition, this surgery would be far more complex. Originally, it was essentially one large mass, either draped over organs or pushing them out of the way. Now, in addition to that, it's also wrapped up into Teresa's intestines. And, he said, looks to be adhered and/or pressed up against other lower abdominal organs. If he did surgery now, he estimates that in addition to the cervix (to complete her hysterectomy) he would also have to remove her bladder, her rectum sigmoid colon, some of the intestines, some of her vaginal canal/vagina, and possibly some of the liver.



She would have to have colostomy and urostomy bags - for the rest of her life. (I asked about bladder reconstruction but he said it wouldn't be an option in her case, and it's much more difficult than reconstruction for things like bones, because the bladder has to be so flexible.)

It would be a 2-3 month recovery period -- and a full recovery may not happen. She would have to be off of chemo the entire recovery period, and if they couldn't get it all, the tumor would start regrowing again, and the surgery could possibly have been for nothing.

Right now, he only sees surgery as any kind of immediate option if the tumor causes a localized point of obstruction (i.e. in her stomach or bowels), where he'd have to create a bypass so she could still get nutrition.

If she has a dramatic response to chemo (rare, but can happen), they could take her off of chemo, and let her immune system come back up. If the tumor stays stable (i.e. doesn't grow off of chemo), then he could do surgery at that point. If the tumor starts to regrow, surgery becomes risky.

If surgery did happen, he may also do radiation to try to shrink the tumor margins from the other organs to make resecting it easier, and also minimize damage to (or removal of) other organs.

Right now, Dr. Kane says he is in the background of her treatment plan, but he gave us his card and told us to contact him if we need to.

He said Teresa just needs to do chemo for now, until we hopefully find a mostly or fully successful one. And that she could expect to be on chemo for many months.

It was still really good to hear that we are following the best course of action at this time. If surgery becomes a viable option, or a necessary one, we will go back to Dr. Kane. We've heard wonderful things about him, and from actually meeting him, we know he is someone we can trust.

Also, from our understanding, it sounded like they would be presenting her case to the tumor board, so there's a chance more information may be forthcoming from them.

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We want to sincerely thank everyone who has donated to Teresa's [YouCaring](#)\* fund, and to those of you who have shared it. It is greatly appreciated.

\*[Or via PayPal, Google Wallet, or checks/cash.](#)

## Comments

Phew! Glad you were pleased with the competence of the team. So important! I was grateful to see you both

looking so strong psychically. You are amazing. Also glad you're home safe. Loving you!

—Sally Treanor, February 26, 2018

Sounds like the Drs took plenty of time to explain things and answer questions! That's why we love specialist. Should the time come, I have both a urostomy and colostomy, though my tumor wasn't quite as invasive. They were not able to remove the entire tumor, and had to follow up with radiation, but then I went over a year before needing chemo again. Keep moving forward!

—Michele Dillon, February 26, 2018

Glad you got information confirming the course you are on and hope you will feel like coming to the concert Friday night.

—Lana Whited, February 26, 2018

I am glad you had a successful trip. Sorry it was not better news. I am glad you know T is on the right course of action. XOXO

—Maura Fischer, February 26, 2018

I'm glad you found those doctors, and that they are doctors you and Teresa can trust. I am sad it isn't good news, but there's some rays of hope, if the chemo works. I am continuing to pray and keep you both in my heart, Amanda. xoxoxoxo

—Melissa Fields, February 26, 2018

## Post-CT Reaction

*Amanda Grabler, March 2, 2018*

We were able to schedule the CT Teresa needed (the one Dr. Grand'Maison wanted her to have ASAP) very quickly. She had it yesterday (3/1) afternoon at the Volunteer Parkway Imaging Center. She's been there before. Same contrast as always - maybe a little less than usual, but otherwise the same. Same prep drink (think Vanilla Boost but... gritty).

This was her 5th CT. She's never had any issue until now. This time, she had a 'delayed IV contrast' allergic reaction: rash, swelling (wrist, fingers), and itching. Going forward, she can now only have CTs at the hospital,

and she will have to be premedicated (presumably with Benadryl, steroids, or both).

T had to take her wedding ring off -- her fingers didn't get \*that\* swollen, but she didn't want to take the chance she'd be unable to get it off later and it would become painful, but her watch, LMS bracelet, and MedicAlert bracelet all became noticeably tight on her wrists. :(

She was prescribed methylprednisolone and told to take Benadryl with it, and go to the ER if it "gets worse".

She is the itchiest on her extremities, particularly her hands (fingers, palms). No rash on hands. The biggest rash is on her chest, but she is not itchy there. (She does have some overlapping areas of itch/rash.)

Can anyone tell us how long it should take the two medicines to work, if they're going to work? Especially for the itching -- any idea when she should feel some relief there?

## Comments

Amanda (Do not be offended, please, )the only thing I can tell you is when Kodiak had an allergic reaction he was given steroids and basically an injection of Benedryl which can take swellbig down (he had hives also) . It did not work immediately so I think it depends on the individual. He has the have oral steriods and Benadryl afterwards. The sooner Benadryl is taken the better it works. If T has to take it beforehand next time that might elieviate her having a reaction (I hope)

I am so sorry T and you have to go theu this

XOXO  
Maura

*—Maura Fischer, March 2, 2018*

Hugs, strength, and continuing love to you both.

*—Marcia Horn, March 2, 2018*

Sorry I'm a little late with this but I know there are prescription creams which might help with the itching-if she can use them. Also Aquaphor for the rash.

*—Christine Daly, March 9, 2018*

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## Cycle 3, Day 1 & CT Follow-Up

*Amanda Grabler, March 13, 2018*

Teresa started Cycle 3 of Dox/Olara today.

Her numbers, overall, were very good! Her hemoglobin was *\*normal\** for the first time since before any of this happened. Even after surgery, before she started chemo, it never went up into the normal range. And this happened without any transfusions (she hasn't had any in weeks).

The range used is 11.7 - 15.0 g/dL. Hers is 11.8! Her WBC is 6.1 (3.5 - 11.0 K/uL), her RBC is 3.96 (3.79 - 5.11 M/uL). Her platelets are a little high again (they weren't on 2/27 but were on 2/15) but Dr. Musgrave didn't seem concerned. Her neutrophils and absolute neutrophils were in good range to receive chemo.

Her CMP (metabolic) was good too. The only thing out of range was her total protein at 6.5, but the range is 6.6 - 8.7 g/dL, so she's only *\*just\** under normal.

Creatine, bilirubin, BUN, eGFR, liver panel, all great!

Dr. Musgrave is submitting a request to T's insurance to get her approved for the heart protectant Zinecard. If approved, she'll receive it on Day 1 of Cycle 4 (it's only administered right before the doxorubicin).

As of now, her hair is still (slowly) coming back in.

When her numbers are great like this, it means it's a good time for (healthy) visitors!

### **The CT:**

As a reminder, this was done as a baseline CT, even though she'd already had 2 cycles of this chemo, because one had not been done in January (only an ultrasound; the last CT was early December). If you (re)read the previous journal entry, you'll find where we explained that even if this CT showed growth in comparison to December, it doesn't necessarily mean it isn't working.

Overall, most of her other organs are good. Her heart is still showing as "normal size," but we'll need another echo (which should be scheduled after next week's chemo) to see if her [ejection fraction](#) is still within normal limits.

**Lungs:** New, 4mm subpleural nodule along the right major fissure. Primarily atelectasis overlying the right-sided pleural effusion.

**Pleura:** Similar moderate right and decreased trace left pleural effusions.

Without a biopsy, there's no way to tell if the nodule is a metastasis\* or something benign. I've learned from other people with LMS that the general rule of thumb seems to be that if the nodule is 10mm or less, don't touch it. Dr. Musgrave wasn't concerned (I asked specifically about it).

\* See end of post for an explanation of metastasis.

There are things that can cause benign nodules (ex: pneumonia and other disease which causes inflammation) scar tissue, etc. We're going to get hold of this CT scan as soon as possible so we can see for ourselves exactly where it is located and see if it's anywhere near where her right thoracentesis procedure was done. She did have quite a bit of pain during the healing time period, and said it felt like the muscles were torn and pulled a bit.

The nodule was not there before the thoracentesis, and no CT was done after them until this one on March 1. Hopefully it will turn out to be something like that, and not be a met.

She is still using her incentive spirometer, which in basic terms, checks how well your lungs function. The highest number on it is 2500. She can repeatedly hit numbers from 2000 and up. This is better than what I can do on the spirometer.

**Musculoskeletal:** Degenerative changes of spine (Dr. Musgrave said some of this is just going to be from aging). No aggressive osseous lytic or blastic process. Probable Tarlov cysts. (Tarlov cysts are fluid-filled sacs that affect the nerve roots of the spine, especially near the base of the spine (sacral region). The fluid is cerebrospinal fluid - ie fluid that leaked out of the spine. This is the clear fluid found in the brain and spine.) If it is this for sure, and they progress, in addition to pain, they can cause neurological problems. Right now she only has a little back pain but it is not limiting her activities.

*That's all we know for now. She's due for her next chemo (Day 8, olaratumab only) on Tuesday, March 20.*

*We are resting in Abingdon through Friday, and then will get to visit with family we haven't seen in awhile! If you'd like to call and talk to Teresa, you can reach her on the cell phone or on our home number.*

### **Helpful Sites:**

1. What is Ejection Fraction - <https://www.mayoclinic.org/ejection-fraction/expert-answers/faq-20058286>
2. Tarlov Cyst Foundation - Info <https://www.tarlovcystfoundation.org/info/>
3. National Organization of Rare Diseases - Tarlov

Cysts: <https://rarediseases.org/rare-diseases/tarlov-cysts/>

4. What is Metastasis (often abbreviated as met or mets)  
- <https://www.cancer.net/navigating-cancer-care/cancer-basics/what-metastasis>
5. CT or CAT Scan - <https://www.radiologyinfo.org/en/info.cfm?pg=bodyct>
6. Thoracentesis - <https://www.radiologyinfo.org/en/info.cfm?pg=thoracentesis>

If you're not sure about a word I've used, please ask! You can email me at [amanda.grabler@gmail.com](mailto:amanda.grabler@gmail.com) if you're not comfortable asking in a comment. Believe me, I look up a lot of the information myself before I post so that I can figure out the easiest way to explain everything. But I realize there may be things we understand that most people wouldn't, but we forget that and don't explain.

## Comments

Going great! sending love.

—Heidi Baird, March 14, 2018

Am I correct in reading all of this as very positive?

—Maria Yakkey, March 14, 2018

We are so appreciative of these excellent, caring and timely updates, Mandy. They are very helpful in understanding Teresa's situation. This one feels encouraging. Please know that you both are in our prayers.

—Roger & Patti Ackley, March 14, 2018

Sounds like good news in general! Continuing prayers. Thank you for update.

—jim bier, March 15, 2018

## Cycle 3, Day 8

Amanda Grabler, March 20, 2018

Teresa had her olaratumab-only infusion today.

Her numbers (WBC, neutrophils, absolute neutrophils) that they look at to determine if chemo is safe to give were low, but Dr. Musgrave okayed the infusion.

(It looks like, and the oncology RN agreed, that despite that the Neulasta patch last week worked correctly, it may have technically failed. I've read that this does happen. It will work fine for many treatments . . . and then sometimes it doesn't do anything. She did not receive Neulasta today. We're told it is usually only given once per cycle.)

Teresa is currently at elevated risk for infection. In large groups, or around people she knows are sick, she needs to wear a face mask and have good hand/face hygiene. (Ideally, preferable not to be in close proximity to sick people, but sometimes this is unavoidable.)

Her RBC and hemoglobin are down too. If they go back up next week, her off week, then we think we can just consider the drop a chemo-reaction.

The RN oncologist we talked to before leaving said T's numbers will most likely rebound over the next week, but to take precautions in the meantime. Although next week is her off-week, we're going to call Monday and ask if she can come in either that day or on Tuesday just for labs so we can find out how she's doing.

Her next chemo (plus labs and an office visit) is scheduled for Thursday, April 5th. She will have her next echo that morning (to see how her heart is doing on doxorubicin), and her next palliative care appointment on Friday, April 6th.

So, if her numbers are good, and her echo is good, she should be able to start Cycle 4 on April 5th. She is also due to begin Zinecard that day. That is the heart-protective medication I wrote about in an earlier post.

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It is possible that she has had the beginnings of CIPN (chemo-induced peripheral neuropathy) in her feet, but we won't know unless it repeats. A few days ago, T had some symptoms which *could* be a match for CIPN, but could have just been a random pain that is unrelated.

## Comments

It surely is a daily watch, keeping track of everything in a minute way. I applaud you both for continuing your careful zeal making new goals as new info presents. Bless you both and know how much we care about your progress!

—Sally Treanor, March 20, 2018

Thinking of you

—*Maura Fischer, March 20, 2018*

Alpha lipoic acid for neuropathy. I remember taking a higher dose, but then read there was no difference in response of people who take more than 600 mg. Hope her numbers rebound quickly!

—*Michele Dillon, March 20, 2018*

Oh my, I'll be thinking of Teresa even more. Your strong dedication and love for each other is helping Teresa through this. You're in my heart.

Lee

—*Lee Ware, March 21, 2018*

Hugs all around??

—*Sue Harris, March 21, 2018*

When I had chronic leukemia in 2013, I got through the chemo (Jun Jul Aug) fine. I was warned about being susceptible to infection, but apparently I didn't take it seriously enough. I became sick in Sept. with high fever & taken to the Virginia hospital center. 5 days of antibiotics day & night. Then stayed home and my white cells very gradually increased. Then in Jan. I was still very vulnerable, and got a fierce case of shingles. Misery. Please be extra cautious!! Don't take any chances for now.

much love, Lee

—*Lee Ware, March 30, 2018*

## Teresa's Blog & a Reminder

*Amanda Grabler, March 27, 2018*

Teresa has updated her blog! You can find her latest post at: <http://teresa.grableronline.com/smoky-mtns/>



Also, as a reminder, since there's been some confusion for a few people, if you're wanting to donate specifically to Teresa, please visit <http://teresa.grableronline.com/help-me/> for the various options (YouCaring, PayPal, Google Wallet aka Google Pay).

If you donate through CaringBridge, you are donating **TO** CaringBridge. CB does not ask families to pay for an account on this site, so to reduce their costs, they do their own fundraiser, and ask people to donate in honor of their person to help keep CaringBridge online. We completely understand why they do this; they are providing a great, free service. But we also realize their donation banners are misleading, and have led people to donate to them when they thought they were donating to us. CB told me yesterday that they absolutely want to honor people's intentions, so if you've made a donation to CB thinking you were making a donation to a friend/family member (T or anyone else), CB says [you may contact them](#) for a refund.

## Cycle 4, Day 1

*Amanda Grabler, April 6, 2018*

This was yesterday (April 5).

It was a long day. It started by being at the hospital at 9:45am for her echo. The cardio tech had a student/intern with her. He did a lot of practice scans, and then the tech came back and she did the actual exam. Longest. Echo. Ever. (Over an hour.) But they were both VERY nice.

And best news - we got the echo results today. NORMAL. Her ejection fraction is still 55%. (Simply put, EF tells you how much oxygenated blood your heart can pump through your left ventricle each time. Normal range is 55% - 70%.) Doxorubicin hasn't changed anything. Yesterday Teresa also started receiving Zinecard, which is a chemoprotectant for the heart for those receiving doxorubicin. T will be at her cumulative dose after Cycle 5. I've learned recently that apparently a number of patients, especially with LMS, surpass the lifetime dose by using Zinecard

We went back home after the echo. I wanted a nap, but with only an hour before we had to head down to the Cancer Center, I didn't dare. I had lunch. T did not. She always makes sure she has fasted 8 hours before labs so that she can monitor her glucose levels. (So she takes something with her so she can eat as soon as the blood is drawn.)

Teresa's numbers? Much awesome!

White Blood Cells: 7.6

Red Blood Cells: 3.80

**Hemoglobin 11.9!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!** (So, she's always tired 1-2 days post-chemo, but in general her energy level has been improving, and this is a big reason! 11.9 is the best it has been since before she started getting sick last summer. 11.9 is NOT ANEMIC!!) Happy tears? Yes, I have these.

(The highest her hemoglobin ever got before was 11.1 on October 4, 2017, but that was prior to starting any chemo, and probably before the tumor regrew very much. Standard range: 11.7 - 15.0.)

A big part of her anemia last year was because the tumor was taking so much blood for itself. So this change is highly encouraging.

Platelets are a little high, but they fluctuate between normal and high, fairly regularly, and Dr. Musgrave doesn't seem concerned. We asked one of the chemo nurses, and she said it's likely just chemo-reactive (as opposed to something being actually wrong).

Everything but her total protein on her Complete Metabolic Panel (CMP) is in range, and that is only off (low) by .1.

We had a great office visit with Dr. Musgrave, who answered several questions for me. She also felt T's abdomen, and said that she feels "squishier". :- ) (Her abdomen used to feel hard and rigid. You can still feel some of the hardness when T is standing up, but it is likely just the tumor shifting - now that there's probably more room in there for it to move around. Although we won't know for sure until the next CT, it sounds like the chemo may truly be shrinking the tumor. Fingers crossed!)

I asked about the lung nodule, and Dr. Musgrave confirmed what I had been told in the Leiomyosarcoma Direct Research Foundation (LMSDR) group: it could have been a minor infection, it could be scar tissue from the thoracentesis. It is very tiny, and unless it shows up larger in the next CT, right now it is not a concern. Her lungs still sound good. She can still do (consistently) way better than I can on the incentive spirometer.

Teresa suspects she may be starting to have peripheral neuropathy (toes, fingers), and a friend recommended Alpha Lipoic Acid. I asked about it. Dr. Musgrave is not familiar with it. I told her I would look it up and bring information back for her, and she said that sounded good. We're also going to see about T trying powdered Lion's Mane mushroom in some meals (i.e. obviously not in cereal!) as it is also supposed to help with nerve regeneration - and is also good for memory.

I asked if Dr. Musgrave could check T's vitamin B12 levels. They'd been super high last fall. A deficiency in B12 can make you more likely to develop neuropathy. T's levels are still high but coming back down into normal range.

This cycle, Teresa will receive the Neulasta patch on Day 8 instead of Day 1. Day 8 has less chemo, and is also obviously when T's numbers are lower to start off, and our understanding is that with less chemo to fight back against, the Neulasta may work again. (Out of all the chemo weeks, it was only there last cycle where it didn't

seem to do anything.)

Her next CT should happen after Cycle 5. It will be at the hospital and she will be pre-medicated. Hopefully she will not have another contrast dye reaction. Dr. Musgrave said it is unlikely that T will have to deal with seafood allergies because of this, but we will make sure to test this cautiously just to be safe.

After the next CT is also when Dr. Musgrave would decide if Teresa needs to be restaged. (Original staging was 2b.)

Dr. Musgrave is going to check in with Foundation Medicine as she still hasn't heard anything yet (genetic testing/gene mutations of tumor).

T will get Aloxi+Emend on Day 8 now too (so she won't get nauseated on olaratumab-only weeks).

I also had 2 very detailed questions for Dr. Musgrave about metastasis and having T's tumor tested and re-tested for a few things. But those I gave a printout to her for, since I also provided links to a number of medical/scientific journals to back up my questions and research. I gave her my email address too, because they were questions that would take time and consideration, and I knew we probably weren't her last patients that day.

She said she'd definitely look through all of it and get back to me. If you're interested, you can see what I shared with her here: <http://teresa.grableronline.com/research/>

Next Thursday (April 12), is Cycle 4, Day 8.

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I will do a brief post here whenever Teresa is able to write about our recent (and amazing) short trip to Dallas. (We drove. My Mom went with us.) I'll also be sharing the photos on and off Facebook, since I know not all of you do Facebook. I'll share the photo link here too, to make sure you all get a chance to see it. I probably will not be able to process the photos until we're back in Roanoke (next weekend). The laptop I use in Abingdon, and our internet, are simply too slow.

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More on Ejection Fraction: <https://www.mayoclinic.org/ejection-fraction/expert-answers/faq-20058286>  
More on chemoprotectant drugs: <http://chemoth.com/chemoprotective>

## Comments

Good to keep up with you guys. Things sound like they going well.

—Heidi Baird, April 6, 2018

We are always glad to hear when there's encouraging news.

—Lana Whited, April 8, 2018

## Cycle 4, Day 8 + Cycle 5, Day 1

*Amanda Grabler, April 28, 2018*

I realized as I went to write about the start of Cycle 5, that I'd never posted about Cycle 4, Day 8. Wrote it. Never published it. Instead of doing 2 posts back-to-back, I decided to combine them.

### **Cycle 4, Day 8 (April 12):**

Chemo itself was pretty uneventful. Her numbers had gone down some, but considering she'd received doxorubicin and olaratumab on Day 1, this wasn't very surprising. They were still within range enough to receive Day 8's treatment. She did not get Neulasta on Day 1. It hadn't done much the previous cycle, so Dr. Musgrave said she'd get it on Day 8 instead, which she did.

We had asked for her to get the pre-med Aloxi+Emend (potent anti-nausea). She had received it on previous Day 8s, but I think it may have been before her insurance plan changed slightly, because on this request, even with doctor approval, it was denied on the basis that olaratumab alone doesn't make most people nauseated.

But it made T sick when she got it alone and no anti-nausea. But she's in the minority for that reaction, so the only thing they could give her was zofran. She has pills of that to take at home, and it does work, but it's neither as powerful nor as long-lasting. So that was disappointing.

Otherwise everything went well. She slept through much of it (as is usual) and did well afterwards. She did have some pain we're pretty sure we can attribute to Neulasta, so hopefully it really did something this time!

(We went to Roanoke's Pride in the Park on April 14th, and according to my phone's health app, walked nearly a mile, which for us these days is a lot. She thought maybe she was achy from that, but I pointed out that we're in equally bad shape for doing a lot of walking, and I wasn't having any pains from walking, so, most likely it's her body being forced to produce white blood cells super fast.)

## Cycle 5, Day 1 (April 26):

Teresa's labs were good. Her WBC count was at 18.0 (range is 3.5 - 11), so we know that the Neulasta DID work when administered on Day 8 instead of Day 1, which is a relief! Her hemoglobin dropped a little, but is still above 10. Her platelets are elevated again, but the FNP we saw for this appointment told us that it's reactive with what the WBC, RBC, and hemoglobin are doing, which is why it's been going up and down. There's nothing to worry about.

In her metabolic panel, her total protein is still a little low, but higher than it was 2 weeks ago. Her bilirubin is back in range. Everything else on her metabolic panel (these are things like sodium, potassium, glucose, calcium, liver panels, etc) are all great! So there were no problems in starting Cycle 5!

Like Cycle 4, it was pretty uneventful as far as the actual treatment went. We did narrow down the restless legs and slightly blurred speech (temporary on both counts) to the benadryl. So after they administer that, but before it makes her too sleepy, she gets up, IV pole in hand, and does a few laps around the infusion center. Not only does this help with the restless legs, it can help her prognosis. We've figured that whenever it was possible for her to get some kind of exercise, she should -- always within reason depending on current treatments and hemoglobin levels. And then yesterday, I read this article which was shared by the Sarcoma Alliance, but is good information for cancer patients in general:

### **"Physical Activity Significantly Boosts Survival in Cancer Patients"**

<https://www.medscape.com/viewarticle/895564>

So what made this past Thursday's appointment eventful? Well, we got Teresa a new wig at Pride in the Park, and she wore it to the Cancer Center. *Everybody* loved it. She got so many comments and compliments from people of all ages. We've since shared the photo in two cancer groups on FB, one of them is the LMS Direct Research Foundation, and so many people loved it so much. Several said it inspired them to go get the fun wig or (safe) hair dye they'd wanted to do. They appreciated seeing one way she is able to keep up her spirits throughout these trying times.

Many of you got to see it on Facebook, but I know not everyone is on there, so I'm including it in this post too. Enjoy!

Also, Teresa wrote a blog post about our trip to Dallas to attend the 40th anniversary reunion event of the Dallas TV show. We got to meet 4 cast members. It was an amazing time! It was March 30 and 31 (though March 30 was certainly the better of the 2 days!). I put together a video of our experience on March 30 (if you're a fan of Dallas, or if you've ever seen the intro, you'll understand why I put the video together the way

You can read her post here: <http://teresa.grableronline.com/dallas-40th-reunion-and-more/>

And you can see my video here (be sure your sound is on!): <https://youtu.be/jq85ASpQc6s>

## Comments

Great job on capturing the glamour of the setting for Dallas. What a fabulous place and how wonderful that you were able to make the trip. Good for the spirit!

—*Sally Treanor, April 28, 2018*

Love the Dallas video! Glad you girls had that adventure. Love the new hat too. Inspired by your living each day to the fullest. Hugs all around???

—*Sue Harris, April 28, 2018*

What a cool trip! Enjoyed the video. Glad treatment is going fairly well.

—*Michele Dillon, April 28, 2018*

## Cycle 5, Day 8

*Amanda Grabler, May 3, 2018*

Her numbers were low, but not too low for chemo, and she got Neulasta today. Neulasta boosts her white blood count.

Her nurse today said we are fine to travel. We are leaving for NYC on Monday, for about a week. We will stay with T's Mom, and hopefully get to see family and friends.

She did have some mild nausea tonight; so far, this has thankfully been a rare side effect with this chemo.

A few days after we return, Teresa will have another CT. This will tell us how well (or not) that this chemo is working. If the results are good, we expect her to start Cycle 6 of doxorubicin and olaratumab that afternoon.

## Comments

Sounds good you guys!!!!

Hope T is over the nausea and your trip to NYC is great!!!

Mandy, as you noticed I chin dialed you while in the middle of a training session with Avanir!!!! I told Peggy and she said you figured it was a butt call. Sorry to Shave had to hang up!!!!  
I love the new job People are smart and.nice. YAY!!!!  
Love you guys!!!!!! Thanks for keeping us in the loop!!!

—Terry Werick, May 4, 2018

It's wonderful that both of you are traveling next week to New York! I travel to NYC often, sometimes several times a week. I'd love to see you both if your schedule allows. Let me know a good place that would work for you. Hugs to you both!

—Marcia Horn, May 4, 2018

This all sounds good. Trip to NYC sounds great. Good time of year to be there. Safe journey.

—Sally Treanor, May 4, 2018

Sounds as though things are going well. Love to you both!

—Heidi Baird, May 5, 2018

## A Change is Gonna Come

*Amanda Grabler, May 23, 2018*

Teresa started Cycle 6 of Doxorubicin/Olaratumab on Thursday, May 17. She was supposed to have her CT that morning, but a communication error somewhere meant there was no pre-medication. So her CT was rescheduled for EARLY the next morning.

We waited anxiously for the CT results, which came the morning of Tuesday, May 22, in the form of a voicemail. Progression of tumor. Need to be seen

immediately. Need to change to a new chemo and/or get into a clinical trial. Well. That was unnerving!

So we saw Dr. Musgrave today (Wednesday, 5/23) instead of tomorrow. We were very nervous going into it. We did manage to get a printout of the CT report prior to the appointment (at the cancer center). It was ... so disorganized and vague. Tech-in-training? The report is read by someone in radiology at Bristol Regional Medical Center, in Bristol, TN, and then sent to the doctor or FNP who ordered it at the Cancer Center.

Dr. Musgrave agreed it was not a good report. (Ex: On March 1, Teresa's CT mentioned a mass attached to the right side of her liver. This report said it was on the left side.... There was so much of just ... bad reporting (or bad reading skills followed by bad reporting skills).

There has been tumor growth on doxorubicin/olaratumab, but compared to the period before she started chemo, and the period she was on gem/tax, it's pretty minimal. Since her March 1 CT, she's had approximately 1.5cm of growth on the primary tumor. Leiomyosarcoma is an aggressive, fast-growing tumor, so even though it's still growth, it's pretty awesome.

We discussed how there was possibly just too much tumor for the chemo to be truly effective against (and there may be some resistance of the doxorubicin). My visual analogy was, "trying to hunt an elephant with a BB gun". Dr.



Musgrave agreed this was an apt description. (Do please note that I absolutely do not condone shooting elephants with anything!)

In an online group for the LMS Direct Research Foundation, a friend told us that her understanding was that Dana-Farber Cancer Institute, in Boston, Massachusetts, was more aggressive than other big sarcoma centers. I also had that impression from posts I've read from other patients, and from medical journals. There is also a lot of innovative sarcoma (and cancer in general) research that comes out of DFCI.

Before I could ask Dr. Musgrave about Teresa going there, she brought it up - mentioning Dr. Suzanne George as an excellent medical oncologist to work with, and that she'd worked with Dr. George on another patient. Dr. Musgrave told me to apply for an appointment, and she'd work on contacting Dr. George to discuss treatment — and discuss expediting an appointment at DFCI!

She told us that the team there is much more likely to be willing to do surgery, which Teresa is definitely up for. We know from Roswell that there is a chance that Teresa would need permanent colostomy and urostomy bags. Teresa says it's worth it if it means she has a better chance of surviving this.

But, who knows? Maybe DFCI wouldn't need to remove any, or as many, abdominal organs as Dr. Kane at Roswell said he'd have to remove.

I have applied for an appointment with Teresa, and the site said we should hear from a Patient Coordinator within 24 hours. I let Dr. Musgrave know as soon as I submitted the form.

Dr. Musgrave also told us about a local cardiologist who is changing his practice around to just treat oncology patients. As a reminder, doxorubicin can be very cardiotoxic. T has had 2 cycles of the chemoprotectant Zinecard, but that doesn't mean she couldn't still have problems from the doxorubicin....even as far into the future as 10 years (or more) from now.

A potential next chemo to try is Trabectedin (Yondelis), which can also be cardiotoxic... but there is no chemoprotectant for Trabectedin. She has her first appointment with Dr. Eduardo Fernandez this Friday morning. Originally the earliest we could get was at the end of June, but Dr. Musgrave talked to their office and said Teresa needed to get in sooner.

Our understanding is that he will follow and monitor Teresa's treatment from here on out!

Today was labs (bloodwork) and the office visit. Her labs are where we'd expect after Day 1 of this cycle. Because the chemo is helping keep her relatively stable, Teresa will go ahead with Day 8 (olaratumab only) tomorrow afternoon. And get the Neulasta patch to boost her white blood cells. The chemo protocol will not be changed at this time. We will wait and see what

happens with DFCI.

Despite the alarming voicemail yesterday, once we actually got to speak with Dr. Musgrave, we felt much better about the whole thing.

This is not great news, but it is way better than we expected, and we are excited about the possibilities that going to DFCI brings.

\_\_\_\_\_

### **Definitions:**

**Colostomy:** A surgical operation in which the colon is diverted into an artificial opening in the abdominal wall, bypassing damaged colon. The diverted piece is sutured into place. The artificial opening is called a stoma. A small pouch (bag) is placed over the end of the stoma to collect waste products. (If this is done with the small intestine instead, it is called an ileostomy.)

**Urostomy:** The same type of procedure, but for the urinary system.

## Helpful links:

**Dana-Farber Cancer Institute:** <https://www.dana-farber.org/>

## DFCI Sarcoma

**Center:** <https://www.dana-farber.org/sarcoma-and-bone-cancer-treatment-center/>

**Trabectedin (Yondelis):** <https://www.yondelis.com/patient>

(An interesting bit of trivia, Trabectedin is sourced from Colonial Sea Squirts. Yup, you read that right! You can learn more about it here: <https://www.britannica.com/animal/sea-squirt> )

Trabectedin is given over a period of 24-hours via IV or central line (she'd get it in her port, presumably) once per each 21-day cycle.

Dr. Musgrave also offered the names of 2 other chemos that Teresa could potentially try, but as I mentioned before, there's no plans to change anything until DFCI is involved. Those other two chemos are:

**Votrient** (this comes in a pill, not an IV, and patients take 800mg a day, every day): <https://www.us.votrient.com/advanced-soft-tissue-sarcoma/>

**Halaven** (this is an IV, and is taken on Day 1 and Day 8 of each cycle): Do not have a link to share for this yet (just medical journals and clinical trial studies).

## Comments

You are both so strong. Your love for each other, as well as the drive to access the best information for T, keeps adding strength to you both!

—*Marcia Horn, May 23, 2018*

I second what Marcia said! xoxoxo

—*Melissa Fields, May 24, 2018*

Amanda, you probably could easily get a PhD in medicine! Wonderful, clear reports. Most important is how Teresa is doing. What a fighter - and she will win if possible.  
love, Lee

—*Lee Ware, May 24, 2018*

Teresa and Amanda you are both in our thoughts and prayers. Love and hugs to you both. Uncle Frank and Aunt Anne

—*frank wagner, May 24, 2018*

I hate to hear there is growth, but it's always good to hear there is a plan in place. You really do have a gem in Dr. Musgrave!

—*Michele Dillon, May 24, 2018*

I am astounded by the psychic energy that you both have in abundance.  
Please know that you are much in my thoughts. Thank you for keeping us apprised.

—*Sally Treanor, May 25, 2018*

## Cycle 7 (Days 1 & 8) & Specialist #2!

*Amanda Grabler, June 16, 2018*

Apologies for the delay in updating you all about the beginning of Cycle 7. Ran into several non-Teresa complications that kept me from sitting down to write!

Teresa has also updated her blog, which you can [read here](#).

So, since the last time I updated, Teresa had her first appointment with her new cardiologist, Dr. Eduardo Fernandez. We REALLY like him! Very nice person, and he knows we like information, and goes above and

beyond to give it to us. That appointment was the day after Day 8 of Cycle 6. He scheduled her for an echo on May 30.

We weren't going to see him again until after the start of Cycle 7, so I called the cancer center to try to find out the results, or at least get someone to tell me what the [ejection fraction](#) was. As a reminder, that is the main number they check to see if the doxorubicin is causing damage. Hers was 55% the last two times. This time it was 57%! So, that was good news. Most sites (and her doctors) say that normal range is 55-70%.

### **Cycle 7, Day 1 (June 7):**

T's nurses started prepping her for a regular Day 1 cycle (dox/olara). Dr. Musgrave was out-of-town, but there's always a doctor in the infusion center until all patients leave, just in case. A pharmacist too. T was close to her lifetime limit of doxorubicin (if I understand correctly, this dose was either the last one, or the one that would put her over the limit -- it's not uncommon for this to happen, especially in sarcoma from what I've read), so the pharmacy flagged it. The doctor there reviewed it and made the call NOT to give her any doxorubicin.

T said she would do whatever I thought was best. I agreed that it was better to be safe than sorry since her doctor wasn't there, and we hadn't seen the cardiologist yet.

Also, we found out what T was suspecting -- that she needed a blood transfusion. The first one since early January. Her hemoglobin and dropped to 7.9, and anything under 8.0 is considered critically low. Her transfusion was scheduled for early afternoon the next day.

### **Cycle 7, Day 2: Cardiologist**

We met with Dr. Fernandez. He said her echo looked really good. He asked when she usually started to have really negative reactions to the chemo, and T said she doesn't. (This is true. This isn't to say she doesn't have side effects, but they've been really mild. Especially for the "red devil" of chemos!) He told us he's not seeing any markers in her echo that would signify oncoming problems with cardiomyopathy, and the fact that she's had 3 cycles with Zinecard should help. (It doesn't always work for everyone, and doctors/researchers are not clear yet on why this is the case. Doxorubicin, likewise, doesn't always cause a cardiotoxic reaction in every patient - even years later, but it can, so there is a limit.)

Dr. Fernandez said this is the point where we (including Dr. Musgrave) have to decide if the benefits of further doses of doxorubicin outweigh the risk of taking it.

A chemo that Teresa may start next (Yondelis aka Trabectedin) is also cardiotoxic. Teresa asked if that risk was cumulative from the doxorubicin. Dr. Fernandez said it wasn't. He also pulled up a journal to show us a chart about the potential cardio effects from doxorubicin to give us a clearer picture.

Her next appointment with him is in mid July, just before we go to Atlanta, GA, for a Sarcoma conference for patients and doctors. The Sarcoma Alliance is covering the cost of the hotel rooms for the conference!

After we saw Dr. Fernandez, we went to the hospital for the transfusion, where she received 1 unit of blood and enjoyed lunch!

### **Cycle 7, Day 8 (June 14):**

Cycle 7's dates worked out really well! Day 1 happened after our 5th wedding anniversary, and Day 8 fell shortly after T's 50th birthday!

Driving down to the Cancer Center, we had no idea if she would end up receiving the missed doxorubicin now that Dr. Musgrave was back, but she only received the olaratumab. (Incidentally, there are patients who max out on the doxorubicin, and then continue for months only on olaratumab, so the fact that she only received it this cycle is not unusual.) She was very excited because not getting the doxorubicin meant she didn't need to receive the Neulasta patch this time! The olaratumab hasn't been decimating her WBC like the doxorubicin does!

We also received excellent news. In the past, when she got to the point of needing blood transfusions, 1 unit would only sustain her for a week, and then she would need another the next week. We were afraid that would be the case this time. We didn't know how much of the anemia was the chemo and how much was the tumor (despite that growth slowed considerably on this regimen).

So last week, her hemoglobin was 7.9. This week? 10.4. That's not too far from the low end of the normal range! She had a feeling she wouldn't need a transfusion -- she can hear her heartbeat in her ears when she does - but we weren't expecting this much of a jump!! Her other numbers, including her total protein, are going back up too, and her platelets dropped back down into normal range.

Yay!

### **Other:**

In between the end of Cycle 6 and the start of Cycle 7, we worked on getting an appointment with Dr. Suzanne George at the [Dana-Farber Cancer Institute](#). Our patient coordinator, Ellen, at DFCI told us that Dr. George was not taking new patients at this time, but Ellen said she would reach out to see what Dr. George wanted to do with Teresa's case. Dr. Musgrave let us know that Dr. George was not returning her calls (and said it was unusual). When I let Dr. Musgrave know what our patient coordinator said, she told me to go ahead and get the names of Dr. George's partners.

So, I posted to the LMSDR group on Facebook, and asked for people to tell me their \*personal\* experiences with other sarcoma doctors there. I'd already read the profiles on the DFCI site. I wanted to know what the profiles couldn't tell me. Then, once I had the names, I asked again to see if anyone could tell me something about the 2 doctors who hadn't been mentioned the first time.

One of them, we eliminated immediately despite hearing good things about him. This was because he only works 1 hour on Mondays and 1 hour on Thursdays, and books \*way\* in advance. We don't want to wait that long.

The second post brought us information about a doctor who really fit the bill of what we were looking for: kind, smart, up to the challenge of sarcoma, may run late -- but that's because he won't leave your appointment until he answers \*all\* of your questions, gets you copies of scans without you having to ask, sits with you and explains your scan and compares it to previous ones. And has great nurses.

I texted back and forth with Dr. Musgrave, and then made the call to schedule an appointment with Dr. Michael Nathenson. We got in on Monday, June 25th. It's an early morning appointment so we're going to see if it's possible for us to go up on Saturday the 23rd so we're not too tired or rushed come Monday.

We've gone ahead and scheduled her next chemo (Cycle 8 of current chemo or Cycle 1 of new chemo) for June 28th. We're still hoping surgery will be an option, of course, but we don't know if her medical oncologist (Nathenson) at DFCI will want to try her on another chemo first or not. But it's easier to have the appointment and cancel/move it, than try to get one for the date her next chemo would be during that same week.

It is likely that I will not be able to update about what we learn at DFCI until we return, but I will get it up ASAP. (It's much easier to update from my computer than on my iPad.)

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You can read Dr. Nathenson's profile here: <http://www.dana-farber.org/find-a-doctor/michael-j-nathenson/>

## Comments

Glad to hear things have been going fairly well!

—*Michele Dillon, June 16, 2018*

Glad to hear Teresa's numbers are going up and you are in our prayers. Love and hugs.

—*frank wagner, June 16, 2018*

Thank you for your diligence in keeping friends updated, Amanda. I know that writing about this ordeal also helps you to organize the information and think through it. We wish you a very beneficial trip to Boston.

—*Lana Whited, June 16, 2018*

Safe journey on your new phase. Everything seems to be falling into place nicely, thanks to your diligent careful work. Don't forget to take care of yourself, too, Amanda. Love!



—Sally Treanor, June 16, 2018

Thank you for the update!

—jim bier, June 20, 2018

Many hugs to you both on T's encouraging update!

—Marcia Horn, June 26, 2018

## Dana-Farber Cancer Institute: Appointment #1

*Amanda Grabler, June 25, 2018*

Today Teresa and I met with Dr. Michael Nathenson, a medical oncologist and sarcoma specialist. He came highly recommended by another patient of his.

He is kind, intelligent, easy to talk to, willing to explain - in depth - a great wealth of information and provide explanations to our questions. And even some we hadn't asked.

1. Surgery might be an option.
2. If it isn't, Trabectedin (Yondelis) makes the most sense to start next.
3. Clinical trials aren't off the table, but they're better saved until T has tried all the other known chemotherapies, rather than taking a blind chance.
4. Clinical trials would really have to wait anyhow, even if she'd already exhausted her other chemo options, until we get the results back from Foundation Medicine. There's been some hiccups there but her case has now been expedited.
5. DFCI pathology confirms it is definitely myxoid leiomyosarcoma.
6. She is definitively stage 4. The distant metastasis in her case is the secondary tumor next to her liver. Since it was a uterine/pelvic area tumor to begin with, the liver site is distant (abdominal region).

Surgery isn't without risk. The regular risk of any surgery, but also because not only is the primary tumor quite large (again), but a second tumor is very close to the liver. I asked if it was invading the liver or simply next to it. He said it is just next to it, not in it.

Teresa asked for more clarification on the nature of her tumor. The original tumor had enveloped one of her

ovaries, but did not invade it. Dr. Nathenson said there are cases of LMS where it remains in the abdominal area and doesn't metastasize to the lungs, which one of the usual first places it goes. He agrees that the nodule in her lung, is likely scar tissue. Unless it grows larger, or develops spiculations (spikes), they really wouldn't be able to tell because it is so tiny (4mm as of March 1; the May CT simply said "still tiny"). I had begun to speculate about this possibility, and had tried to search about LMS which didn't metastasize outside of the abdomen, but wasn't finding any case studies or journals, so it's good to hear that is an actual possibility.

Dr. Nathenson said we would really need to speak with a surgical oncologist though to determine if surgery is a viable option. Before we left, he went and got us an appointment with [Dr. Jiping Wang](#). Under diseases treated, it says soft tissue sarcomas, but among his clinical interests are issues involving the liver. This makes us even more comfortable given the location of the second tumor.

While we know that he may not feel it is safe to operate at this time, we feel that Dr. Nathenson wouldn't have gotten us an appointment with Dr. Wang if he thought there was 100% no chance of Teresa getting an operation at this time.

A question I have for him is if there is risk of too much bleeding from removing the tumor next to the liver, could they simply resect a margin of the liver, since that organ can regenerate?

I also want to ask why her weight isn't going up as the tumor regrows. This tumor is nearly the size (cm-wise) as the one they took out in August, but her weight is staying stable at her final post-op weight. What's in it? What's different about this tumor that it's nearly 30cm at it's largest point but doesn't appear to weight 32lbs like before? (There is some fluid in the abdomen too, but clearly not 8lbs worth like before.)

There's also risk of extensive bleeding from removing or debulking the primary tumor; as happened the first time. Hopefully this time they could also complete her hysterectomy and remove her cervix. A big advantage this time is that despite having stage 4 cancer, SHE IS IN MUCH better health than she was for her August 25, 2017, surgery. Her hemoglobin, despite still being under the low end of normal, is considerably higher than it was last August. Her other numbers, both on her CBC and CMP have been good, and I don't think anyone would consider her malnourished at this point. Aside from some on/off issues with taste and swallowing, chemo hasn't caused problems with eating. She still has a good appetite.

We will meet with Dr. Wang at 9am on Thursday, June 28th.

We have tentatively scheduled a chemo and office visit for her on July 5, but if surgery is viable, we will reschedule again.

I will update again as soon as possible after the appointment this Thursday.

## Comments

Thanks for the updates, Amanda. We continue to hope for the best possible outcome and send you both love.

—Lana Whited, June 25, 2018

Thoughts and prayers with you both ???

—Jim Constantinides, June 25, 2018

Our thoughts and prayers are with you both.

—frank wagner, June 26, 2018

Sounds as if you've hit a good resource in Dr Natherson. That's quite reassuring. I'm always in awe of the bravery you both portray and how strong you are together. Continuing good thoughts and best wishes!

—Sally Treanor, June 26, 2018

Thank you for detailed update!

—jim bier, June 26, 2018

Looks like you two are making good, positive progress with each new initiative. Really appreciate these very descriptive and helpful updates. Please know that you both are in our prayers with each healing step. With Love and caring ... Uncle Roger and Aunt Patti

—Roger & Patti Ackley, June 27, 2018

Im not the type that prays much, but I am now... love you both, you are both an inspiration.

—Joseph Lorenzo, June 29, 2018

Thank you again for including friends on T's journey! Love you both!

—Marcia Horn, July 2, 2018

## Dana-Farber Cancer Institute: Appointment #2

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*Amanda Grabler, July 2, 2018*

On Thursday, June 28, we had our second appointment at DFCI. This was to meet with oncology surgeon Dr. Jiping Wang. We had high hopes, because why would Dr. Nathenson set us up with an appointment, taking time away from another busy doctor, if he didn't think there was a decent chance that Dr. Wang would agree to operate?

Just in case, we had arguments ready for why now seemed like the best time. (Not to mention that a major part of referring us to DFCI was to find a sarcoma surgeon willing to operate. As a reminder, the gold standard treatment for LMS is surgery with clean margins. Dr. Greene couldn't get clean margins in 2017 because of the risk to Teresa. He did a fantastic job, but he was also a general surgeon, not a sarcoma surgeon. He saved her life in that operation and we're beyond grateful.)

But now she needs surgery again. She has failed 2 chemos and we were hoping to get an agreement on doing surgery before trying a third. Her tumor is nearly as large as it was in August. As she told Dr. Nathenson on Monday, "I'm almost back to how I was in August, except now I'm bald".

Dr. Wang declined to operate. He said it was too risky. We were also left with the impression that even if Teresa came back and presented as an emergency case, just like last year, they still might not operate. I asked what were we supposed to do if her next chemo doesn't work, and she ends up like she did last August, and we're stuck in SWVA, 12 hours from either sarcoma surgeon we've seen. Do we look for the best general surgeon possible and hope he can do it right? (Dr. Greene retired in December.)

I asked the room (at this point, it was Wang, Nathenson, Wang's PA, Nathenson's Resident, and a visiting physician from China), "If this was your daughter/spouse/sister, would you make the same call?" I believe Nathenson when he said he would. Wang said yes, but looked away from me when he said Yes. :-)

So now, we're back in Roanoke. Teresa will start Yondelis/Trabectedin on Thursday. It's a 24-hour infusion, given once every 21 days (same length cycle as before, but only one chemo). I know that sometimes this chemo is given inpatient. The other option is to wear the infusion bag home.

I've asked Dr. Musgrave what her thoughts on inpatient chemo for the first 2 cycles is. The first 2 cycles of chemo are when you are \*most\* likely to have a reaction. If she wears it home and has a problem in the middle of the night, we're 30 minutes from the hospital!

I've also asked about getting T's next CT scheduled before Thursday, so unlike with Dox/Olara, we'll have a baseline scan immediately prior to starting Yondelis. And we let her know that T is concerned that this CT may also show that she needs another thoracentesis (or two) done. (Reminder: A thoracentesis is an outpatient procedure to drain fluid off of the lungs.) She is having trouble taking deep breaths again, and is easily winded. It's either a medium-to-large pleural effusion on one or both lungs, pressure from the tumor (which feels higher up to T), or a combination thereof.

Dr. Musgrave wrote me back after business hours yesterday (Friday), and said she will take care of the

scheduling on Monday.

### **Options:**

I told T that no matter how great DFCI is supposed to be, if they are too nervous to operate, these aren't the doctors she wants operating on her. When we saw Dr. John Kane in Buffalo, NY, he said he didn't want to operate at the time, but "never say never". He would operate if the tumor became obstructive or if it became a quality of life issue. T thinks it's definitely a quality of life issue. In addition to breathing trouble, she's having trouble sitting up again, and her back pain has returned.

If the tumor is putting pressure on her lungs, it may also qualify as an obstructive issue.

Since Yondelis is the next line chemo for T, it is likely he would want to see at least 2 cycles worth of data on Teresa trying Yondelis. So we're going to try that. And then I am going to contact Roswell Park and see if I can send in this next CT and the one following 2 cycles (Nathenson recommends scans every 2 months instead of waiting 3), and see if he would be willing to meet with her again.

Given that this coming week has several appointments happening, I will probably wait to update again until next weekend (July 7 or 8) at the earliest.

Please let us know if you have any questions.

### **-----Donations Reminder-----**

If you are trying to / wanting to donate specifically to Teresa, please visit <http://teresa.grableronline.com/help-me/>. If you use the donation/tribute options on CaringBridge (CB), you are donating to CB. They get the money, not Teresa. I know this has caused some confusion in the recent past, and since CaringBridge just did another big fundraiser where CB makes it look like you're donating to your friend/loved one, but you really aren't, I thought this would be a good time to post this again.

## **Comments**

Some people have no issues with Yondelis. I hope Teresa is one of those. (she's handled others well, so probably is!) However, if she experiences nausea, ask for Varubi the next cycle. Sorry DFCI was not what you had hoped.

*—Michele Dillon, July 3, 2018*

Sorry to hear this news. Hope the next treatment has benefit.

—Lana Whited, July 3, 2018

Good Morning my dear ones. It seems like your hopes have a cloud over it now. However, keep looking for the sky to get clear and a ne day to begin. My love and prayers. Ellie

—Ellie Novak-Scofield, July 3, 2018

I am sorry the docs weren't able to respond positively to your needs. I hope the next therapy yields some improvement.

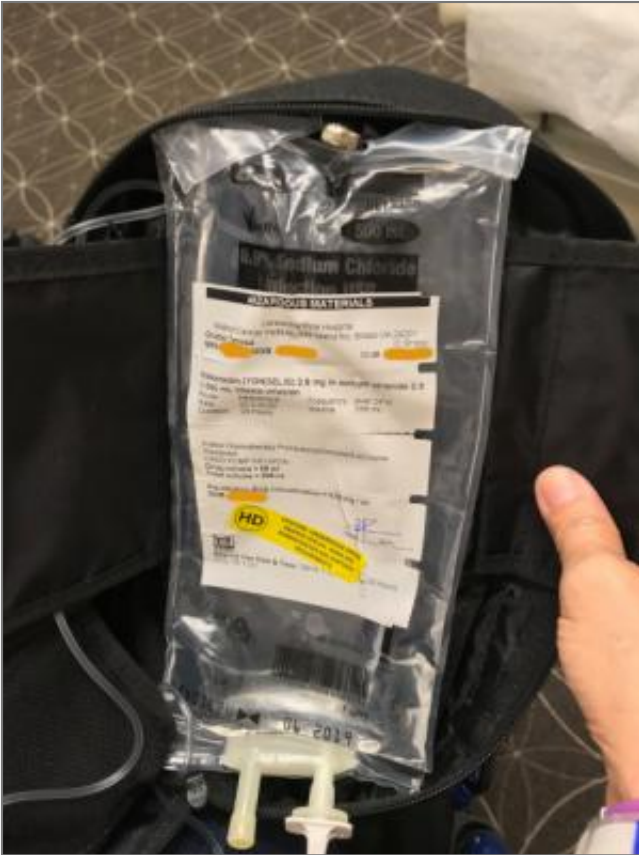
—jim bier, July 3, 2018

Dears! How frustrating! But how heartening that you are looking at this news as an opportunity to explore different solutions. You continue to gain my admiration for how strong you are as a team and how well you apply your intellectual gifts to proceed. You never lose focus. Love you both. Good job!

—Sally Treanor, July 4, 2018

## The Week of Yondelis

Amanda Grabler, July 9, 2018



The first week of July was a busy one for us!

Here is how our schedule went:

**Monday, July 2:** Received call from Dr. Musgrave's NP in Norton, VA, that a baseline CT could be set-up for Teresa, and that someone from Bristol would be calling us to set-up a time. Also, that her pre-meds had been called in. (Prednisone, taken at 13 hours, 7 hours, and 1 hour pre-CT, plus OTC\* Benadryl and hour before.)

Next, Laura called from the Cancer Center, to give us the time of T's CT - at Volunteer Parkway. I thought this was odd because we were told it had to be at the hospital from now on, but I thought maybe since the premeds are handled by us, it was okay. The CT was scheduled for 10:45am, and the Parkway location is further into TN than the hospital is.

Also, there was no way we could go down Tuesday morning and get the Prednisone in time, so I had the prescription transferred to a CVS in Roanoke. Then we had dinner and got packed up, and she had her first dose, and we left close to midnight.

**Tuesday, July 3:** Early this morning, Imaging Center on Volunteer Parkway calls to tell us they've moved her to the hospital for 11am. Even though T took her pre-meds herself, when a patient is pre-medicated, there must

be a radiologist on hand, and the Imaging Center didn't have one on hand.

Luckily, they got hold of us before we drove all the way down!

So, now we're at the hospital for her CT. We wait for maybe 10 minutes, but she goes back relatively quickly. T had been having a LOT of trouble breathing. She'd been very winded. I had listened to her breathing and her breath sounds on her right side were decreased to the point of being absent. It also felt like her left lung was being crushed if she tried to sleep on her left side. She couldn't get up 1 flight of stairs without wheezing.

We suspected she needed another thoracentesis done, at least on the right side. (Her breathing on her left sounded deep, and loud, but in December, she had to have one done on each side.)

Teresa talked to the nurse during the CT and told her how hard it was to breathe. The nurse said she'd have a radiologist look at the scans right away. 1 - 1 1/2 hours later (it was very fast), they had everything arranged through Dr. Musgrave for T to have a thoracentesis. It was all done shortly after 1pm.

They drew 3 liters off\*\* of her right lung. Or, for visual which has helped several people we've described this to, approximately 8.5 12oz cans of soda.

They couldn't get all of it, because she started coughing too much, but the radiologist who came to talk to us said they really got almost everything. He also showed us with his fingers about how much lung she had available before -- a measurement about 2 inches long and 1 inch high!

A sample of the fluid was sent to pathology to see if there were any malignant cells in it. We're still waiting to hear. (I think the mid-week holiday threw everything off.)

**Wednesday, July 4:** This was a relaxing day for us since the cancer center was closed.

**Thursday, July 5:**

- Labs: 8am
- Office Visit with Dr. Musgrave: 8:40am
- Chemotherapy: 9:15am

Of course, things rarely run on time. Labs are often slow to go out to the doctor, even though they do them in-house. And since it was the day after a holiday, they were very busy (many extra patients who had to move from Wednesday to Thursday).



But eventually everything got started. Chemo Education for the new chemo was done at the infusion chair. I already knew everything they told us about the chemo, thanks to the [ChemoCare](#) site and the Yondelis site which offers a video to watch about how 24-hour outpatient chemo works. [You can watch a virtual infusion here.](#)

Thanks to my parents, we stayed in the Fairfield Inn across from the hospital on Thursday & Friday nights. This way, we were only minutes away if Teresa developed an infusion reaction (which thankfully didn't happen).

Early Thursday evening, our friend, and T's PCP (and my Abingdon-area PCP), Sally Blackburn, came by our room to see us. It was really great to see her! She's truly one of the kindest people you would ever meet!

### **Friday, July 6:**

At 10:30am, we had an appointment with one of the Palliative Care NPs. We talked to her about T's pain, got new prescriptions, and asked about any exercises she can do which won't do more harm than good.

She'd been scheduled to have her Yondelis pump removed at 11:30, but the infusion hadn't started until around 12:30p the day before, so it was still running. We left to get something to eat. When the pump beeped to let us know it was finished, we headed back.

I'm including photos on this post so you can see what the infusion bag, pump, and chemo look like. Not pictured are the bio-hazard waste bag and the instructions they send you home with on how to clean up properly if there is a chemo spill. We're both very relieved we didn't need them!

But when we went back, we found out that the Neulasta approval had expired in June, so they were waiting on a new approval. It still hadn't come through by the time the chemo was undone, so we went to do errands. We were working with Nurse Tonya, and she estimated 3p, but I left her our cell number in case it was earlier.

About 10 minutes into my walking around Food City (grocery store), she called to say it had come in, so we headed back and got the Neulasta patch applied!

It was a very busy week! We stayed one more night just to be safe (and to avoid having to drive back up 81 to Roanoke in several nasty thunderstorms). Then left Saturday, early enough so that Teresa would be resting comfortably on the couch, or in bed, when the Neulasta patch started dispensing.

So far, she has had mild nausea from this chemo, and for several more days than she'd had nausea in the past. She's taking Zofran, which is helping.

In addition to waiting to hear about the results of the pleural fluid, I asked Dr. Musgrave this morning about getting Teresa scheduled for a paracentesis. We had discussed the possibility with her on Thursday. She has an appointment the morning of Friday the 13th. Dr. Musgrave's nurse in Bristol, Cathy, called to let me know the date/time of it just a few minutes ago. She said T should have a similar recovery time to this as she did the

thoracentesis.

This procedure is similar to a thoracentesis, except it would remove fluid from her abdomen. This should help alleviate a fair bit of pain and pressure, and hopefully reduce the size and distension of her abdomen. We hope that this will also help reduce her back pain. Dr. Musgrave says it should.

If you're so inclined, you can watch a [paracentesis performed here](#), if you want to know what it involves. It is done outpatient.

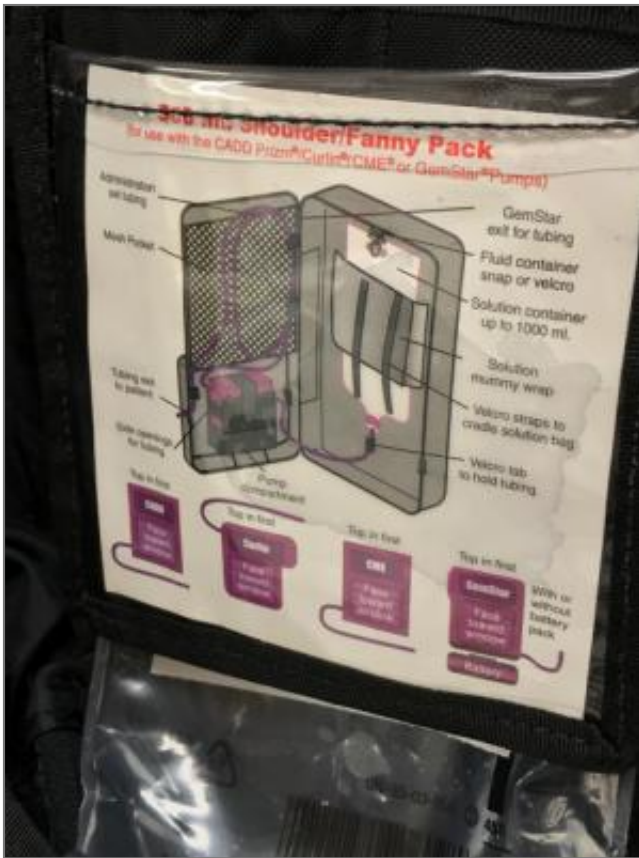
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\*OTC -> Over The Counter / Non-Prescription

\*\*As a reminder, the [pleural effusion](#) is in the pleura which surrounds the lung and lines your chest wall; the fluid is not IN the lung.

YONDELIS® (trabectedin) is indicated for the treatment of patients with unresectable or metastatic liposarcoma or leiomyosarcoma who received a prior anthracycline-containing regimen. (Doxorubicin is an anthracycline.)

## Photos









## Comments

Teresa is still smiling and brave, a winner. She'll persist until she has beaten the cancer, with Amanda's amazing dedication to Teresa.

Lee Ware

*—Lee Ware, July 9, 2018*

Thanks for keeping us updated. Glad you got some down time on the 4th!

*—Lana Whited, July 9, 2018*

You two could be training for a marathon. Thanks for the update and all its intricate detail. Your spirits are so focused and embracing of all you need to know. Loving you both.

*—Sally Treanor, July 10, 2018*

## Paracentesis & Sarcoma Conference

*Amanda Grabler, July 18, 2018*

On Friday the 13th, Teresa had her first paracentesis done. We were hopeful there would be a lot of fluid to pull, which would both help reduce her back pain, and reduce the size of her abdomen.

Unfortunately, there was only about 1/2 a liter in there (1 pint, 1/2 a quart, 16 ounces, 33 tablespoons, you get the picture).

We still think that finding a surgeon who will operate, even if they just consider it a palliative operation, is probably going to be her best pain-reducing option.

But it's unlikely anyone will be willing until she's got at least 2 full cycles of Yondelis accomplished, and another CT done. So... that's a waiting game.

Of course, what would be fantastic is if Yondelis is the magic chemo, and the tumors start shrinking (which would also make surgery easier and safer).

We're still waiting to hear from Foundation Medicine (long story), but I can at least tell you that her tumor sample is actually in \*active testing\*. I'm hopeful that we'll hear by the end of next week. They'll email me the results, so I don't have to wait until we see Dr. Musgrave to get them.

Tomorrow (well, okay, later today, in about 13 hours), Teresa has a check-up with her cardiologist.

This Friday, we will drive to Atlanta, GA, to attend the first conference by the Sarcoma Alliance. There is no fee to go, and they're paying for the hotel rooms! Although they don't have the finalized schedule up, you can get an idea of what we're going to get to do if you visit this link: <https://sarcomaalliance.org/event/sarcoma-exchange-2018/>.

We hope to learn helpful things and we're looking forward to meeting some of the people we've met through the LMS Facebook group.

## Comments

You are always productive, even while you wait. Safe journey.

*—Sally Treanor, July 18, 2018*

Safe travels!

—*Jim Bier, July 18, 2018*

Love and strength to you both!

—*Marcia Horn, July 18, 2018*

I'm so glad you have the conference opportunity and hope you learn a lot and expand your network of experts and those whose experiences are similar. (And if you have any free time, the Carter Center is a great visit!)

—*Lana Whited, July 19, 2018*

## Yondelis Cycle 2 (and cabbages and kings)

*Amanda Grabler, August 1, 2018*

On July 26, Teresa started her 2nd cycle of Yondelis. Her CBC was good (as always, some numbers in the low range, like hemoglobin, but not horribly so (10.2 - as a reminder the lowest end of normal is 11.7). In turn, of course, RBC is also low, but not too badly. Her CMP was good. Protein is still a little low but is not off by too much.

Since she had nausea the first week of cycle 1, I asked if she could have Emend this time too, like she did with the Dox/Olara (Aloxi+Emend to help prevent both immediate and delayed nausea). Cycle 1 she just got Aloxi.

Her insurance approved it immediately (within 30 minutes I believe), so she got both drugs. She also has zofran (1 every 8 hours) and compazine (1 every 6 hours) to take at home.

Unfortunately this time, she had Breakthrough Nausea, which is nausea that happens within 5 days of the infusion. And it hindered her ability to eat and drink, which made dehydration a risk. With this chemo, she was told to drink at least 3 liters of fluid a day. She wasn't getting close to that.

We're in Roanoke, so a 2 1/2 hour drive down to the cancer center and/or hospital would have been a terrible experience ... for both of us. So I double checked and confirmed that Lewis Gale Medical Center (hospital) was in network. Then I called the cancer center and spoke to one a nurse.

**Lots of back and forth, so here's a summary of events:**



1. Phenergan gel (to help with nausea) called into CVS.
2. CVS Pharmacist calls me to tell me it's a compound, which they can't do. She called it into West Pharmacy in town, as they do compounds, but they can't take the insurance for this compound because of some licensing restriction and the closest pharmacy that could is in Richmond, VA. (This is not close. We might as well go to Bristol!)
3. CVS pharmacist tells me without insurance West Pharmacist estimates \$40-\$45 for the dose prescribed, but it might be higher. But that the Rx is written wrong and he can't do it as ordered.
4. Nurse calls me back while I'm talking to CVS Pharmacist. I explain the situation. She says it's peculiar because no other pharmacist has had any trouble with the same order, but she'll call West directly and talk to the pharmacist for me. In the meantime, she has sent orders by fax to Lewis Gale to draw port labs and do fluids if necessary. We can go any time.
5. I update my 3" 3-ring binder of T's medical records just in case LG needs anything (medicine list, treatments, etc), and we get ready to go.
  
6. We stop at West Pharmacy on the way. Pharmacist says no one from the cancer center ever called him and he can't help me. He does offer phenergan suppositories. I refused.
  
7. We're told to go directly to Labs at the Hospital.
8. Labs sends us back to Admissions.
9. Admissions people are fantastic, but it takes forever. The order isn't right. Something special has to be filled out for port labs so pharmacy can authorize the heparin flush, and so forth. Admissions gives me a form to take back to our cancer center so that Dr. Musgrave can authorize a standing order for pharmacy so that if this happens again in Roanoke, there won't be any issues.
10. Teresa agrees to have a the labs drawn from a vein and we head back to labs.
  
11. While we wait on results, I call the Wellmont Triage line and eventually get a nurse who leaves a message for an oncology nurse to get back to me about the gel (West Pharmacy is now closed).
  
12. Everything goes fairly smoothly until the lab techs panic when her WBC comes back at 48 (normal range is 3.5 - 11.0). We apologize for forgetting to tell them she just received Neulasta and it should be elevated. They are MUCH relieved!
13. We get her labs back. NOT DEHYDRATED!
14. Also, her liver enzymes are considerably elevated, and her kidney function is slightly decreased, but we know from a mid-cycle CBC/CMP we had done in cycle 1, that this happened before. We decide not to worry about it unless we hear otherwise from Wellmont or the numbers are still high on August 16 when she's due to start Cycle 3.
  
15. I talked with the oncology nurse as we leave the hospital. She says she'll see what she can do.
16. Minutes after we're back at the house, she calls to tell me she found another compounding pharmacy in Roanoke. They close at 7. It's 6:30, but they promise to fill the order for me. She gives me the name and number. They're 30 minutes away in Botetourt (north of Roanoke) County. Yikes!
17. I call the pharmacy. They tell me to bring a check so the pharmacist can just hold onto it for the next day.

He'll be having dinner at the deli next door, and will have the script ready for me.

18. And remember how the West Pharmacy estimated a minimum of \$40-\$5 for it? Still without insurance, I paid \$11.69 to Down Home Pharmacy. They're a family owned pharmacy. Incredibly kind people. I got there at 7:09 and he came over from his table and explained the dosing worked and how to administer it. If you're in the area and need a compounding pharmacy, I definitely recommend them!

19. One of Dr. Musgrave's nurses calls me today to let me know they're not concerned about the liver enzymes since it can very well be from the chemo and not something actually wrong with her liver. (One of the tumors is situated very close to the liver, but so far has not caused any obvious problems.) The Yondelis paperwork from Dana-Farber Cancer Institute specifies that elevated liver tests can happen with this chemo. So we'll see how it is on the 16th.

Last night the nausea hit the worse point and progressed to vomiting; thankfully short-lived. She's feeling better today, though still having some nausea, and dizziness if she bends over. We're really hoping that this will ease off as we head into week 2 of this cycle over the weekend.

If you haven't checked out Teresa's blog yet, she'd love it if you did. I've set-up multiple ways for you all to leave comments. Hearing from friends and family REALLY lifts her spirits. While her blog does have a summary-timeline, research info, and so forth on it for easy reference, the blog itself is not medical updates like what I share with you here. Several of you said in the past that while you really like getting these updates, you would LOVE to hear from Teresa. The blog is a great way to do that. You can access it at <http://teresa.grableronline.com>

We know it's not practical for everyone to visit, but if you can, she really does love getting to see people. Cancer can be very lonely. We both also realize that visiting can seem awkward the first time because cancer is very scary, and maybe you're not sure what to say? What's okay to say? If it's okay to ask questions?

Teresa is letting me post "From the Caregiver" posts on her blog, and I wrote something about this topic, called [When a Loved One Has Cancer](#). It's based on our own experiences as Teresa struggles with cancer, and also our experiences when we were the ones visiting and/or working with someone struggling with cancer. We hope it will help you see things from another perspective and help you make that decision to visit sooner than later, or if visiting is not feasible at this time, to reach out to her on the phone. Or on Facebook Messenger. (Tip: she's not super fast with email, so it's the last option I'd recommend! ?)

Teresa is *very* easy to talk to, whether it's about cancer, childhood memories, or what she's been watching on TV.

As always, please feel free to ask me questions if you don't understand something in my updates. You can ask in comments or privately (email, FB message, texting, etc). I will always respond to comment-questions

privately, unless I think it's something everyone would benefit from knowing. In which case I'll address it in my next post.

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**Glossary:**

CBC = Complete Blood Count

RBC = Red Blood Cells

WBC = White Blood Cells

Dox/Olara = 2nd chemo regimen, made up of Doxorubicin and Olaratumab

## Comments

Teresa and Amanda you are both in our prayers. Thanks Amanda for keeping us posted on what is going on. ??

—*frank wagner, August 1, 2018*

Love you both! Thoughts with you every day ??

—*Jim Constantinides, August 1, 2018*

I just finished reading T's and your journey, and I'm amazed. She's a fighter, and I'm so happy she has you by her side. Much love to you both!

—*Michelle Brazeau, August 1, 2018*

Ask about Varubi. It is the only anti-nausea that worked for me. My Dr and I discussed it a while back, and I am not get only patient that feels this is a miracle drug.

—*Michele Dillon, August 2, 2018*

Poor girls, constantly fighting the cancer. If I were visiting, I'd want to read short stories to them. I'll send you one called "Morsi the cat", from the New Yorker. It takes your mind off the bad things for a while. The British couple stays in Cairo for about a year and, having mice in their apartment, they get an Egyptian cat, which the writer called Morsi. Morsi is the name of Egypt's president. It's amusing and interesting. I'll look for your email address.

much love, Lee

—*Lee Ware, August 2, 2018*

Glad to hear there are still some caring people out there like the pharmacist at Down Home. Hope it worked. Our thoughts and prayers are with you both. Again Amanda thanks for all you are doing.

—Christine Daly, August 2, 2018

You are both incredibly strong and you will continue to be in my prayers.

—jim bier, August 6, 2018

## Yondelis Cycle 3 (And Everything in Between)

*Amanda Grabler, August 19, 2018*

So, a lot has happened over the last 18 days (last post 8/1/18).

For those of you who don't know, Teresa was employed by K-VA-T Food Stores, Inc., when she got sick last year. She's been with them since May of 2000. She worked at the Help Desk in the Corporate Office, in Abingdon, VA, since October 2003. K-VA-T held her job for 1 year to see if she would recover from an incurable cancer and become NED (No Evidence of Disease; as opposed to remission in other cancers). It is not an impossibility; we know many LMS survivors who have been stable for years. Unfortunately, Teresa has not reached that point yet. The first 6 months she was on short term disability from work, and received 60% of her regular pay. That ended around February 25th.

Then she could take 2 90-day periods of unpaid leave, but her insurance would have to be paid at full cost out-of-pocket and upfront of each 90-day period. We were told this covered medical, life, and dental. With 2 weeks left to go this month, we found that the eye insurance policy was still active. If you're being treated for cancer, make sure you have eye insurance. Steroids, especially if you're on them long-term, can put you at risk for developing cataracts. But we learned that from a friend of mine who ran into this problem while taking steroids for another issue. Not from the cancer center. And I don't remember reading anything about it any of the "Things I wish I knew before chemo" posts we've read either.

So... hopefully none of you will need it, but if you're taking steroids, get your eyes checked regularly. I was able to get Teresa an eye exam last week and besides needing new glasses, the doctor said her eyes are fine! (Phew!)

Anyhow, so with August 25th looming on the horizon, we had to make a decision about if we thought she would be able to go back to work or not. (We actually started thinking about this well ahead of time in June, but have been discussing it mostly privately with people who have SSI/SSDI experience and could advise us best.)

With 2 failed chemos and no certainty about the 3rd, and an aggressive cancer center who declined to operate,

we came to the consensus that Teresa would not be able to go back to work come August 25th (Dr. Musgrave would have had to clear her too).

Not going back to work would mean Teresa would have to be able to afford COBRA to keep her insurance, and from personal experience, I knew COBRA can be ridiculously expensive. We still don't know how much it will run. When her end-date with K-VA-T syncs into BCBS of TN's system, the insurance company will generate the COBRA papers to go out. We expect to receive them some time the last week of August.

With no income since February, and no chance of returning to work, we started to apply for SSDI. T's good friend Maria helped us initially. She tried to file online, but that wasn't an option for Teresa's situation, and we got a phone appointment. (And you all know how much I love the phone!)

Shortly after that, we had a visit from Teresa's PCP and she advised having the SSDI interview in person so that they could actually see how Teresa looked. Her abdomen was becoming quite distended (this was early July) and unfortunately, it has just grown larger since.

I got our phone interview switched to in-person. This meant we wouldn't have the interview until Monday, August 6, but it seemed worth the delay.

We worked with an extremely nice woman at SSA to get everything filed for Teresa. She was approved within 3 days -- and has already received her back pay. The first 5 months don't count, so she became eligible for pay starting in February, and she will see her first monthly check in September.

On Tuesday, July 7th, we met with Teresa's supervisor at K-VA-T, and an HR Specialist, to confirm that Teresa would not be returning to work, and to find out what we needed to do to have the transition of leaving be as smooth as possible, to find out what policies could be rolled into individual ones, learn about how we got the COBRA paperwork (as mentioned above), and so forth.

On Wednesday, August 15th, Teresa had an echo to check how her heart is doing, primarily her ejection fraction (how much blood is pumped out of the left ventricle with each beat), as Yondelis is another cardiotoxic chemo.

When T had her first echo, her EF was 55%. Now it is 59%. The toprol she is taking may be a factor in the improved number. As long as the EF stays between 55 and 70%, she's good in that regard.

On Thursday, we went to the Cancer Center. Her labs were fine for starting Cycle 3 of chemo, but Dr. Musgrave noted that T had decreased breath sounds on her right side again. T told me she'd just started to notice the night before that it was hard to breathe if she rolled onto her left side -- a sure sign to her there was another pleural effusion. But she hadn't really been having trouble breathing, so it *couldn't* be as bad as before (3.1 liters) right?

Nope. But it could be worse. ?

Dr. Musgrave arranged for us to go over to the hospital to radiology to have a thoracentesis first, and then come back for chemo.

They took out 3.3 liters, making Teresa 7.6lbs lighter than she was that morning.

This is what is called a large-volume thoracentesis. They probably could have gotten more but T was coughing a lot by that point. There is risk, as any of you in the medical field know, about removing a LOT of fluid in one ago and the risk of re-expansion pulmonary edema . . . although it could also be said that 1 large draw would be safer than multiple small draws. So....

In any case, her breathing has become substantially better and she can see the difference on the incentive spirometer. She also saw an immediate difference with her pulse ox. I want to get a pulse oximeter for home use to have another way to keep tabs on future pleural effusions. Can anyone recommend a good brand? (I'm particularly interested in ones which will sync up with an app to keep accurate logs.)

A sample of the pleural fluid was also sent to cytology. We're still waiting on the results.

Then we went back to the cancer center for her chemo. Dr. Musgrave wrote her a 3-day prescription of dexamethasone (steroid) to try to help boost the staying power of the anti-nausea meds Aloxi+Emend. Sunday was her first day of breakthrough nausea in Cycle 2, so we'll see how things go (fingers crossed!).

Next week, on Wednesday the 22nd, we'll take a day trip down to see her cardiologist, Dr. Fernandez, to follow-up on the echo. In our last visit with him, he prescribed furosemide (Lasix) as needed to see if it would help with fluid build up. I'm going to ask about him prescribing it as daily or every other day, since usually by the time T realizes she's having build up, it's already large enough to warrant a thoracentesis. (And the less times she has to have a catheter and tubing in between her ribs, the better.)

Many of you have asked about her next CT -- the moment of truth scans which will tell us if the Yondelis is working or not. Dr. Musgrave wanted to get it done as close as possible to Cycle 4 to give this cycle as much time as possible to work. But the closest we could get an appointment is August 31. Because T has to be pre-medicated for the CT (due to a contrast dye reaction), she can only have it done in the hospital (not the imaging center), which reduces the number of available dates for testing.

We'll go down on the 30th and come back up on the 31st after the CT.

And then we'll return again on the 5th, unless Dr. Musgrave texts or calls to let us know we need to come down sooner -- this has happened before when a previous CT showed progressive disease.

In the midst of all of this, we finally got the results back for Foundation Medicine. Rather, I got them because I

called on the day I'd estimated we'd get them back after the last delay, when nothing showed up in my email. I'm told they were sent, but they sent them again - I got the second one. They never sent anything to Dr. Musgrave! So I sent her the results instead.

This test was to find out if her original tumor had any genetic mutations which were associated with targeted therapy drugs.

Teresa's tumor tested positive for 5 genetic mutations. **With zero available FDA-approved options for leiomyosarcoma.**

One of the 5 mutations had 2 FDA-approved options for another tumor type, and then 8 clinical trial options were given for that mutation.

If you're curious, the mutation is MET D1010E:

**Gene and Alteration:** MET encodes a receptor tyrosine kinase, also known as c-MET or hepatocyte growth factor receptor (HGFR), that is activated by the ligand HGF; MET activation results in signaling mediated partly by the RAS-RAF-MAPK and PI3K pathways to promote proliferation<sup>1,2</sup>. Alterations such as seen here have not been functionally characterized and are of unclear significance. However, similar alterations have been reported in the context of cancer, which may indicate biological relevance. Multiple MET activating alterations have exhibited clinical sensitivity to a variety of MET inhibitors in multiple cancer types<sup>3,4,5,6,6,7,8,9,10,11,12</sup>.

**Frequency and Prognosis:** MET amplification has been reported in 2% of sarcoma cases in the

MSKCC/Broad dataset<sup>13</sup>. MET amplification has also been reported in 20% of malignant peripheral nerve sheath tumors (MPNST)<sup>14</sup>.

*There's a lot more information about this mutation, but I'm sure it won't mean anything to most of you. If you're in the medical field and interested to read her report and give me your thoughts, please let me know!*

The two FDA-approved therapies listed for other types of cancer are called: Crizotinib and Cabozantinib. If I remember correctly, Dr. Musgrave sounded more interested in the Cabozantinib.

An earlier, short report from Foundation said that T's tumor is completely negative for PDL/PDL1 making her unlikely to respond to immunotherapy drugs like Keytruda, but that PDL/PDL1 can be an inaccurate bio-marker and I've read reports about people being negative for the marker but still responding well to Keytruda...



Of course, we're hoping that the Yondelis will be the third time's the charm drug and she won't need a clinical trial.

After I got the report, I emailed Dr. Nathenson (Boston, Dana Farber Cancer Institute) and asked if I could send him the report for his insight. He agreed. I sent it along with some questions. He called and discussed it with me for 10-15 minutes, told me I had good questions, and answered/explained several things.

He said while it's unlikely that Teresa is carrying any of the genetic mutations herself (probably just in the tumor), it's not 100% impossible and a genetic counselor could help with testing Teresa. Dr. Musgrave is referring us to someone in Kingsport, TN.

Also, cancer is a clonal disease. Therefore, the tumor(s) will always retain the original mutations that caused the disease to happen in the first place, **but** the regrowth and any new tumors could develop other mutations (which may or may not be targetable). But unless we can get someone to operate, there's no way to test the regrowth or the new tumor and nodules for mutations because a biopsy on LMS could be just as risky for spreading tumor bits (by penetrating the fragile outer layer) as a surgery that doesn't remove the tumor intact).

I think that's everything we've been dealing with.

I know it is a LOT of information. And honestly, there's probably more that I'm forgetting.

If you have any questions about anything, ask!

If you're in a medical field and want to read her Foundation One report and get back to me on any insights, please ask!

**There are no silly questions.** This is a lot of information to process, especially for those of you who haven't gone through something like this. If you don't want to ask something in a comment for everyone to see, please feel free to send me a private message via CB, in [regular email](#), or in PM on Facebook. Or text me if you have our phone number. I'll get back to you as soon as possible.

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In non-medical news, Teresa is working, albeit slowly, on a post on [her own site](#) about things she enjoys doing since some of you have been wondering. :-)

## Comments

Love you both and I pray for you every day. I know you will win you battle T, you are as strong a person I've ever known. ???

—Jim Constantinides, August 19, 2018



Hugs always to you both!

—Marcia Horn, September 5, 2018

## Thoracentesis Cytology Results, Chemo & CT Results

Amanda Grabler, September 5, 2018

For the last several fluid draw procedures (thoracentesis, paracentesis), either they didn't get a good reading in cytology and couldn't say if there were malignant cells, or they didn't send the sample to cytology at all. For Teresa's 8/16 thoracentesis, we got good news: Negative, no malignant cells! **PLEASE NOTE:** This test was JUST for the fluid (pleural effusion) around her lungs! It does not mean the cancer is gone.

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Yesterday, however, we learned that the CT shows increased disease. We haven't seen the report yet, so I don't know if it is with all of the tumors or just some of them. Or if there are even more tumors. But it's not good news. We haven't really reacted to it emotionally yet.

Dr. M told us we will need to come with a new game plan. We see her in the morning to discuss that. There's one regular chemo left that's been suggested: Votrient (Pazopanib). It's an oral chemo. From what I know of it from others, it's more geared towards stability than shrinkage. And I think it's the one that turns your hair and skin very white.

But the 3 of us are all pretty much in agreement that it seems like T would have a better chance with chemo if there wasn't so much tumor for the chemo to have to work against. So we're all pushing for a surgical option. I want her to have surgery (she's wanted it since last September) and I'm *terrified* for her to have another surgery. Last August, there was very little time between the shock of "it might be cancer" to "being wheeled down to the OR," and, thus, very little time to think about it (and overthink it) and process.

Now there's LOTS of time for that. :-(

Tumors aside, though, Teresa is in way better shape than she was in August, so logically it seems like she should handle this surgery even better than her first one. But I'm still a huge ball of nerves and anxiety and tears thinking about it.

Dr. Kane in Buffalo, NY, at Roswell Park Cancer Institute declined to operate in February, but said he wouldn't rule it out forever. He has many good reviews. He was very nice. He spent a lot of time talking with us. We

liked him.

In the LMS group we're in online, another LMS patient described a surgery which was much more extensive than Teresa's initial operation. I asked where she had it done, because these surgeons sounded like the ones we need for Teresa. She told me Duke. And that the entire experience was wonderful. She's since written me privately to give me names of who to ask for at Duke.

There would certainly be a large benefit to only being 1 state away from home, instead of 4. But we have family in NY, and not in NC.

I asked Dr. M what she thought, and she told me to reach out to both, so I will. And I'm going to ask what kind of surgical plan and team each place would be able to put together for Teresa, to help the 3 of us decide.

Tomorrow we will go to the Cancer Center to get her labs done, and to have the appointment with Dr. M. We don't think she's having chemo at all tomorrow. If not, then that tells us right away that it wasn't even slowing the growth of any of the tumors.

T speculates that maybe she was always meant to have the surgery, and that's why every chemo has been a fail.

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Also, last week we met with a Genetic Counselor in Kingsport, TN. She took a family history, and had a blood draw done. She will be looking for DNA mutations which could indicate the cause behind the leiomyosarcoma, although it's likely it was just random chance. But the tests could also shed light on if there's anything else we need to be aware of, and if any of Teresa's immediate family should have any testing done too. We should have the results of that in a couple of weeks.

## Comments

Prayers every moment for you both ???

—*Jim Constantinides, September 5, 2018*

Hang in there - sending love, prayers & hugs.....

—*Kim Eller, September 5, 2018*

Your mountain never seems to level off. You both continue to be in my thoughts and prayers.

—*Sally Treanor, September 6, 2018*

Continued prayers.

—Melinda Davis, September 6, 2018

I hope a plan evolves very soon for Duke or NY, lots of positive thoughts, energy ,prayers and HOPE coming your way!???

—Sue Harris, September 6, 2018

Remembering how exhausting it all is and admiring how tough you guys are.

—Margaret Frey, September 6, 2018

Continued prayers for you both.

—Joyce Reynolds, September 6, 2018

I am so sorry to hear this. Pinning my hopes on surgery. Love you!

—Heidi Baird, September 7, 2018

## Thoracentesis, COBRA, and Referral to Duke Cancer Institute

*Amanda Grabler, September 9, 2018*

**Thoracentesis:** September 6, 2018, would have been her next day for chemo, but since the CT showed it wasn't working, she didn't have that. She did, however, get to have another thoracentesis. They took another 3 liters off her right lung and sent a sample to Cytology. As a reminder, that's about 7lbs.

Teresa's last day of work was August 25, 2018, but her employer policy became inactive on August 24, 2018. We didn't find that out until September 6, when she went to have the thoracentesis, and we had to sign a self-pay guarantee for not having insurance.

I called BCBS TN and they spoke with the woman registering T in Radiology. Once COBRA was elected and the policy reactivated (with no lapse in coverage dates), we would be able to calling billing and have them resubmit the procedure.

I guess the policy retro-deactivated on the 24th when BCBS received the termination date (from K-VA-T) on

September 5th, because we didn't have to sign a self-pay agreement for her CT on August 31. That's a relief too, since a CT costs a LOT more than a thoracentesis. (CT runs about 7K.)

In any case, we were told we would get the COBRA forms in about 2 weeks. Which wasn't a long time. But this abruptly became a problem when the wonderful women at the Wellmont Cancer Center worked to get Teresa an immediate referral for surgery at Duke Cancer Institute (North Carolina) and Duke said they couldn't accept a referral for a patient with an inactive insurance policy.

I woke up to a voice mail about this on Friday. I called\* the direct **COBRA** number I'd been given the other day. Long story short, I got them to expedite the processing from 2 weeks to 24-48 hours, and they would send me an email with the enrollment paperwork by end of day Friday or Monday.

I got them Friday. I read them to Teresa, she signed them. I scanned them to my computer (into a PDF) and emailed them back. Then I called to make sure they got them, and then paid for the last week of August and the full month of September.

Since it was end-of-day, everything, including the payment, still has to be fully processed, but the latest the policy will be active again is Wednesday. And, the second wonderful COBRA rep I spoke with said that I could give anyone from Duke the direct line, and they would verify that the policy was processing - and paid for - and would be good to go very soon (if it isn't already come Monday morning - they've put a rush on it).

**Duke Referral:** The upshot is that Trish at the Cancer Center explained our situation, and that we would be electing COBRA for Teresa, and the policy would re-activate, and I was trying to get BCBS to expedite the enrollment process. They (Duke) were understanding, and the (I believe assistant) for the doctor we want to see (recommended by another LMS patient I met online) is going to call me Monday morning. When Trish told me that, I didn't yet have the enrollment forms, but once I got them Friday, and got them back and paid, I knew I had a really good shot of Duke getting T registered.

And, since Duke is on the Epic system, they already have the majority of Teresa's records!

Trish told me that she was told that I should get a call Monday morning from Zack, and I could update him at that time about COBRA. And, that it looked like they did have openings next week (if I understood her correctly). So..... it's possible that Teresa could be seen at Duke sometime this week .... and hopefully get the operation she's been wanting since September 2017.

We don't think she can wait much longer.

**CT note: The CT results are long, so I will be putting them in a separate post. Most likely sometime this evening. And as soon as I know about Duke, I will write another post about that.**

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\* I know that several of you have been told I don't like making calls, that the phone stresses me out, and so forth. And now you read here about me making all these calls. I've not been lying to get out of phone calls. The phone truly does stress me out, often to the point of cold dread when I'm on the phone, with some exceptions for people I actually know or if I've told you I find you easy to speak to on the phone. And I have some hearing loss which makes it all harder.

But what stresses me out way more than being on the phone is the idea of not having my Teresa around, and I will call anyone as often as needed to get things done so we can get her where she needs to go. So if I tell you it's too stressful for me to be on the phone, know that (1) it really is, and (2) I'm saving up [all my spoons](#) for phone time for getting Teresa everything she needs. Thank you for understanding.

## Comments

Thank you, Mandy  
Lee Ware

—*Lee Ware, September 9, 2018*

Our hearts & prayers are flying to you guys!!! Great job. Hopefully you get into Duke this week. They have a amazing reputation !  
Love you guys. Uncle Rog & Aunt Patti

—*Roger & Patti Ackley, September 9, 2018*

We do what we have to do for our loved ones! I hope you get to Duke ASAP. It is a remarkable place and it's close. Hugs, positive vibes and prayers for you and the medical team.  
? and ???

—*Sue Harris, September 9, 2018*

Thoughts and prayers with you both everyday ???  
I hope Duke is the answer.

—*Jim Constantinides, September 9, 2018*

Keep on keeping on! You are strong enough to do what's needed.

—*Sally Treanor, September 10, 2018*

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## CT Results (August 31, 2018)

*Amanda Grabler, September 10, 2018*

I decided to make the CT results a separate entry, since there is a lot of detail in the report this time (not as thorough as others we've had, but certainly better than some recent ones).

I know CT reports generally contain more medical detail than many of you can follow. Ask questions, in comments, or privately, if you don't understand something! I am providing as much "plain, very basic, English" clarification as I can, and will include some links (bold and underlined) to helpful pages.

There will be a third post as soon as possible after this one regarding our going to Duke Cancer Center (Durham, NC).

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### FINDINGS:

**Chest:** Small right-sided pulmonary nodules are new from previous exams. Largest nodule involving right lower lobe near the fissure measures 13mm in long axis. Additional new nodules are present on images 24 and 38 series 3 within the right lung. A new less than 6mm nodule present in the left lower lobe (image 36 series 3). Moderate to large right pleural effusion is redemonstrated (NOTE: This was drained as much as possible on 9/6). Small to moderate volume left pleural effusion redemonstrated. Overall pleural fluid volume on the right appears slightly diminished from July 3, 2018. No pneumothorax or pericardial effusion. MediPort catheter appears adequately positioned. The heart is not enlarged. No thoracic aortic aneurysm. Osseous structures demonstrate no new aggressive focal or lytic blastic change.

**Chest in plain terms:** In earlier scans, they found a 4mm, non-spiculated (no spikes) nodule in her lower right lobe. The lungs is a common first place for LMS to metastasize to. But malignant nodules are spiculated, and this one wasn't. There was a good chance it was scar tissue from her first, painful, thoracentesis. The CTs that followed we were told it was "still tiny" but no actual size. I requested they specify this time. The report doesn't mention anything about the appearance, just the size. It is possible for benign nodules to grow, but the bigger they get, the more likely they're malignant. A small one could be malignant, but it is more likely once they get larger than 30mm.

However, it is discouraging that there are more showing up. And it's less likely now that these are spots of scar tissue from the thoracentesis procedures.

The pleural effusion is the liquid that is drained off the lung during the thoracentesis procedure. Her most recent one was on 9/6, so the fluid the CT is referring to on her right side is the fluid that was drained out (nearly 3 liters) this past Thursday.

**No pneumothorax:** No collapsed lung.

**No pericardial effusion:** No fluid around her heart.

**MediPort:** This is the port she receives her chemo and other fluids through. They check it on each CT to make sure it hasn't moved out of place - which can happen.

**Osseous structures:** No bone changes.

**Abdomen:** Extensive intraperitoneal disease is redemonstrated. The underlying peritoneal disease is difficult to discern between ascites and necrotic mass. The overall transverse dimension of the peritoneal abnormality equals 30.3cm. This previously measured up to 26.4cm. No free intraperitoneal air. Peritoneal disease again results in lobulated abnormality along the anterior capsular margin of the left hepatic lobe and inferior right hepatic lobe. There appears to be a new moderate size gastric hernia. Spleen, pancreas, adrenal glands, and kidneys appear stable. The gallbladder is present. The abdominal aorta demonstrates no indication of aneurysm. Bowel gas pattern is predominantly located cephalad within the peritoneal space.

**Abdomen in plain terms:** There's a lot of disease in the peritoneum. This is a thin, transparent membrane which lines the walls of abdominal (i.e. peritoneal) cavity and encloses the abdominal organs such as the stomach and the intestines. There is difficulty telling the difference between ascites (fluid in the abdomen) vs necrotic (dead) tumor. It's possible the chemo did kill some of the tumor, and then the tumor became resistant. But it is also possible that parts of the tumor died because it ran out of food. That's not really a good thing, despite how it sounds, because the food for the tumor is the blood supply.

*The primary tumor has now regrown to 30.3cm on the largest side. The tumor Dr. Greene removed last August was 30.5cm.*

**Hepatic lobes:** The liver. This second tumor is now on both sides of the liver, not just one. There's been risk mentioned in extensive bleeding from the liver when resecting this tumor, despite that from everything we've been told, the liver is not invaded (and I like to think they would have said so on this last CT if it had, since that would be a pretty major change). I've asked if the liver can be partially resected, since it can regenerate, and Dr. Musgrave said they should be able to. I'm also going to ask at Teresa's surgical consult if they can do any pre-op radiation on that tumor and the other smaller ones, and the nodules, to give the surgeons a better chance at clean margins.

**Gastric hernia:** There may actually be 2 now. I see two spots (along the original incision near her belly button and on the top of her abdomen). We know the first is a hernia per Dr. Musgrave. The second, I think, is also likely, but we won't know for sure until Friday. Muscle weakness along an incision can cause these, but in Teresa's case, I suspect it is more likely that it is just the size of the tumor and the pressure it is causing. The second is nowhere near the incision.

**Spleen, pancreas, adrenal glands, and kidneys appear stable. The gallbladder is present. The abdominal aorta demonstrates no indication of aneurysm. Bowel gas pattern is predominantly located cephalad**

**within the peritoneal space.** These organs are unchanged from previous CTs, and there's never been a problem with any of them (aside from that she seems to have extra spleens).

**Pelvis:** Contiguous axial imaging through the pelvis demonstrates continuation of the marked abnormal peritoneal disease. The mixed right attenuation right paramidline component/mass measured 15cm in long axis, enlarged from July 3, 2018. The bowel is without evidence of obstruction. The urinary bladder is obscured or nearly entirely decompressed.

The osseous structures of the abdomen and pelvis demonstrate no aggressive new focal lytic or blastic changes.

**Pelvis in plain terms:** Contiguous means sharing a common border, or touching; next to each other in sequence. No gaps in between. Axial is the plane of acquisition. An explanation with visuals can be [found here](#).

**Attenuation** is a general term which refers to any reduction in the strength of a signal. In radiology, this is the reduction in power and intensity of sound waves as they travel through the tissue. Paramidline - next to/adjacent to the midline of the plane, which for this section would be the pelvis.

It is not clear if this measurement is referring to another side of the 30.3cm tumor or not. Until we're told otherwise, I'm assuming it is, as the original tumor was debulked down to the cervix, which is in the pelvis.

Her bowel is not obstructed by the tumor (but she could still require bowel - and/or bladder ostomies in surgery all the same), and her bladder was not visible. T believes she did not have a full bladder prior to the CT, which could explain this.

She is not currently having bowel or bladder problems, but if having ostomies will give her a better chance of survival, she's accepted having to have them.

**Benign Tarlov Cysts:** These nonaggressive cystic changes at the sacrum appear stable to left of midline. Tarlov cysts appear unaltered dating back to at least August 23, 2017.

Follow [this link](#) for an explanation of Tarlov cysts.

**IMPRESSION:** Interval disease progression above and below the diaphragm including new pulmonary nodules and enlargement of extensive peritoneal disease. (i.e. There's more disease and more nodules in the lungs; whether the nodules are benign or not we do not know at this time.)

New moderate size gastric hernia.

Moderate/large right pleural effusion (again, she had this drained on 9/6), less conspicuous in size from July 3,



2018. No apparent change involving small to moderate volume left pleural effusion.

## Comments

I hope T can be scheduled for surgery at Duke ASAP.

—*Lana Whited, September 10, 2018*

I'm thinking of you always now. Please write when you arrive there.

Lee

—*Lee Ware, September 11, 2018*

## Duke Cancer Institute: Update

*Amanda Grabler, September 11, 2018*

### Duke Cancer Institute is in Durham, NC.

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Last week, Dr. Musgrave & Company began the referral process to Duke for emergency surgery. Dr. M. wants her to have the operation ASAP, especially since, cancer aside, T's in pretty good health. Some of her labs are a little low, but not horribly so like in August 2017 when she went into Surgery #1 terribly anemic, terribly malnourished -- but still recovered quickly. Mom & I joke that she has *Buffy the Vampire Slayer* magical healing powers!

On Friday morning, I woke up to a voicemail from Karla, one of the admin/registration people at Wellmont Cancer Center. We usually speak with her when we check in. She said that when Trish (one of the people we usually work with when we checkout) had finally spoken with the scheduler for the doctor we wanted. Unfortunately, he told Trish that the insurance verification failed.

I called Karla back and explained how we were in the process of switching T from her employer-based coverage over to COBRA, but that BCBS of TN had said there wouldn't be any lapse in coverage. (That turned out not to be entirely true.)

She passed word on to Trish. I called BCBS in the meantime. It was supposed to take 2 weeks to get the COBRA paperwork, which was clearly far too long to wait. I explained the situation and got them to expedite the initial processing period down to 24-48 hours and the promise that they would email me the forms instead of mailing them.

Trish called me back and said that Zack, the scheduler for Dr. Berchuck, told her that without active coverage, they couldn't schedule Teresa. But he was sympathetic about what was going on, and told her that he would call me ASAP Monday to see how the policy re-activating was going. And mentioned that they had spots next week. (Now this week.)

I got the COBRA forms from BCBS TN at *nearly* end-of-day Friday. Printed them out. Read them to Teresa. Had her sign them. Scanned back to PDF. Emailed back. Called to make sure they went through. Paid for the last week of August and all of September.

Now we were just minutes from end-of-day, so I was told that the COBRA department would put a rush on processing for Monday morning, and the very latest that the policy should be re-activated was Wednesday. However, I could give the direct COBRA line to Duke, who could then call to check, and BCBS would verify to Duke that the policy was processing and that the first payment was in the system.

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Monday I waited. And waited. And waited.

And waited some more.

I texted Dr. M. to find out if I'd misunderstood. Maybe Zack was calling her or calling the cancer center back? She said she'd check, and seconds later, Zack called me after all! I quickly texted her back to let her know.

Zack told me that BCBS still showed as inactive. He gave me the number for Duke's financial group. I called COBRA first. The woman I spoke with said the policy was absolutely active, and had been for just over an hour. If it wasn't coming up as active for Duke, someone was doing something wrong, and they should call COBRA directly.

Next I called Duke's Financial Group and explained what BCBS said. I was told it was *still* not showing as active to them. I said it definitely was on my end when I pulled up her account on the BCBS website. He wanted me to call them back and have them call him. I said they wanted him to call them.

He called them!

He called me back about 10 minutes later and said we were good to go, and he'd put a note in the account!

I called Zack back and left him a message. He called me back pretty quickly.

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***Teresa is now scheduled for an 8am appointment with Dr. Andrew Berchuck on Friday, Sept 14.***

Yup, we're driving TOWARD the hurricane. I'd much prefer to be going the \*other\* direction! We're planning to head down EARLY Wednesday to get to Durham *before* the hurricane, or any hurricane-related weather arrives. My understanding is Florence is currently expected to make landfall Wednesday night. Right now, Friday is looking like the worst day for Durham. :-)

(Though the weekend doesn't look that hot either. Mom and I spent quite a lot of time hunting down a room which would work for the 3 of us. The rooms were selling out faster than I could register, so I was thwarted a few times!)

We really, really, really want her to have her next surgery \*before\* her body starts decompensating like it did last August, which obviously makes the surgery riskier. I'm terrified for her to have the surgery -- but also terrified for her not to have it. Not to mention that she's terribly uncomfortable right now. She really needs these tumors out!

This appointment is a 30-minute consult. We will find out during it about a date for surgery, and whether or not he thinks she can wait for a regularly scheduled appointment, or if she needs to be scheduled in ASAP. I will update CB as soon as possible on Friday.

We are really hoping that the surgeons at Duke will be able to fully resect Teresa's tumors, and not leave behind little pieces to regenerate like Dr. Greene was forced to do last year. We don't know if anyone will touch the lung nodules or not. If they do, they will probably use a VATS\* procedure, which is less invasive.

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A gentle reminder that her cancer is Stage 4 and there is currently no cure for Leiomyosarcoma. There is a chance that this surgery will bring her into what is called NED: No Evidence of Disease, which is what is said when someone with Stage 4 cancer has no detectable signs on scans/tests that cancer exists in the body.

But this is an extremely aggressive cancer, and Teresa's tumors have shown that they grow very fast. LMS can come back even *years* later. She would need to continue to have CT scans every 3 months for as long as possible (which can be a struggle with insurance companies not wanting to approve so many scans).

*But she is not fighting a battle.* A request from both of us: please do not use war language to describe Teresa's experience. We have asked this before [on her blog](#). (Note: If you use this language for \*you\* and it makes you feel good, that's totally cool. We're not asking you to change how you talk about your own experience with cancer; just hers. War language *doesn't* make her feel good, and she's not alone in this in the cancer community.)

**You can read about Dr. Berchuck here:**

<https://obgyn.duke.edu/about/our-faculty/andrew-berchuck-md>  
<http://www.foundationforwomenscancer.org/andrew-berchuck-md/>

\* **VATS:** Video Assisted Thoracic Surgery: a type of thoracic surgery performed using a small video camera that is introduced into the patient's chest via small incisions. The surgeon is able to view the instruments that are being used along with the anatomy on which the surgeon is operating.

**Thoracic:** Relating to the thorax.

The thoracic spine is located in the chest area and contains 12 vertebrae. The ribs connect to the thoracic spine and protect many vital organs.

*As always, feel free to ask if you have any questions!*

## Comments

Somehow, having an impending hurricane intrude into your schedule provides a scenario worthy of Hollywood. However, no one could make this stuff up. Be safe. And hold on to your loving strength.

*—Sally Treanor, September 11, 2018*

Thank you for the update. Now be safe in driving to Duke and know we are thinking and praying for you both.  
??Aunt Anne

*—frank wagner, September 11, 2018*

Dr. Berchuck looks extremely well qualified. I hope the weather odds work out in your favor!

*—Lana Whited, September 11, 2018*

## Duke Update #2 - Change of Plans due to Hurricane Florence

*Amanda Grabler, September 11, 2018*

This morning, after reading numerous weather reports, and watching the weather, we tentatively discussed rescheduling - if we weren't going to have to wait forever. We really want Teresa to get in ASAP but we don't want to put ourselves in danger either. Before we had decided for sure one way or another, a very nice nurse, Charlotte, at Duke called us. They're moving as many patients as they can (chemo too) to next week.

So we rescheduled. I won't lie, while I'm nervous about any delays in T's potential surgery, I am very glad not to be going to NC this week!

(Also while Mom, T, and I all get along fabulously, we weren't looking forward to sharing 1 King bed for 5 nights. It was the **only** room we could get!)

So, now, T has an appointment on Tuesday, September 18, at 1:30pm, with Dr. Angeles Secord. She sounds fabulous! T said maybe a woman surgeon will make the difference. She's been seen by 3 male surgeons, and they've all declined to operate. The new patient scheduler, Zack, also called me, and he said she's an *excellent* surgeon!

You can read about her here:

<https://www.dukehealth.org/find-doctors-physicians/angeles-alvarez-secord-md>

<https://www.healthgrades.com/physician/dr-angeles-secord-2qqhv>

### Comments

Thank goodness. I've been fretting all day as the weather prospects have broadened and worsened. Thanks for sending this so soon!

*—Sally Treanor, September 11, 2018*

Sorry to hear you can't make it there sooner, but happy to hear you won't have the added worry of driving in that weather. ??

*—Michelle Brazeau, September 11, 2018*

I think you two made a wise decision in light of Hurricane weather coming! I hope next weeks appointment brings the results you want.

Hugs?

—*Sue Harris, September 11, 2018*

If you are ever stuck with one bed and too many people, you can take off mattress. One group on floor mattress and the other group on box springs.

—*Gray Johnson, September 11, 2018*

Interesting, but besides involving more strength than we may have, I can't imagine trying that even in the cleanest of hotels. Hotels make me squeamish to start with...

T wouldn't be able to get up off the floor, and would be too uncomfortable on just box springs. She can't have any added stress to her body right now. ?

—*Amanda Grabler, September 12, 2018*

I'm happy to hear (we were worried) you're rescheduled for next week-they're saying this storm has the potential to be very dangerous. Safe travels when you do go. Hugs.

—*Christine Daly, September 11, 2018*

Great news. Thoughts and prayers everyday.  
Love you both.

—*Jim Constantinides, September 11, 2018*

What a relief, Mandy. I felt that going tomorrow was suicidal. I hope that the roads will be OK when you go (Monday?). Please keep us informed.  
love, Lee

—*Lee Ware, September 12, 2018*

## Duke Update 3: Crash & Burn

*Amanda Grabler, September 19, 2018*

CN Warning:

Language (swearing)

Question re: Physician Assisted Suicide

We texted or called a few people immediately after. Nearly everyone's reaction was "WTF?"  
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Going to Duke was the biggest waste of time. It was a resounding failure. And is made worse by the fact that this doctor could have communicated her main point (no surgery) over the phone, and saved Teresa a long, agonizing round trip in the car. No point in staying overnight since we weren't getting anything out of this trip.

We had heard SO many good things about Duke. They're sooo aggressive in treatment, and will do so much to help cancer patients with the most sparing of surgeries unless there's no other options. What a laugh. No help at all.

We got checked in promptly, and the people prior to the doctor were all very nice, though in hindsight I don't care for her NP much, because I can't believe she didn't know that the surgeon was going to walk in and tell us no way without evening examining Teresa.

Dr. Secord: You're a disappointment. Have you forgotten about first do no harm? You caused Teresa a great deal of physical distress by not having the kindness to review her records, which Duke received last week, ahead of time, and tell us no over the phone or in a secure message in MyChart.

Sure, surgery carries risk. All surgery does. Yes, this one would be extremely risky, but we're at the point where not doing anything is worse. Is more harmful. Physically and emotionally.

You caused Teresa and myself a great deal of emotional agony by telling us no, and then continuing with demonstrating ridiculous skills in the inability to listen or to use logic.

You caused all of our family a great deal of emotional agony by telling a woman who, cancer aside is in pretty great shape, that you were basically sending her home to die. She is not ready to die; I am not ready to be a widow. Dr. Secord was unmoved.

Reason given? "It's not ethical in my heart" to do surgery.

She told us she went into the profession because she has so many family members who have/had cancer. I find it hard to believe that she went to that much trouble and expense of medical school to turn people away like this. I can't believe she wouldn't go out of her way to find any solution for someone she actually cared about.

She won't operate because? The cancer will grow back. Well, no shit! Especially if you can't resect with clean margins, but guess what, *doctor?* It took a YEAR to regrow to the size it was last year. And most of that year was spent without being in agony *every day* from the weight of this fucking tumor! That would be a YEAR's

chance to try new chemos. To try clinical trials. To get a chance to try the latest drugs and cancer "vaccines" which are having remarkable success in animal trials. But they take ages to get to human trials.

Give Teresa that chance, damn it!

She wants that chance.

Maybe it wouldn't have grown back if Dr. Greene had been able to get clean margins, but Teresa was too anemic, too malnourished. She bled too much in the surgery for him to continue. We don't begrudge him that at all. He saved her life that day.

So, yeah, it might grow back. But it might not if you can get the margins. And Teresa knows full well that there's a lot of risk with this operation. She knows that even though her bowels and bladder are working fine, she might wake up with 2 ostomy bags, but that is far preferable to being sent home without even an attempt to save her.

There's no more room in her abdomen for this fucking tumor. She's getting hernias now from it. She rates her pain an 8. But higher if she has to cough or sneeze. We're afraid of what will happen if the hernias get worse. If her intestines get strangulated in/by one.

Dr. Secord said she's seen other patients go through hard surgeries like this and it didn't end well for some of them. Some. Not all. The cancer might grow back. And that if we know other people who had major surgeries, that surgery probably only happened for them because it was their FIRST surgery. There's no point when it's their second, is basically what she continued on with.

Based on the 'logic' Dr. Secord presented us with today, she shouldn't be operating on anyone, because even if the first surgery is done by a specialist....it could still grow back.

I asked Dr. Secord how this surgery was riskier than the first one, given Teresa's labs are better, and Teresa is just physically in far better shape than in August 2017. She could not give me a straight answer. She kept bringing up all the chemo T has had. And, may I point out, has recovered from. If she didn't have such short hair, I challenge anyone to know she'd had any chemo at all over the last year; much less 3 different regimens (5 drugs total), not to mention a slew of pre-medications and medicines to take at home.

Dr. Secord just kept on with there was no point. That the risks outweigh the benefits. She didn't examine Teresa. I doubt she looked at recent labs. I doubt she looked back in her file to see how ridiculously fast she recovered from her first surgery.

No point?

Well there sure as hell is a point to us! Teresa wants *every* chance. How long before the tumor compresses all of



her organs?

I asked the doctor about physician assisted suicide when it became clear that she wasn't going to listen to any logic. That she was going to ignore our continued explanations that we were looking at this as a palliative surgery, not a curative surgery. That she didn't care if she came out of it without all of her insides if it meant they could get rid of all or most of the tumor to *give her the time she wants!*

This question brought her up short. She said it wasn't legal in NC (which I knew when I asked). But she could put Teresa in contact with colleagues in other states if she was serious. I then said, "If you're okay with putting us in contact with people for that, how is it any different then you refusing to operate and sending her home to die?"

She couldn't (or wouldn't) answer me.

She had the gall to continue apologizing that she couldn't help and had the gall to hug Teresa and try to comfort her after all of this crap.

She moved towards me. "Please, do NOT hug me. Do not even come near me."

She backed off.

The ONLY good thing is she said she wouldn't charge us for our arduous trip and appointment which could have been condensed to a 10 minute phone call or brief email.

First do no harm? Dr. Second, you did NOTHING but harm today. Shame on you.

We are ***furious.***

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Tomorrow I will be recontacting a surgeon we spoke with before who said while he didn't want to operate when we saw him, he would reconsider if it became a palliative need or the tumor became obstructive. Fingers crossed. If that doesn't pan out, we have to start all over again.

She'd probably have to try Votrient, but would rather try a chemo that would target a mutation (MET) in her tumor, if Dr. Musgrave can get a compassionate release for it. It has been approved for other cancers, but not LMS. Dr. Musgrave said she may be able to get a release because of the results of the Foundation Medicine tests.

Then we have clinical trials. I'm told by a research oncologist that there's a clinical trial coming up in a few months which Teresa may be eligible for . . . it's in Seattle. I don't know how it works to do a clinical trial that's on the other side of the country from you. **Anyone have any input on this?**

Those of you who had surgeons who were willing to do multiple surgeries, no matter how aggressively fast growing your tumor was/is, who do you see? Did you have to convince them or were they willing from the start? Are they taking new patients? Do you know which insurances they accept?

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(So far, the best treatments she's received are/were from Dr. Musgrave (hematology/oncology, not a sarcoma specialist) and Dr. Greene (general/vascular, not an oncology surgeon). Wish we could talk Dr. Greene out of his retirement from surgery.)

## Comments

Heartbreaking. I am stunned.

—*Heidi Baird, September 19, 2018*

I've never heard of such a horrible medical situation. A story in the Washington Post would shame Duke and that doctor, but it wouldn't help Teresa-- unless it brings volunteer doctors who want to try a most difficult operation.

I'm so sorry! It's a catastrophe.

love, Lee

—*Lee Ware, September 19, 2018*

I'm sorry the trip was a waste of time. Maybe because I'm at that point also, but it seems like a lot of doctors

—*Michele Dillon, September 19, 2018*

??

Was there more to this sentence?

—*Amanda Grabler, September 19, 2018*

I can't even begin to fathom this doctor's behavior or to comprehend what you guys must be feeling now. This is not only the worst story I have ever heard about Duke but the worst consultation story I have ever heard, period. It is clear that she's not your surgeon. I'm sorry she had you drive all the way to Duke just to learn that.

—*Lana Whited, September 19, 2018*

I am sorry to read this heartbreaking news.

—*Sue Harris, September 19, 2018*

I am so sorry Duke put you thru that-how utterly unprofessional of that Doctor.

—*Christine Daly, September 19, 2018*

THis is so awful that this Doctor put you both through this. I am so very sorry for what you are going through. I also know how determined you both are and I feel you will find some help.

—*Denise Metzger, September 19, 2018*

I'm speechless. All I can offer are my heartfelt prayers.

—*Sally Treanor, September 19, 2018*

Saddened deeply by this news. Thoughts and prayers with you both. I must as as my brain continues to process all the possibilities but have such little knowledge as you do, is Immunotherapy a possibility at all? Love you.  
Jim

—*Jim Constantinides, September 19, 2018*

Keep fighting! I'm with you both!!!

—*Marcia Horn, October 6, 2018*

## Going (Slowly) Forward

*Amanda Grabler, September 20, 2018*

We decided to take a couple of days to just be angry and upset and ..... GRRRR....Argh!

We're not sharing the Duke experience outside of CaringBridge, yet. It will be briefly mentioned that we did go to Duke in the timeline on Teresa's blog, but that's all.

We don't want to turn any potential hospitals/surgeons away from helping us, and going forward, I'll be requesting that surgeons let us know their decision over the phone or, preferably, in email, rather than making us take a long drive to tell us no.

We are going to be contacting a surgeon in Buffalo whom we saw in February who said he would reconsider in a different situation -- which we're in now. I drafted an email last night, and we're going to polish that up and send it off this weekend so he'll have it in his inbox come Monday morning.

Thanks to the genius of Teresa's dear friend Maria, and my Mom, we've got another plan for if the Buffalo surgeon declines our request. We'll explain it in more detail once we've got it all fleshed out. We may need some brainstorming help from you all!

For the question about immunotherapy, yes, we know about it. Teresa's Foundation Medicine test came back that she would have 0% response to immunotherapy drugs like Keytruda, but we've read posts by/about people who got the same result and still did great on Keytruda. And then there's other things like CAR-T therapy, but it is not yet approved for leiomyosarcoma.

It is possible in some instances to get compassionate release on drugs, but Teresa really wants to get most or all of her tumors out before trying any more chemo, if at all possible.

Medical-updates aside, anyone want to come visit? We know it's short notice, but this is the soonest we are able to post and tell you all this. If you've been wanting to visit (or re-visit) Teresa, this weekend is a great opportunity for that!

Back pain from the weight of the tumors aside, she's feeling pretty good, and she absolutely loves company!

*If driving long distances is difficult for you, and if you don't like to fly, Amtrak has a station in Roanoke!*

The only thing we ask is that if you or anyone in your immediate household (or someone you share an office with) is sick, or if you've had a live vaccine w/in the last 6 weeks, you call instead of visiting in person. Teresa will be thrilled to speak with you on the phone! If the surgeon in Buffalo says next week that he'll take her on, we'd hate to have to pass because Teresa caught something at the last minute. I'm sure you all can understand! We all want Teresa to get better!

(Please note that we are currently unable to host anyone in the house for sleeping purposes, but can recommend a variety of nearby hotels in a range of prices.)

She also has a new post to share with you, about her favorite things and what she enjoys doing, which you can find here: <http://teresa.grableronline.com/a-few-of-my-favorite-things/>

She would really love to have more people reading (and responding to) her blog! It often takes her a long time to do each post. Hearing from you all in the comments over there means a lot.

## Comments

You are both amazingly resilient. What a team. I wonder if we could clone your attitudes. I hope my positive thoughts and prayers can boost your own synergy. Blessings, my dears.

—*Sally Treanor, September 20, 2018*

Bobby and I already have plans to travel North this weekend, but hope to get a chance to head towards Roanoke soon. Isn't it nice to have a plan after floundering for a while? Best of luck!

—*Michele Dillon, September 21, 2018*

## Brief Update

*Amanda Grabler, October 3, 2018*

Just wanted to give you all quick update.

1. On 9/26/18 Teresa had an emergency appointment with Dr. Musgrave for labs and to check her breathing.
2. Labs generally good but hemoglobin had dropped down to 8.6.
3. Definite decreased to absent breath sounds on right lung again.
4. Scheduled same-day thoracentesis at BRMC nearby in Tennessee.
5. Teresa got 4 liters taken off her right lung.
6. In the middle of the night between 9/27/18 and 9/28/18, I sent Dr. Kane at Roswell Park Cancer Institute (Buffalo, NY) an email requesting an urgent surgical consult for Teresa, in which I outlined why she wanted surgery and acknowledged various points up front (ex: we know if you need to resect part of her liver, her recovery time will be longer; depending on the placement of the tumors you may

need to do at least one ostomy, and so forth). I also provided him with a link to all of the CTs T has had since he saw her in February, labs, the Foundation Medicine test results, the genetic test results, etc.

7. On 9/28/18 we drove up to Buffalo, NY. I got a read receipt from Dr. Kane that morning as well.
8. We had a vague memory from our February appointment that Mondays were the day cases were presented to the tumor board, so the earliest we expected we might hear back was Tuesday 10/2/18.
9. We didn't hear anything from Dr. Kane which was both good and bad. Bad because we're obviously anxious to hear from him. Good because it let us have a more relaxed celebration of my birthday (which we'd started the day before with a fun trip trip to the Walden Galleria Shopping Mall). T does have to be in her wheelchair to go out, but right now she still can go out, which is good.

1. Got an unexpected call from the Wellmont Cancer Center about an oral chemo drug they were trying to call in and having trouble with the insurance. I texted Dr. M to find out which chemo it was. It's the [Cabozantinib](#)! This is the targeted therapy chemo for the MET mutation which is in both Teresa's primary tumor (could be the others too but they can only test what was resected last year) and in Teresa's actual DNA. (It's FDA approved, but not for leiomyosarcoma.)

Dr. M said she wanted to have a backup plan in case surgery was a no-go, and she was worried it might take awhile to get or that Teresa might have to get into a clinical trial for it, but it looks like that won't be the case (thankfully). Currently, the Walgreens speciality pharmacy at the Bristol, TN, hospital is working on getting it pushed through. Dr. M is awesome. We're so glad she's Teresa's oncologist.

2. I did discover last night, however, that she is having **very** visible swelling (edema) in her feet, which makes me understandably nervous. This was one of the last things which happened last August before surgery became a "has to happen RIGHT NOW" event. She needs help getting dressed now.

10. As of 1:30pm today we hadn't heard anything, so Teresa called and left a detailed message with the sarcoma clinic. (As a reminder, here's info about [Dr. Kane](#).)

1. Still waiting for a call back at 4:10pm, so she called again and got a live person. Eventually I got to speak with a nurse who is going to try to expedite everything. She said Dr. Kane has

been in scrubs nearly all day, so it makes sense that we hadn't heard anything yet today. Sounds promising we may get a call back tonight, and possibly the chance to wheel over there and get her evaluated in person (our hotel is connected by a tunnel with Roswell). \*fingers crossed\*

2. Teresa napped much of the day (slept on/off until @noon, had her breakfast/lunch meal and went right back to sleep). Her breathing while asleep sounds labored.

11. If anyone calls to talk to Teresa, please be aware we may have to hang up on you abruptly if Roswell calls. Yes, the iPhone has the option to switch calls. No, we're no good at actually using that feature. :-)

## Comments

Fingers crossed!!!! Thanks for your update!!! ?

—*Sara Poston, October 3, 2018*

Thinking about you both. ??

—*Michelle Brazeau, October 3, 2018*

Thank you for posting these updates! Love to you both!

—*Bridget Gall, October 3, 2018*

I so want this to happen for you. You are both at the front of my mind every moment. Love you.

—*Sally Treanor, October 3, 2018*

Keeping fingers and toes crossed! (thanks for the update) sending you both Love Light and Blessings<3

—*Harriet Berk, October 3, 2018*

Praying? alot tonight.

—*Jim Constantinides, October 3, 2018*

Praying things go the way you want them too. I know there have been other disappointments. Love to both of you

—Maura Fischer, October 3, 2018

I hope that call comes soon! Teresa and you are in my thoughts!

—Alyce Bowman, October 4, 2018

Thanks for the up-date. I was worried not knowing what was happening. Is surgery still an option??? Take care , my thoughts and prayers.

Love, Ellie

—Ellie Scofield, October 4, 2018

## Back to Roanoke We Go

Amanda Grabler, October 6, 2018

Roswell seems to be a bust.

Back in February, Dr. Kane told us that he never says never, and if the need for surgery became palliative or obstructive, he'd operate.

The nurse we spoke to on Thursday told us that he says the real reason he didn't operate in February was the disease was "too extensive" (and therefore, would definitely not operate now when it was surely more extensive).

Best as we can tell, he never read the entire email (or perhaps any of it) that I painstakingly wrote (and nervously sent). He never looked at any of the CTs, labs, reports, etc. The nurse called only to find out where she had the scans done so they could order the CD, which would take days to get. She didn't know anything about the email or that I'd digitally provided everything needed. Luckily I had the CD on me, and they sent a volunteer up to get it.

Dr. Kane had been in surgery pretty much every day, and was Thursday, so he wouldn't get to look at the CD until late. But we never heard anything Friday either. The nurse also said that Kane doesn't do emergency surgery and that it "isn't a thing". (How is emergency surgery not a thing?!)

If it's true that he didn't operate in February because he thought the disease was too extensive, then he lied to us and intentionally gave us false hope that he would operate when he never intended to do so. Which is complete



crap to do to people. We've been holding on to him as hope all this time that if nothing else, we could go back to him, and he'd help her, when apparently, he never was going to do anything. \*Grrrr! Argh!\*

I asked him to please let me know something. But we had to reach out. Days after I got the read receipt for the email. They were never going to call us. This has been an exercise in futility.

Reasons we got for a probable NO here was:

She'll never be NED. (Well, not if you won't even try!)

It's risky. (No, really?)

It's too extensive. (Let me find you that article about the woman with the 160lb ovarian tumor ... which she got removed.)

And so forth.

And, really, how do you KNOW she will never be NED? Sure, maybe that's true, but if you don't try, she certainly won't be! It takes years for some people to get to NED.

He's the one who told us back in February that everything would be different if a sarcoma doctor had operated first. Yes, we get that, but we didn't know we needed one. And really, you can't expect me to believe that everyone who has surgery for what they think are benign reasons (ex: routine hysterectomy) and end up with a "Surprise, it's cancer!" outcome, are never, ever, ever able to get a second operation? That's utterly ridiculous.

If you aren't willing to try, then of course, she will never reach NED! You gotta try.

**If you have had multiple surgeries for cancer, especially one that is rare and/or extensive, please tell me HOW you got your surgeon to do more than one surgery? Because we are battling zero, even at centers which are reported to be very aggressive in treating patients, and thus, very aggressive about operating. This is a serious question. We want to/need to know. Sooner rather than later.**

In the meantime, while we were up here, Dr. M has been pursuing getting hold of a targeted chemo drug called Cabozantinib. This will target the MET mutation in her tumor (she also has this mutation in her DNA). T says she has a good feeling about this chemo. I'm trying not to be hopeful, because every time I've been really hopeful, the news gets progressively worse.

This is an oral chemo which she will take (I believe) daily.

It's FDA approved, but not for leiomyosarcoma, which is why it can be difficult to get for T outside of a clinical trial. But because of the Foundation Medicine and the Genetics test results, Dr. M thinks she should be able to get it. She didn't know if we'd be successful in getting T a surgery, so she started working on this chemo as a

Plan B.

Dr. M is really awesome. T said she's glad to be getting back to the safety of her care.

We will get back to Roanoke on Sunday (we're splitting the trip sort-of in half) and then on Tuesday, we will go back to Abingdon.

On Wednesday, she has labs and an appointment with Dr. M.

On Thursday, she has an appointment called "Interventional Radiology". It's painful, and uncomfortable, as I'm sure you all can imagine, for multiple liters of fluid to slowly build up on T's right lung. And then have to get a large-volume thoracentesis done. The worst part for T is the part after the fluid is drained. As her lung re-inflates, it makes her cough a lot. And if she takes too deep a breath, she has pain from that. Within 1 - 1 1/2 days, she's usually fine. But it is a lot to go through every 2-3 weeks.

So the outcome of Thursday will be a pleural catheter inserted in her chest wall, so that up to 1 liter can be drained slowly at home by a home health nurse (or, eventually, a trained family member). She will get 6-8 weeks of home health care, done in Roanoke.

These are usually done for patients with malignant pleural effusions, but sometimes now also for benign effusions, when they're reoccurring.

Hopefully she will get approved for, and be able to start the next chemo soon. Once Dr. M knows about approval, then we can see about getting T a baseline-CT. The closer to the chemo start date, the better.

A friend gave us the name of a surgeon up at VCU (Richmond, VA, area) and he sounds promising. We won't get our hopes up because we've been down the "sounds promising" road with surgeons in the past, but what I've read is encouraging. Not just for surgery, but that he may actually be able to offer other options which no one else has so far (like targeted radiation).

It was also suggested that we try to track down Dr. Greene and ask for his professional opinion, since he was the one willing to operate in the first place. That perhaps if we had even a general surgeon backing up a request for surgery, someone may be more willing.

Let me know if you have any questions, or if you would like to visit Teresa once we're back from Abingdon!

**EDITED TO ADD:** Like with Duke, we will not be posting any reviews, or writing any public articles, of Dr. Kane at this time. We don't need any additional road blocks to getting Teresa in to another surgeon. Thank you for understanding.

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I don't know the specifics of the catheter Teresa will be getting, but if you go to the following site, you'll get an

idea of what a pleural catheter involves: <https://www.bd.com/en-us/offerings/capabilities/interventional-specialties/drainage/about-the-pleurx-drainage-system/patient-information-pleurx-system>

## Comments

Fingers crossed

—Michele Dillon, October 6, 2018

Your valor is astounding. It's always the necessary ingredient. Bless you both. So sorry this has happened.

—Sally Treanor, October 6, 2018

I hope T. won't suffer too much with the lung procedure. And I hope the Cabozantinib works. Thank you for writing - This is so sad.  
Lee

—Lee Ware, October 6, 2018

Thanks for the update, I hope all procedures go well this week. Hugs all around!!

—Sue Harris, October 6, 2018

## Not Good News

Amanda Grabler, October 10, 2018

I'm writing this update from Bristol Regional Medical Center.

We were scheduled to see Dr. Musgrave today, but we never got to. When she saw Teresa's CBC, her nurse Cathy came to tell us we were to go to the hospital immediately for a transfusion. Her hemoglobin is 7.6. (The lowest normal number is 11.5.)

Although her Blood Pressure is good at 115/74, we're very much back at ground zero of last August where she desperately needed surgery. **Do you know anyone who WOULD be able to help us?** None of the surgeons we've seen so far are willing (which eliminates MSKCC, Dana-Farber, and Roswell Park as options).

- Her pain is 9/10.
- She is a fall risk.
- Her abdomen is very distended. (As of 8/31 her primary tumor was at 30.3cm. The next largest, which is on both sides of her liver, was 16cm.)
- Her legs and feet are extremely swollen.
- She has 3 gastric hernias which right now are not a risk, but if they suddenly become one (which can happen fast), i.e. her intestines get strangulated in one, she will need IMMEDIATE surgery. It would be so much better if a surgeon skilled in cancer, gynecology, or, even better, sarcoma, would operate before that point happens. **Can anyone help us?**

These are all things she had last year when Dr. Greene said she was decompensating fast. One other difference, a good one, is that her appetite is still GREAT. She wants to eat and, unlike August 2017, can eat plenty! So her stomach is (somehow) not compromised (squashed).

Tomorrow morning she gets a pleural catheter put in her right lung. She will also get the fluid on her right lung drained off. The catheter means we will be able to drain up to 1 liter at a time at home. Radiology will teach me how to do it, and she will get home healthcare next week.

The swelling in her legs is most likely lymphedema. I'm sure that it is the tumor blocking the lymphatic system from draining properly. Untreated this can have painful consequences.

She is on furosemide (Lasix) to help reduce fluid, and I talked to her cardiologist's nurse over the phone yesterday about increasing the amount she's on (20mg). He agreed to increase it to 40mg and prescribed potassium too (this time in a powder instead of those monstrously sized pills, as she is having trouble swallowing the big pills these days).

We will pick that up tomorrow.

The catheter procedure is at 8am tomorrow; we check-in at 7:30am. (groan)

We will go see Dr. M after that procedure and before the CT later that day. She will get her hemoglobin levels checked again to see if she needs another transfusion because of the procedure.

At 3:00pm (checking in at 2:30pm) tomorrow, she will have a baseline CT before starting the next chemo. . . .

Which we're still trying to get approved as medically necessary. The insurance has denied it twice. Dr. M. said they had a 1 month supply to get her started. I'm hoping that if it does well for her, that can be some of the supporting evidence.

This chemo (cabozantinib) is technically not indicated for use in LMS, but it is an FDA approved therapy for other cancers.

It is recommended for Teresa because of the mutation in her tumor (MET) that this chemo targets.

I know it is in trials (past and current) for LMS, but because of everything she has going on, getting her to a clinical trial site will be difficult at best.

**If anyone with access to scientific/medical journals finds something supporting the use of this chemo in sarcoma, and especially LMS, please send them my way!**

## Comments

Have you seen this link? It mentions trials, as well.

<http://www.cancernetwork.com/ctos-2017/cabozantinib-shows-early-promise-soft-tissue-sarcoma>

—*Kim Eller, October 10, 2018*

Sending love

—*Michele Dillon, October 10, 2018*

## Clarification For Today's Earlier Post!

*Amanda Grabler, October 10, 2018*

Thank you to everyone who has sent me clinical trial links! Apologies for the misunderstanding. We are NOT looking for a clinical trial for her to join.

Her awesome medical oncologist is working on getting the chemo for her to take just on her own. Additionally, at this time, Teresa is in no shape to make trips to a clinical trial. It's hard enough just to take the 30 minute drive to the cancer center from our apartment (or the 2 1/2 hour drive from my parents' house).

Today was actually the anniversary of her first day of chemo. She is in worse shape now than she was then. It really is almost like the surgery never happened and we're repeating this last year . . . but with more tumors. ?

Open clinical trials, even if they're for sarcoma, even if specifically LMS, are not going to be seen as supporting evidence for her insurance either because it won't tell them any factual evidence outcomes that will help prove medical necessity.

However, completed clinical trials with accessible results which support cabozantinib for sarcoma/LMS, should/would be considered supporting evidence for her insurance, I believe.

Hope this clarification helps. Sorry for any misunderstandings that we were trying to get her into an actual trial right now!

## Comments

What an ordeal! Thank you, Amanda, for being so diligent about keeping us up to date. Wish there was something that I could do other than sending loving thoughts and positive energy.

—Sally Treanor, October 11, 2018

## A Whirlwind Week

Amanda Grabler, October 19, 2018

And then some.

Apologies for the delay. I know, for those of you who follow Teresa's new (public) page on Facebook that I kept saying I'd update here with more detail, but I've simply lacked the mental and physical energy needed to write a comprehensive update. If you're not following it yet, you can [find it here](#). Even if you're not on FB, you should be able to see posts to the page since it is public. If you get a pop-up asking you to sign-in or register, there should be an option to click "not now".

To try to simplify things, I'm going to start with her first appointment last week, and run down the schedule by date for you. In the midst of everything going on, know that we were actively trying (us and Dr. M & team) to get Teresa's insurance to approve the targeted therapy chemo cabozantinib.

BCBS of TN denied it on October 8, October 10, and October 14. That left us with only an external "civil action" available to try to appeal it. Foundation Medicine connected us with an organization they work with for genomic support testing who could help us appeal.

But we didn't end up needing them. You'll see why as I go through the past week of events.

This is a long post. There's a lot of information. Teresa's situation is still .... not great to put it *extremely* mildly. But we did get some good news this week.

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### **Wednesday, October 10:**

Today was just for labs and an appointment with Dr. Musgrave. Unfortunately, Teresa's hemoglobin had dropped to 7.6 and Dr. M sent us to the hospital for an emergency transfusion. We never got to see Dr. M. We were told to come back the next morning after Teresa's radiology appointment, and they'd fit us in. And they'd check Teresa's blood again to see if she needed another transfusion post-radiology.

Her eGFR (kidney function) had dropped to 71. It's supposed to be greater than 90. The only time this had happened before was with chemo, particularly gemzar, but she hasn't been on chemo for over a month.

It wouldn't be until late Thursday night/early Friday morning that I would start to put the probable pieces together.

So we went to the hospital for her to get a transfusion.

I'm pretty anxious now because she has terribly swollen legs, a very large abdomen (we're still waiting on the latest CT results for most current size), and a hemoglobin in the 7's. This is reminding me far too much of last August when a trip for an emergency transfusion turned into emergency surgery.

(Of course, now we desperately want the surgery can't get anyone to agree to do it.)

She has the transfusion and we go home.

### **Thursday, October 11:**

She has her Interventional Radiology appointment. They drained off about 2 liters of fluid (it was all she could tolerate) and then inserted the PleurX drainage system. You can learn more [about it here](#). (Hers is in her right lung.) The doctor was very nice (as is everyone in Radiology) and it all went very smoothly. She's dealing with back & side pain from it, and may have that pain for 2-3 more weeks.

From there we go back to the Cancer Center, where we see NP Jennifer. She answers as many of the questions that we had for Dr. M as she can. One of our current biggest concerns is the possibility of cachexia -- wasting syndrome. Symptoms include weight loss, muscle loss, a lack of appetite, fatigue, and decreased strength. The only one she definitely doesn't have is a lack of appetite. But we worry the tumor may be getting most of her

nutrients. It can be reversible if caught early, but simply changing the diet isn't enough to reverse it if the tumor is still taking away what she needs. Her weight is up, but this is clearly a combination of the tumor weight, and the weight of all of the fluid in her legs. In person, it is easy to tell she's had significant weight loss in her arms, chest, back, and shoulders.

After this appointment, we get lunch and wait for it to be time for her CT. This goes smoothly. At request, the check to see if there's any fluid in her abdomen. The nurse tells me there's some, but not enough to bother with doing a paracentesis to drain it.

We head back home. T works on getting enough fluids to flush out the CT contrast. Later that night, she tells me she can't pee. Hasn't actually peed all day. She feels like she needs to go, but can't.

This is what triggered our late night trip to the ER on Thursday night. Our dear friend Sara meets us there and stays with us all night.

### **Friday, October 12:**

Teresa was triaged somewhere between 1am and 2am.

It took 2 tries to get the Foley catheter in, and we suspect this is why there were little blood clots or pieces of tissue in her urine at first. We haven't seen any in a few days now. One of the nurses who helped took care of Teresa in the ICU last year. She remembered us; we remembered her! So that was really nice!

We actually saw an ER doctor, which seems rare. Usually just nurses (not that we mind, we love nurses - RNs, LPNs, NPs/FNPs - nurses have been fabulous for us). But since a doctor came by I thought I could ask him more questions. Not so much. Did finally convince him to run a CBC and CMP panel.

A good friend of mine was also giving me great suggestions of what to ask for over messenger, which I think is what helped push the doctor to agreeing. He didn't do everything I asked about, but at least he ran the labs, plus the tested the urine for infection (none).

Her hemoglobin, which was 8.3 Thursday afternoon was now back to 7.6. I'm not sure why I had to push this one, but finally he agreed to give her another transfusion.

It's amazing Teresa wasn't more uncomfortable. Very shortly after the catheter was securely in place, they had 1 liter of urine in the bag! That's 33.8 fluid ounces. For fellow Starbucks fans, for comparison, a Venti is 20 ounces. The Trenta is 31 ounces.

So where's the connection with not peeing and being anemic? (Or, a lot more anemic than she usually is?)

Her hemoglobin on 9/6/18 was 10.3. By the 26th, it had dropped to 8.6. Low, but not low enough to transfuse. By the 10th it was low enough, at 7.6.



In mid September, she had started noticing she was having a little difficulty peeing. But if she sat long enough, she'd go. And then her legs gradually started swelling, but I assumed that was mostly because the tumor was surely blocking her lymphatic system, just like in August 2017. We're pretty sure, actually that the leg edema is one of the key reasons Dr. Greene took her into emergency surgery last year. Wish it was a good enough reason now!

Teresa hadn't complained much about the peeing difficulty so it never got mentioned to any doctors/nurses.

How many of you know that your kidneys produce a hormone called Erythropoietin (EPO)? Guess what it does? Stimulates red blood cell production. Guess what it stops doing if you have kidney disease or damage? Yup.

Unless something changed drastically (we still haven't seen the CT report - I was hoping I'd have it before updating here), the tumors have never invaded any organs. Most of them (organs) have remained stable this whole time, including her kidneys. The tumor is obstructing the bladder however, and obviously caused urine to backup in the kidneys because the bladder was unable to release. Hence the catheter.

So this fluid retention could certainly have been the reason for the abrupt decline in eGFR. It was 62 in the ER. The doctor said he couldn't do anything, and that they only refer to nephrology when a patient needs dialysis, which she didn't. (Nephrology focuses on kidneys.)

[Here's an interesting abstract from 2006 re: bilateral leg swelling + distended bladder, wherein correction of the urinary obstruction brought improvement in leg swelling. <https://www.ncbi.nlm.nih.gov/pubmed/17390552>

Teresa's legs are still swollen, but are no longer hard and solid since the catheter has been in place.]

Oh, and Teresa was supposed to start her new chemo on Thursday night (they'd been able to get her a sample bottle), but when I realized we needed to go to the ER, I advised her not to start it. No sense in introducing new variables into the situation. I texted Dr. M to let her know. She wrote me back early Friday morning and agreed with that and said to hold off starting it until her labs were stable.

We were discharged not long after shift change -- which resulted in us not leaving with everything we needed, and the new people on the floor sped up her transfusion to get her out faster . .

We were out in the parking lot by the time we realized they didn't give us anything to empty the catheter into, or any new bags. Sara said she'd follow us back, but stop at CVS to get us something to drain the leg bag into (they'd switched her from a night bag to a leg bag at some point).

The 30 minute trip back was, shall we say, not fun. I'd had no sleep for far too long. I never heard Sara arrive or leave. I still feel like I haven't caught up on sleep from that night.

I forget if we went back to Roanoke on Friday or Saturday.

### **Sunday, October 14:**

The first Home Health nurse comes to the house to drain fluid through the PleurX system and show us how to use it. We've been told someone will be coming a few times a week for 6-8 weeks. Nurse was really nice. Told us another nurse would come Monday to draw labs so we could find out ASAP if she could start her chemo.

She shows us how to work the drain but promises we'll get instruction multiple times until we're comfortable.

This is also the day we get the third/final denial for insurance coverage of the targeted chemo. I ask them what it would cost retail, without insurance.

\$19,000. NINETEEN THOUSAND DOLLARS.  
A MONTH.

So... no buying it out-of-pocket, then.

### **Monday, October 15:**

I speak with the case manager for the genomic testing support. They've been looking to see if they can get a successful appeal, and have let us know there's options they can help with if the appeals are exhausted.

On the previous Thursday, I had let Jennifer know about the option of getting the chemo free directly from the manufacturer. We learned about this from the wonderful Oncology RN who is helping us from afar (Teresa Darr, TY!!!!). She had faxed info about it to Dr. Musgrave's office twice.

Dr. M, via Jennifer, texted to let us know that the CT shows no bowel obstruction, but did show hydronephrosis with bladder surrounded by tumor, and that Teresa can be referred to urology for stent. (Hydronephrosis is basically just excess fluid in the kidney(s) due to a backup of urine. This is now hopefully resolved w/the catheter, but does nothing about the tumor surrounding the bladder issue.)

Everything I've read so far about stents indicates they are temporary until obstruction is resolved; usually within 3 months. The obstruction, of course, is the tumor, so now we're back, again to that problem. Removing or debulking the tumor would resolve numerous issues. \*sigh\*

Home Health didn't call by mid-afternoon, so I called. Not on schedule, no idea about labs or anything. Their triage nurse calls back later and leaves a voicemail to tell me they'll come on Mondays and Thursdays - not asking if this works with our schedule, but telling us that's when they'll come...). The labs will get done Thursday. This puts an even longer delay on starting chemo.

**Tuesday, October 16:**

I receive a call from an unknown 1-800#. So far, these have all been from the insurance denying chemo appeals, but we've exhausted them, so it seems unlikely they're calling back.

Nearly immediately I'm asked for T's date of birth, so now I'm somewhat suspicious.

After some back and forth, it's clarified that she's legitimately calling from the EASE program for Cabometyx (cabozantinib) about providing the drug directly to Teresa, bypassing insurance. Dr. Musgrave's office had applied that morning.

I receive a patient authorization form to be filled out and then signed by Teresa. We do that and send it back.

A few hours later, I receive this e-mail:

"Teresa has been approved for the patient assistance program with EASE from 10/16/18-10/16/19. She will receive the medication at no cost to her. McKesson Specialty Pharmacy will call you within 24 hours to set up delivery of the medication."

Holy crap!

HOLY CRAP!

I never thought it would actually happen.

**Thursday, October 18:**

Home Health came today. Drained 1 liter off of Teresa's lungs. Probably could have gotten more but they're limited to 1 liter at a time to reduce risk of things like a collapsed lung, which is more likely with large volume procedures.

Nurse tells us her visit is the last one; that the insurance only approved 2 visits even though we were explicitly told we'd get 6-8 weeks. But the nurse is trying to get us more since she can see that Teresa needs a lot more help between getting labs done, drainage done, and resolving the edema (or lymphedema) in her legs as best as possible. (The denial letter from the insurance came Friday, that out of 15 visits possible, only 2 were approved because 15 were "not medically necessary for disease of the uterus" . . . so while the home health team may be trying to get more visits approved, I'll be calling BCBS too to find out exactly what we need to do, and why it

was put in as "disease" and not "cancer".)

McKesson Specialty Pharmacy calls this day too to arrange shipment of the cabozantinib. It's arrived here by 10:15am, on Friday, October 19th, via FedEx! We received additional chemo education over the phone, including careful explanation of the more severe, rare side effects of this drug. We're told we will get a welcome kit of sorts with the drug. They don't just send the chemo, but a booklet and supplies to help with the more common side effects (lozenges for nausea, anti-diarrhea tablets, and lotion for hand-foot syndrome).

You can read about the [EASE program here](#), and it also describes the chemo and side effects.

So now, we're just waiting on the chemo kit and the okay by Dr. M that Teresa's labs are stable/good enough for her to start the chemo. Out of all of the chemos T has tried, this one has the best chance of working because it is targeted to a mutation in her tumor, but please keep in mind that does not mean it will work.

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I know that this is a LOT of information, so please ask if you have any questions!

## Comments

Been thinking about you all a lot. My prayers are with you.

—Brenda Boyer Smith, October 19, 2018

Thank you for the update. Continued prayers for you both. Take care.

—Joyce Reynolds, October 20, 2018

I am so glad you resolved the issue with the chemo. Fingers crossed that it helps. As for the stent, I have had one for almost 5 years because of scar tissue in my ureter. It needs changed every 3 months.

—Michele Dillon, October 20, 2018

What a roller coaster! Firstly, I am so, so glad you were able to get access to the chemo drugs. But I'm still so sorry to read about your struggles with the insurance and having access to a nurse. I hope that the chemo helps once you're able to get going on it, and that this can hopefully lead to the surgery you want (that nobody seems willing to attempt.) It's hard for me to wrap my head around the US medical system, and it just makes my heart hurt, so I can't imagine how frustrating and stressful it must be to experience it first hand. Sending virtual hugs your way, and will keep an eye out for updates. Love, Neat.

—Anita Higgs, October 21, 2018

<3

—*Harriet Berk, October 21, 2018*

Thank you for the update. You and Teresa continue to be in my prayers

—*jim bier, October 22, 2018*

Thinking about you, Teresa, and Amanda, probably almost every day. I put in a new account which leads to an email that I check more often, I will check out Teresa's new FB page as well. Lots of love to you both.

—*Paula Durbin-Westby, November 15, 2018*

## Into The Woods

*Amanda Grabler, November 15, 2018*

Starting October 24, Teresa began taking her latest chemo: Cabometyx (cabozantinib). She managed 13 days before the heartburn side effect, and by day 13, nausea, became too much for her. We texted Dr. M and got a chemo break for her through her next appointment, on 11/14. The chemo has a long half-life, so it took awhile for the side effects to become somewhat muted as the chemo slowly got out of her system. The heartburn and nausea made it difficult for her to retain foods and liquid, often vomiting to feel better. This, combined with the involuntary anorexia (i.e. cachexia i.e. wasting syndrome), made her weaker and weaker. It also led to dehydration and a severe electrolyte imbalance.

She should have had weekly labs, but her insurance kept denying visits for home healthcare, so they weren't getting done. The last labs from home health showed sodium dropped to 125 and potassium up slightly at 5.5, but no one said anything about this.

November 14th, she saw her cardiologist and her oncologist. Her cardiologist, Dr. F., drained 750ml off her right lung from her pleural catheter. I privately asked him about surgery because of a doctor I'd had recommended up in NYC (a general surgeon with amazing talent) and he said at this point, he couldn't imagine Teresa surviving a surgery to debulk the tumor.

That afternoon we went to see Dr M. Those labs revealed an alarming change:

As many of you know, on Wednesday, November 14th, Teresa was taken by ambulance to Bristol Regional

Medical Center (Bristol, TN), from the Wellmont Cancer Center. We were told that she could just have months left -- but maybe just days. That we needed to have her admitted to the ER immediately to fix her numbers, and to consider hospice.

Her labs were bad overall, but most concerning was sodium, which was down to 115, critically low (range is 135-145) and potassium, up to 6.2, critically high (range is 3.5 - 5.3). Anything higher than 6.0 is dangerous and requires immediate treatment. Too much potassium in your blood can lead to dangerous, possibly deadly, heart rhythm changes.

Originally we considered getting her stable in the Bristol ER and then taking her back to Roanoke before the winter storm hit. But the ER doctor cautioned the temporary medicine would wear off in a matter of hours and she could easily have a heart attack in the car.

I told them to admit her. And we really like BRMC and the doctors and nurses. We've always had good experiences there.

They gave her several meds to bring the potassium down, and also worked to bring her sodium up. That part has to be done very slowly, only a few points at a time, or her brain could swell.

On top of this, her blood pressure was really low. I think the worst was around 58/43. Slowly, slowly, with the help of a lot of pressors, they got her BP back up. When I left the hospital tonight to go have dinner, it was up to 102/66. And they'd severely reduced the amount of pressors she was on and it was still holding steady.

Her kidney function, which should be above 90, has been steadily dropping. Yesterday it was down to 24. Her creatinine, which should be between .50 and 1.10 was up to 2.31. Her bilirubin was up to 2.1 (0.3 - 1.2).

Her ureters are being compressed by the tumor. Today, a nephrologist came by to talk about options, and said he'd send people from urology to see us. Two urology NPs came by later.

In the morning, they're going to either put stents in her ureters, or, if there's no room, see if Interventional Radiology (IR) can put percutaneous drainage tubes in her back (through the skin/muscle into the kidneys) which will drain into bags, much like the Foley catheter for her bladder. This can potentially allow the kidneys to drain properly. This is a Percutaneous Nephrostomy and you can read more about it

here: <http://www.uhs.nhs.uk/OurServices/Radiology-scansandimaging/PatientInformation/PercutaneousNephrostomy.aspx>

The goal with the nephrostomy is to improve her biochemistry by bypassing the bladder and ureters altogether and ensuring that the kidneys drain completely. If her metabolic numbers level out, it should also help her feel much better. The stents could do the same, but the tumor burden may mean there is simply no room to insert them.

If there is no one at IR who can place the percutaneous nephrostomy, they will run her (by ambulance) down to Johnson City, TN, where there is a Level 1 Trauma Center, and have the procedure done there.

On Thursday we were visited by: wound & surgical care for her legs, nephrostomy, urology, a case manager (who would help make sure T's insurance approved real visits from home healthcare, not sporadic ones now and then), someone who works with hospice decisions, a dietitian, and wound care again.

Dr. Vance, who was part of her original surgical team, came by. He has ideas about her legs (non surgical). I asked him about debulking the tumor. He didn't feel he had the skill to do it safely, and does not feel she could survive an operation at this time.

I told him about what I'd learned about proton beam therapy with hyperscan at Georgetown (Northern VA), thanks to paperwork sent to me through my Dad from my Cousin Lee. Proton Beam therapy is super pinpointed radiation. And they're supposedly able to do it there with any tumor in any location. The advantage of this kind of radiation is the radiation beam is *tiny*. Like pencil point, so it can be directed into specific areas. This could let them reduce the margins of the tumors, pulling them back from the organs they're nestled up against, making surgery safer. You can read about that

here: <https://www.medstargeorgetown.org/our-services/cancer-care/treatments/proton-beam-therapy/>

Thanks to another LMS patient (online) I learned about Dr. Tomoaki Kato. You can read about him here: <http://columbiasurgery.org/tomoaki-kato-md>

Like Dr. Greene, Dr Kato is a general surgeon. And he has a very impressive list of expertise and of miles-outside-the-box creative and innovative surgeries. Including a type of transplant surgery which makes immunosuppressant drugs unnecessary. He's very talented at all sorts of abdominal surgeries. He knows about sarcoma too.

If she can defy the odds and get her kidneys, metabolic panel, and legs under control, and improve her nutritional situation, we can see if she could first receive the proton beam therapy and then see Dr. Kato about surgery. He *is* taking new patients.

Now, please note that a lot of these are BIG maybes. She still has a lot of turnarounds needed. She's still very much at risk. They've asked her twice about how much she wants to do in regard to extraordinary measures in case her heart stops or something else happens.

She has a long road to cover before any kinds of big treatments could be real life options. But Dr. Vance seemed to think that if she got to that point, she had a chance of surviving radiation and surgery, then these two options sounded like really good ideas.

She cannot be on chemo at this time, and she was only on the targeted therapy for 13 days, so it'd be really hard to know if it started working yet or not. By not being on active treatment, she could start hospice when she does leave the hospital. We've been told by more than one person that just because you go on hospice doesn't mean you have to stay on it forever. Some people improve once they get a few things under control, and come off of hospice.

But it could also be a permanent solution. :-(

She doesn't want it to be though. Know that. She's not ready for this to be the end. Even with as much pain as she's been in these last few days, she wants to keep moving forward. She's ridiculously hardy and determined - but she has a lot of obstacles to overcome.

She will be in ICU probably for awhile.

She can have 2 visitors at a time. Please let me know if you want to visit. You cannot be sick. You cannot have been exposed to sick people. You cannot have sick people in your home or immediate working area at your job. She cannot afford to catch ANYTHING.

But if you're in good shape, she can still have visitors! She's on strong pain medicine, especially for her legs (the lymphedema got really bad), so she's a little out of it a lot of the time, but even when it doesn't look like it, she's usually paying attention!

There is an ICU waiting area, so if the visitors at any one time are going to go over 2, then if you wait in the ICU waiting area, you'll be close by, and can take turns sitting and chatting with her. She really loves company!

Yesterday and today she spent time with our friends Kristen and Sara, and again today. Also, today, her Mom and brother drove down from Long Island and had a nice visit with her. They did run into difficulties with the weather, and it's still not great out, so if you're coming through any of that, please be careful!

And, yes, as terrible as it is to think about, with everything going on, it could be your last chance to see her. We all hope it isn't, of course, but unless you will risk bringing sickness to her, don't putting off visiting her this time.

## Comments

Sending you both all of my love and virtual hugs. I'm useless with medical talk, but it does sound like there might be hope (even the smallest amount.) I'm still devastated that my timing when we came to the US was so poor and that we couldn't meet in person, because knowing you online, through the fic and the chats and the facebook comments, and now following Teresa's story on caringbridge has been just as real as any "in person" friendships I've had. I'm not good with knowing what to say, but I hope that things go the way you're hoping, that you can defy the odds and that you can try the Proton Beam therapy.

—Anita Higgs, November 16, 2018

Thank you for updating. It sounds as though Teresa is getting excellent care there. You have both been on my mind. I've been sending you both !ove. And whatever else you need, I'm just not sure what that may be...peace, strength,patience...



—*Michele Dillon, November 16, 2018*

There is still some hope. I am still having a cold! My thoughts ( and love) are with you.

—*Heidi Baird, November 16, 2018*

Love you guys and think about you everyday! Hold on to HOPE. You are one of the strongest people i know T.

—*Jim Constantinides, November 16, 2018*

Hugs, hugs and more hugs to you both!????

Thank you for the update. There are people that come off hospice all the time.

—*Sue Harris, November 16, 2018*

Teresa is a strong person .I pray for HOPE and MIRACLES to take over and bring her back to a good day. You have my love and prayers. May the hands of God lay upon your body Teresa and bring healing to you. Love to you both.

—*Ellie Scofield, November 16, 2018*

She is in my thoughts and prayers. I'm glad she is strong and determined. That could make all the difference. She is so lucky to have you by her side too!

—*Kristin Miller, November 16, 2018*

You are both being so brave and strong. T is in my ???. Prayers for both of you.

—*Maura Fischer, November 16, 2018*

A wise man once said, "Happiness can be found even in the darkest of times, if one only remembers to turn on the light." I am holding you both in the light and hope that it gets brighter very soon.

—*Lana Whited, November 16, 2018*

I so wish I could visit! Know I am "with you". Love.

—*Heidi Baird, November 17, 2018*

## Still in ICU

*Amanda Grabler, November 19, 2018*



Teresa has been partially discharged. The kidney doctors have discharged her because her creatinine is normal, as are sodium and potassium, but they won't print out the labs, and they won't release them into MyChart until she's fully discharged, so I have no idea if it's borderline normal or in the middle normal or what. That is super frustrating. (Sometimes the nurses will show me on the computer, but I can't write ALL of the labs down easily, so I can't track her progress myself either, which I'd really prefer.)

Also, no one has mentioned what her eGFR is (kidney function). It should be above 90. Hers was 24 on admittance last week. I don't know how long it takes to recover that.

She will have to see Dr. Beard (the surgeon who placed the ureteral stents) in 6 weeks for follow-up, and to have the stents replaced to minimize risk of infection or them getting blocked.

Her blood pressure was 120/80 this morning, and her color was a lot better. She's completely weaned off of the pressors and of the dilaudid. Her pain is being controlled by oxycodone (without Tylenol).

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They're going to see if someone can drain her PleurX catheter since it hasn't been drained since last Wednesday when Dr. Fernandez did it for her (750ml, stopped on its own). And we're trying to find out if someone can see about doing a paracentesis in case there's any fluid in her abdomen. The last CT said there might be a little. Any less pressure would be a plus.

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Since the kidney doctors have discharged her, there's no longer a fluid intake restriction. And we got a numbing spray for her throat yesterday to make swallowing more comfortable (it is sore from the airway they did for surgery). But she's still not eating a substantial amount. I realize that the kidney failure, combined with the anemia, and the pain medicines, led to depressed appetite, but I also know that she's still dealing with the cachexia (involuntary anorexia) which can become even a bigger problem than the cancer itself, and she **MUST** get her weight back up or it will be very hard to get further treatment for her.

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Sorry this is a little out of order. Without the usual lab paperwork to go by, and our sleep schedules being way off, all of the days have run together.

Yesterday we got her a blood transfusion. (1 unit) I still think she needs another one as she's still under 9 (11.7 is the bottom of normal), but it did help. Her color is better and she's somewhat more alert -- for everyone else; not so much for me.

She's still having some cognitive issues (sporadic hallucinations, for example). A great charge nurse, Betty, got her a better bed the other night (it moves to help prevent bed sores). T was already getting a bed sore, but hopefully it was caught early enough and they are treating it. The new bed should help with that going forward.

**Legs:** They are a much more normal shape and size; the medicated compression wraps are doing a good job at getting the fluid up above her knees, and with her kidneys working, flushed out like should have happened all along. But her skin still looks *terrible*. They changed the bandages today. With the amount of fluid her legs are still weeping, she will probably need that done every other day at least, if not every day. The wound care doctors plan to move her up to higher compression soon (within the week, I think).

As far as her legs go, she is not discharged, which is good, because we wouldn't be able to take care of them properly at home, and then she'd be back where she was. I'm not sure how they plan to resolve this long-term though, because as long as the tumor is still blocking her lymph system, this is going to keep happening.

But the only surgeon I know of who probably has a chance of really getting it out is in NYC, and before she sees him, we think she should have the Proton Beam therapy in Georgetown (NoVA) to get the tumor margins away from her organs as much as possible. This, in theory, will make surgery safer.

But she has to be stable enough to travel, and stable enough to survive both procedures -- which means she has to get her body weight back up, as the tumors have decimated her body fat and muscle. This is an unfortunate, but common, complication of many cancers, especially when it is advanced cancer.

She is still very much interested in having visitors, even if she isn't 100% responsive when visitors are here. But she tries!

**Please be aware that she does NOT look like herself. But please don't let this scare you out of visiting. She's going to continue to have bad and better days. The photo on this post is from a better day. We're not quite at "good" yet. Come anyway. This last week should show you that waiting until things are great could mean not getting to come at all.**

She has a super aggressive cancer that has not responded well to past treatment, and then all of this happened. She is still very tired. But don't say you'll wait until she's not tired, because that might never happen -- or it could take many, many, many months.

Phone calls are difficult for her because she can't hold up the phone -- if nothing else, because of all the wires she's hooked up to, but she loves having people come see her in person.

The only restriction we have is as before: If YOU are sick, if someone IN YOUR FAMILY (at your house or that you see regularly) is sick, or if you have COWORKERS who are sick (or who have sick kids), you cannot visit at this time. Catching something could set Teresa's recovery back weeks or more. Or be fatal. TY for understanding.

Please contact me first before showing up, just in case. (Especially if you've never been before because you'll need someone to lead you back into the right ICU area.) There's also a 2-visitor maximum at any given time.

We don't know yet if, with the kidney discharge, she will be moved up to a regular room or not, which will be less restrictive on number of visitors (but not on health of visitors).

I'll post again as soon as I can.

Please ask if you have any questions.

**Edit:** Just learned (6:50pm) that she had 1 dose of dilaudid tonight for something. I don't know what or why.

## Comments

It sounds like she has made some great progress. I dreaded opening this post, but feel better now. I know sh'e still horribly sick, but at least she sounds more comfortable. Shame you aren't in Roanoke, we are headed there this weekend. (though I know you're much better where you are!) Sending you both our love, think of you all the time, sending energy that way to use however you both need.

—*Michele Dillon, November 19, 2018*

I wish we were going to get to see you! Hopefully one of these days it will work out again! <3

—*Amanda Grabler, November 19, 2018*

I'm presuming you know that dilaudid is a pain medication. I was given it when I had pancreatitis. I'm glad to know there are signs of improvement but sorry there are so many complications. Sending you both love.

—*Lana Whited, November 19, 2018*

Yes, I do. She had it after her surgery last year, and when she was in the hospital overnight in Roanoke for a blood transfusion. When I said I don't know why she took it, I thought I had written somewhere else in the post that she had been weaned off of it because it was causing problems -- like hallucinations and other cognitive issues, suppressed appetite, et cetera. And we were worried about addiction because while her kidneys were not functioning properly, she couldn't get rid of it as fast as you're supposed to be able to do. So we all agreed, including T, that she wouldn't be given it any more except in very necessary situations like having her legs rewrapped. And then I found out she'd gotten it today as soon as my Mom stepped out of the room. And then I found out from our friend Sara that she'd managed to get them to give it to her several times during the night -- whenever the person staying w/her was either not paying attention (possibly sleeping) or had stepped out of the room.

—*Amanda Grabler, November 19, 2018*

I wish I could come up for a visit now. Love to both of you

—*Maura Fischer, November 19, 2018*

Again, your hearts and strength together sing out about perfect love. Thank you for your example of how to treasure each moment and each other. Thinking and praying for always.

—*Sally Treanor, November 19, 2018*

Thank you. Mostly so far she's been ignoring me, actually, and will actively tune me out when I try to talk to her. It started when we were still in Roanoke and has just gotten progressively worse. It's been very hurtful for me to be around her.

—*Amanda Grabler, November 19, 2018*

