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Lymphomania

Kristi S. Martin Kennesaw State University, mihr1@aol.com

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Lymphomania

By

Kristi Martin

A capstone project submitted in partial fulfillment of the Requirements for the degree of Master of Arts in Professional Writing in the Department of English

In the College of Humanities and Social Sciences of Kennesaw State University

Kennesaw, Georgia

2015

Lymphomania is a blog that started out as a way to share details about my health with my family. I had several unexplained symptoms, particularly widespread itching, for about two years and had a very difficult time finding a doctor that could help me. All of my blood tests came back as normal. None of the medications I tried made any difference in my itching. Finally, some swollen lymph nodes and a series of infections ended up sending me to a hematologist-oncologist. After several tests and biopsies, my oncologist was finally able to diagnose me with Hodgkin's lymphoma. The daunting task of calling all of my family members and friends, repeating the same information over and over, led me to writing the information one time and sharing it via email. I then posted that email as the first post of my blog, which follows my journey from diagnosis through treatment, relapse, more treatment, and relapse again. I plan to keep blogging as long as I undergo treatment.

My eventual goal is to turn this blog into a nonfiction book. I've seen other bloggers have success with writing a book once they've generated a sizeable following. *Honest Toddler, Raising My Rainbow, dooce, and The Bloggess* have all released a book after blogging for quite some time. The author of *The Bloggess*, Jenny Lawson, has a story similar to my own. She writes about her life, but she also talks a lot about her medical issues, namely mental illness and rheumatoid arthritis. She is very funny, and often makes her readers look at the light side of life. She looks at the weirdness of her life and laughs at it. Lawson has over a million followers, so when she released her book, it went straight to the top of the New York Times bestseller's list. I have a couple hundred followers, which is definitely not enough to support a book release yet, but that number keeps growing as my friends and family share my blog with others. Once I recover, I plan to turn my blog posts into the chapters of a creative nonfiction book, similar to what Lawson did with her book, *Let's Pretend This Never Happened*. First, I will pursue the

traditional publishing route, but if I am unsuccessful in that endeavor, I will consider electronic publishing. I will, of course, continue blogging to maintain my original platform.

This blog has been a labor of love for me as well as a way to keep my family and friends updated on my progress. I have enjoyed blogging over the past year of my treatment and will continue to do so as long as I am able. Because of the nature of my audience (lots of family, including my parents), I've chosen to focus more on the physical aspects of my disease, rather than the mental and emotional. I've stayed mainly on the surface with this blog because of preference for humor rather than sharing deeply with my loved ones. Much of my audience enjoys the lighthearted look at a serious subject that I provide. I think it makes it easier for them to deal with the seriousness of my disease. I know this seems counterintuitive, but I am more comfortable in sharing strong mental and emotional responses with strangers. I think with the book, I will add more of that aspect in. I will also add in a little more sarcasm and acerbic wit, as I will have a wider audience whom I think will appreciate that aspect of my journey. There are some darkly humorous events that I have written about, but chosen not to share on the blog. The eventual book will be a better platform for those events. This will also help the book to be well-rounded.

Below is the text of my blog in its entirety thus far, including the pictures.

www.seegirlwrite.wordpress.com

About Me

I am a mother, teacher, and grad student. The purpose of this blog is to share my journey with Hodgkin's lymphoma. I was diagnosed in January 2014 after two years of unexplained symptoms and searching for answers. This has been a difficult path to walk, but it has been full of love, light, and learning. Follow my path with me. God is good, all the time.

January 24, 2014

Well, I finally have some answers regarding my health and I wanted to share what's going on with all of you. There are some family members whose emails I don't have, so feel free to forward this info. It's much easier for me to say everything once rather than call everyone individually, so I'm going with this more impersonal route, but know that I have no problem talking with you about this.

- 1. I have been diagnosed with Sjogren's syndrome, which is an autoimmune disease that attacks the regions of my body that make moisture (saliva glands, eyes, nose, etc.). There are some arthritis-type symptoms involved with this as well but as of right now it is not too bad. There is no cure, but it is milder than lupus and manageable with medication. For now, however, we will not be treating it. It goes on the back-burner because:
- 2. I have also been diagnosed with Hodgkin's lymphoma. This is a cancer of the white blood cells. It typically manifests itself in the lymphatic system, and a classic symptom of Hodgkin's is unexplained itching (a-ha!). This diagnosis answers many questions. Treatment of

Hodgkin's has a very high success rate, and I am quite optimistic about a complete cure. Now for the question and answer section.

What stage am I in?

Hodgkin's is staged according to which areas of the body have been affected (just on one side of the diaphragm or on both sides of it). Mine is mainly above the diaphragm but I do have some involvement in my abdomen (which is below the diaphragm), plus my sternum and left hip bone. Both above and below plus the bone involvement puts me at stage 4. Don't freak out. That doesn't make it any less curable. It just means I've had this longer than we originally thought. Why wasn't this caught with the previous biopsies?

Don't know. It just wasn't. Poor samples, sneaky cancer cells...who knows? The important thing is I've got a doctor who kept pushing and testing until she found the answer and now we've got one.

What's the treatment?

Chemotherapy. There are no tumors to cut out and no big masses of lymph-ness to radiate. If my doctor feels radiation is appropriate after chemo, then we will try it. My particular chemo treatment will be ABVD. Those letters stand for specific drugs. If you want more than that, Google it. I can't spell the names. This Friday I will do some baseline tests (lung, heart, brain function, etc.) and next Tuesday I will do another PET scan to have a picture of exactly where the disease is before treatment. I will get a port (much easier than doing an IV every time) and do a chemo treatment every other Wednesday until the end of June, starting next Wednesday. If for some reason we can't get the port done by then, we will start the following Wednesday. Wednesdays are the days my doctor is at the office I chose for treatment. They are also convenient for me schedule-wise. Nothing else special about Wednesdays.

Will I get sick?

Yes. These drugs have some side effects. But I will also get steroids and anti-nausea meds to help with the sickness and the fatigue. My doctor and nurses are very proactive about keeping their patients comfortable. I will not be puking all day long.

Will I lose my hair?

Also yes. Many of you know I have been growing it to donate it anyway. My wonderful hairdresser has graciously agreed to work me in so I can do that before I start treatment. Bobby thinks the Sinead O'Connor look will be sexy on me. I quite agree, though I imagine I'll have to wear a hat until the weather warms up. It'll grow back after I finish treatment. I don't plan to wear a wig because a) just the thought makes me itch and b) I'm not too worried about it. It's just hair.

What about work and school?

For now, I'm going to try to continue to work and do grad school. If I have to cut things out, I will. But first I want to see how it goes. I've promised Bobby that if things get overwhelming, I will take them off my plate. But I don't want to be home on the couch if my condition doesn't dictate that.

Why am I not more upset about all this?

I'm not going to pretend this doesn't suck. It sucks. A lot. But I'm choosing to be positive. I'm choosing to have faith. I believe that my doctors know what they are doing. I believe that God will make me well and whole again, in His timing. I am so grateful to finally have an answer. I am so thankful that the cancer I have is a curable one. I am so thankful that after a couple of weeks of treatment, my itching will go away. That alone is worth trading my hair and a few lunches for. I am also grateful for the wonderful support system I have in all of

you. I am not alone in this. I know that when my strength fails me, I will have all of you to fall back on. So keep the love, light, thoughts, and prayers coming. They mean more than you know. What can you do to help me?

Food – Bobby and I run a crazy schedule. The hours we are home are erratic, and we are rarely all four together at the same time. We've talked about it, and we've decided the easiest thing would be gift cards to restaurants near us and/or walmart/target/publix. This will also save me the trouble of defrosting, washing dishes, finding room in the freezer, etc.

Child care – If you want to help with watching the kids or picking them up from school, email or text me your phone number, email address, and days/hours you're willing to do that. We think we'll have it mostly covered, but we know there will be some days that we'll need help. I'd like to have a list to rotate with. On that note, we haven't talked to the kids yet as we just got all this info today. But we are planning to tell them that I've found what's making me itch and the medicine will make me very tired. Beyond that, we'll just be answering questions as they ask. Please check with me or Bobby before you talk with them about all this. We want to make sure they don't have any worry or anxiety beyond what is unavoidable. Yes, Mommy's sick, but she's going to be okay.

Bills – I don't even know where to start with this one. I've already racked up thousands in hospital and doctor bills. Once we've gotten treatment situated, we will start doing the math and setting up payment plans. I don't have plans for a fundraiser or anything right now. If you want to contribute, let me know. I'll pick a Wellstar bill and send it to you. :)

I love you all to the moon and back. Don't be afraid to ask me questions. Don't be afraid to act like I'm a normal person, either. Definitely don't be afraid to hug me. Don't worry, be happy. Everything is going to be fine.

January 26, 2014

Well, I had my first treatment and it went great. I had a blast entertaining the nurses, walking around with my IV pole, and watching daytime TV. Then I went home. And promptly got knocked on my butt. I think I must've slept for 12 hours straight, and I've been sleeping since Thursday off and on all day and night. The good news is that the anti-nausea meds are working. But I think they make me tired. I'm starting to realize that a good attitude alone is not going to get me through this. But this is the path God has set before me, and dammit, I will crawl it if I have to in order to make it out of the valley of the shadow of death. I am not alone in this, even though it is my path alone. I see all of your footprints around me, and I am grateful.

January 29, 2014

It is four am...again. Not an hour of the day I care to see much of, but one I seem to be getting well acquainted with. Ah, yes...the chemo insomnia. I thought for sure that I would escape it since I had the chemo torpor just a few days ago. Sleeping during the day and at night don't always go hand in hand. Well, c'est la vie, say the old folks, just goes to show you never can tell.

So here I am, sitting at my computer, and it is seventeen degrees outside. In Georgia. It took me seven hours to make it home today. Seven. Someone who works at my son's school had to take him to a friend's house. My husband got in an accident (including being hit by a police car) and had to walk for hours in the snow. My father spent hours in the car on

treacherous country roads trying to get to my son. But we all made it home safely, together. We are all snug in this house with food and water and warmth. So in the long run, it doesn't matter too much that I can't sleep right now. I am able to be awake, alive. I am able to be grateful for the safety of my family.

A few days ago I was looking at this long long road and lamenting. Six months of treatment. It's a long time. But today I am not lamenting. I was strong enough to drive for seven hours with my precious four year old, get her home safely, and do it without yelling! That right there proves there is such a thing as grace in this world. The strength to make it is within me. I know it is going to be much harder to tap into on some days, but it is there. Abiding. God is good, all of the time.

February 3, 2014

My hairdresser is amazing. When I was pregnant with Elliott, my hair was pretty long. I also had what I like to refer to as "the crazy." If you have had a baby or know someone who has had a baby, you are familiar with the crazy. So one day my crazy decided that my hair needed to be cut. Immediately. Where do you go if you need your hair cut immediately? One of those strip mall places. I think it was Great Cuts. I emerged with several inches having been blunt cut off, looking much like I'd cut my own hair. Now the crazy needed to be appeased even more. So I found the Davis Clay Salon in Douglasville, which ironically was even closer to where we lived than the awful haircut place. They took one look at me and told me if I'd be willing to wait, they'd be happy to take me as a walk-in. And that's when I met Valena.

Valena has been my hairdresser for seven years now. She is a miracle worker. When it comes to my hair, she is really more of a lion tamer than a stylist. My hair is very fine, but also very thick. And thanks to the awesomeness of having two babies, there is a weird patch of crazy curly/kinky hair in the back. We've learned that my cuts will take longer than 45 minutes. We've also learned that product and flatirons are my friends. Valena has done all sorts of awesome cuts on me, my favorite of which was a precision angled bob that required monthly maintenance. So, yeah, I ended up growing that one out.



About two years ago, Valena and I discussed my plans for my hair. I was on the fence between growing it out long and going super short, like pixie short. Now this may come as a surprise to those of you who've known me for a long time and seen the rainbow of colors and myriad of styles my hair has been, but I've always been a little scared to go that short. So I asked Bobby what he thought, and he voted for long. I've been growing my hair for a couple

years now, and it's gotten very long indeed. So long, in fact, that I'd started thinking about donating it.



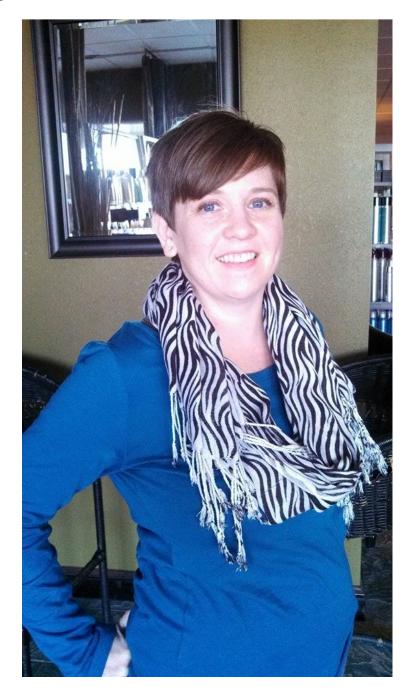
Then I was diagnosed with cancer. The treatment is chemo, which we all know makes one's hair fall out. I talked to my doctor, and she said, "If you want to donate your hair, do it now." As in, do it before we pour all these chemicals into your body, which, by the way, will

definitely make your hair fall out. So I called Valena. Normally I have to wait about two weeks to get in with her. But she and the awesome staff at Davis Clay moved things around so that I could come in on a Saturday morning and get my hair cut. I gave her free license to do whatever she wanted with my hair. My only stipulation was that we donate as much of it as we could.

It ended up being 12 inches. I have never had so much fun getting a haircut in my life.



And Valena created this fabulousness, which I absolutely love. It's taken some getting used to, but it's so much easier. And I think I look pretty darn cute. When it starts to fall out, I'll go back and she'll shave it all off for me.



When I went to check out, the receptionist told us that another client had overheard my story and paid for my haircut. I had been fine up until that point, but that is when Valena, the

receptionist, and I all got a little misty eyed. What a sweet gesture. There are angels everywhere. And now some adorable little girl with alopecia or cancer is going to become a sassy little redhead.

I cannot think of a more blessed trade-off.



February 8, 2014

I had my second chemo treatment on Wednesday. Lots of new stuff to digest. My white blood cells are down, particularly the ones that fight infection (neutrophils). So I'm neutropenic, which means my immune system is not so much right now. It's an expected side effect, though not necessarily expected quite so early on.

What does this mean for me? It means more meds: an antibiotic, an antiviral, and an antifungal to fight anything that comes my way. It also means I get to wash my hands and wipe down surfaces and wear a mask when I'm around people. The hand washing and wiping is no big deal, but the mask...oh, the mask! How freakin' annoying! It's like having my head stuck under the covers all night – no fresh air. And I can't wear my glasses because they fog up no matter how I adjust the mask on my nose, so contacts it is. Sunglasses I can sort of do since the lenses are so much bigger and I can slide them down my nose a bit. I look like a cranky librarian-surgeon.

But I'm taking all of this as a good sign, because the cancer is in my white blood cells. So if the good WBC's are dying, then the bad ones are too. The itching has gone down. And the swollen lymph nodes have gone down. My doctor says with this kind of cancer, we just power through the neutropenia. We don't stop treatment for anything. That makes me glad; I want to keep going and get it done!

I also asked my doctor to cut my Zofran (anti-nausea) from 8 mg to 4 mg. What a huge difference! I can see straight! I can type! I can be awake and sort of make sense to other people! I still have the 8 mg just in case I need it, but now I can take 4 mg several times a day without being high as a kite all the time. Much better.

I even made it to my playwriting class Thursday night, which I desperately needed. I was at a standstill with my play, and hearing it workshopped aloud made quite a few things clear to me. For one thing, I need to get to know my characters better. They're wishy-washy with their actions because I'm wishy-washy about them. Okay, enough use of the word wishy-washy. The point is, I'm still moving forward, I'm still living my life, and I'm still beating this thing. To a pulp. In the ground. Insert your favorite violent cliche here, 'cause that's what I'm doing to this cancer.

I got this.



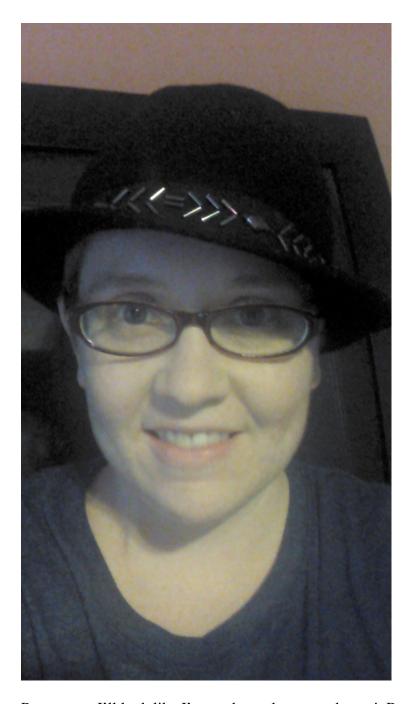
February 15, 2014

Well, it is finally happening. I know many of you have been wondering. My hair started slowly coming out a few weeks ago, but this past week it's been falling out as fast and furious as the

snow came down. Except the snow and ice have now all melted, and there is still hair all over my pillowcase. I don't have any bald spots yet. As a matter of fact, you probably wouldn't be able to tell by looking at me that my hair is coming out in handfuls in the shower. (Really annoying. I have to rinse off like 80 times.) But it's a little thinner, and my part is a little wider. And I look like I've recently acquired a very cuddly cat whose fur is the same length and color of my hair. Because it's everywhere. All over my clothes, the pillows, the bathroom, Bobby... I think I will actually be much happier once it's all gone, because then I won't be constantly picking it off of myself anymore. In a week or two, I will probably go ahead and shave it. You guys know me, and my patience level is not equipped to deal with constant massive shedding. I am, however, for the thousandth time, SO thankful that we have leather furniture, especially since the couch is my favorite spot to be lately.

The other 999 times I've been grateful for leather furniture have all been kid and pet related. For instance, when I found a half-eaten Gogurt in the crevice of one of the arm chairs last week. Fiona had decided she was finished with it. Or maybe she was saving it for later. Either way, half a roll of paper towels and some water and voila, no more Gogurt. And no more Gogurt allowed in the living room. Mean mommy. The kitchen table is no fun to eat at.

Hopefully the weather will warm up soon, since I have no plans to wear a wig. I did get a couple of cute hats on clearance at Target (my happy place), and my dear friend Rachel sent me her collection of hats and scarves from her chemo days. Here is my new favorite. I think I look ready to solve a mystery. Or write one.



Pretty soon I'll look like I'm ready to clean your house! But don't let that fool you.

Mama don't do no scrubbin' no more. That's what we have husbands for. ;)

February 22, 2014

I have an amazing team of medical professionals. My hematologist-oncologist, Dr. McDonald, is quite possibly the most amazing, wonderful woman on the planet. You see, it took me two years to get a diagnosis. Two years of unexplained itching, trying different meds, blood tests, fatigue, stress, you get the picture. In September, when my lymph nodes started going haywire, my general practitioner sent me to a hematologist-oncologist here in Hiram. Bobby and I weren't in love with her. That's when we heard that one of the new doctors in Bobby's practice (Resurgens Orthopaedics) was married to a hematologist-oncologist. Dr. Grimm (no joke, that's his name, thank God she kept hers!) referred me, and I was seen in less than a week. Unheard of. She really took the time to talk to me, ask questions, look at my labs, order labs she thought had been left out, and physically touch my body to feel the problem areas. She's straightforward, kind, compassionate, and has a great sense of humor. When the first biopsy didn't give us an answer, she kept digging. When the bone marrow biopsy, mammogram, and ultrasounds didn't give us an answer, she kept going. When the PET scan showed bright spots, she convinced both me and the breast surgeon to do one more biopsy – a large lymph node under my left arm. So we did it. And lo and behold, there it was. Classic Hodgkin's lymphoma. Praise God, an answer! A real answer with a real plan for how to treat it. I was amazed at how quickly Georgia Cancer Specialists worked with the surgeon and Wellstar (the hospital system here) to get me on my way to treatment. In less than two weeks, I did pulmonary function testing, an echocardiogram, a brain CT, another PET, had surgery to place my port, and did my first chemotherapy treatment. I guess when you're at stage IV they don't mess around. But I'm so thankful they didn't! It may have taken her from September to January to figure it out, but Dr. McDonald truly did save my

life. And she continues to do so, every week. She's proactive about all aspects of my treatment, and to be honest, if she told me to stand on my head every day, I'd do it.



Did I mention she's also named Kristy? And she has a daughter named Fiona? Kismet, I tell you. This is Tuova, Dr. McDonald's amazing, sweet, thoughtful, and PATIENT nurse, me

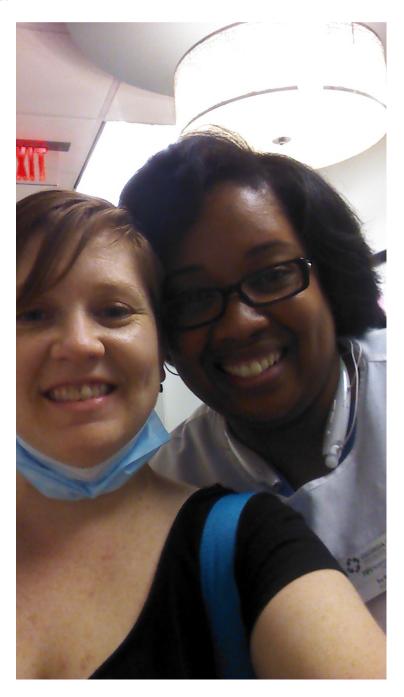
ready for chemo treatment #3, and Dr. McDonald. Two of my favorite people in the world right here.

Here are two more favorites:



This is Derby, my chemo nurse. She's always ready with a warm blanket, a ginger ale, and the good drugs. She's also so patient and hardworking. She's always checking on me to

make sure I have everything I need. I'm usually the last one to leave since my treatments take so long (4-5 hours), so we've gotten to know each other pretty well already! Derby's wearing a party hat because it was a doctor's birthday that day. I love that they like to have fun at the office.



And this, my friends, is Tay, the lab tech. Now I have become a connoisseur of phlebotomists, and this woman is the real deal. The absolute best. She can stick a needle in my arm and make it not hurt. She can get blood out of any vein. She's fun and hilarious and always puts me at ease, even when she's having to flush my port a million times because I'm dehydrated. If I could, I'd take her with me to every other doctor I go to.

So these are some of the people I spend A LOT of my time with lately. They are awesome, and they were all kind enough to allow me to write about them. There are a ton of other people at Georgia Cancer Specialists that do awesome work: the receptionists, the office manager, the social worker...all of these people know me and greet me by name when I walk in the door. It's like Cheers. Except there's no beer. But there are drugs, definitely a lot of drugs. The life-saving kind.

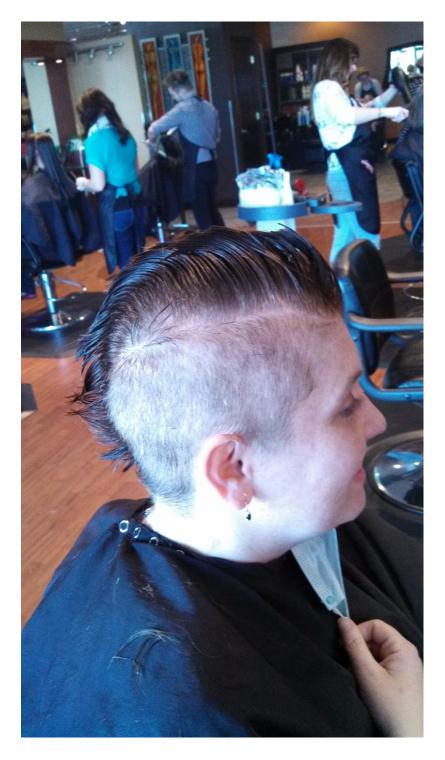
March 3, 2014

So if you follow me on Facebook, you already know that I shaved my head about a week ago.

And believe it or not, it was so much fun! Once again, Valena the awesome hairdresser to the rescue! I got one last fabulous shampoo and scalp massage, and then a mohawk, just for kicks.

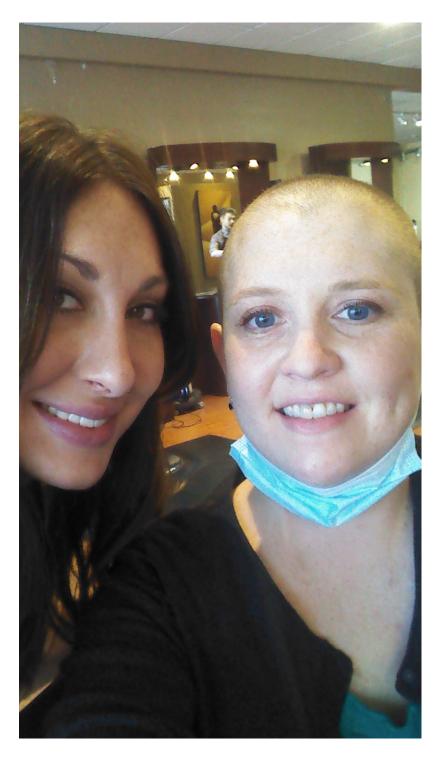


Am I badass, or what? (Yes, mom, I just said badass. Sorry about that...not really.)



I'm thinking I just might go with the rock star look when my hair starts to grow back.

So now my shower time is cut in half – no more rinsing out conditioner for days. And no more handfuls of hair! It's still coming out, but it's not nearly as noticeable now. It just looks a little patchy. We shaved it down to a 1, which is the shortest guard on the clippers. Here it is:



That's Valena. Is it just me, or are all these awesome women in my life gorgeous? (If you are an awesome woman in my life that's reading this right now, that includes you. You are gorgeous.)

And I must say, bald Kristi is not too shabby either. I though shaving my head would be a lesson in humility, but it has turned out instead to be a reminder that we are all so much more than our outward appearances. It has reminded me, yet again, of the astounding kindness of the human spirit; so much love and solidarity has been poured out to me by both people I know and people I don't know. That has been the true lesson in humility for me: the reminder that we are commanded to love our neighbors as ourselves. There have been many times in the past when I have not done so. But instead of punishing me for those lapses, God has heaped His love on me tenfold through all of you. This may sound funny, but I think getting cancer has actually strengthened my faith. It has certainly showed me that the world is still a beautiful place, full of wonderful people. You people.

March 12, 2014

I have now finished 4 chemo treatments out of 12, so I am 1/3 of the way finished. (Who says you can't teach an English teacher to do math?) I feel like I am really starting to feel it now. At first it was kind of like, "Oh, yeah, I'm going to get some medicine and it's going to suck for a few weeks but then I'll be all better!" And now I have really to dig my heels in for the long haul. But that's okay, 'cause I got this. I just have to remember to cut myself some slack every once in a while. I'm not going to be able to sit and do homework for my entire treatment session, I'm not going to feel like cooking on the nights I'm home (not that I ever do!), and it's totally fine to take a nap every day. Actually, I think if everyone in the world took a nap every day, it would be a much nicer place. But that's just me.

So at my treatment last week, my neutrophils were up a little bit (yay!) but not enough for me to stop wearing the mask (boo!). My doctor said they will most like go up and down all throughout my treatment. Up and down are, of course, relative terms. I don't anticipate my white blood cells going high enough for me to leave off the mask until treatment is done. But hey, whatever keeps me out of the hospital, right? Maybe I'll set a new fashion trend.

Here's another fun number: 17. That's how many pills I take every day. Fewer if I'm not feeling too nauseated, though lately I've had to keep some food on my stomach practically all the time to keep the nausea at bay. Which leads to this number:

- 12. That's how many pounds I've gained! In 8 weeks! I'm blaming it on the steroids and the pumping of large amounts of fluid into my body. But that doesn't mean I'm not going to have to work it back off when this is all over. Hopefully that number doesn't go too much higher. Last semester I lost 30 and was getting pretty close to pre-pregnancy weight (okay, I was in the same ballpark). So I don't want to have to start all over again. But if this journey has been about anything, it's definitely been about learning to let go and just do the things I DON'T want to do...you know, for my own good. Like taking meds that make me eat like a man.
- 2. That's how many precious little people like to rub my head every night before bedtime. They are such sweet little munchkins when they want to be. :) They have dealt with this entire situation with such calmness and grace, and they are my constant reminders that there are much more important things in this world than me.

525,600. That's how many seasons of love you have all shown to me. Thank you so much, AGAIN, for the kind thoughts, words, prayers, gifts, and cards. I am truly blessed.

Hey, guys. I'm still here. It's been a crazy few weeks with the final countdown to spring break.

Lots of homework and grading and lesson planning and passing out on the couch...you know how it goes.

One of my favorite things about my students is that they almost always say whatever's on their minds – they don't have that grown-up filter yet. (Well, let's face it, neither do I on a lot of days, which is probably why I appreciate it in my students.) But that means they ask the questions they really want answers to – the questions a lot of my friends are too tactful to ask. So I thought I'd try to answer a few of them for you. This week I'm feeling generous, so I'll spare you some of the more gory details about what it feels like inside my body right now. I'm going to tell you about chemotherapy. I've gone through it five times already, and it still fascinates me, so here's a little peek into the treatment room.

The first thing that happens when I get to Georgia Cancer Specialists is labwork. Tay flushes my port with a saline solution (worst damn part of the whole day – I can't even describe how nasty that stuff tastes) and then she takes blood from it. How does she do that, you ask? Well, she and I both put on masks to be sterile (actually, I'm already wearing one, but I put on a new one) and then I take a deep breath and she pops a needle into my chest. The port has little prongs that poke up into my skin so she can feel exactly where to stick me. It doesn't really hurt. Like I said, Tay's pretty darn good at her job. The needle is attached to a tube with a syringe opening. She tapes all that down so it won't come out while I'm at treatment, and hopefully gets a blood drawback after one flush. Sometimes I'm not so lucky. But eventually we get some blood and they run a full CBC on it. Then I go see the doctor.



See the three little bumps? Those are the prongs on the port. And you can see the tube in the vein that goes up my neck. I think that's why I can taste the medicine – it's so close to all that tasting and smelling stuff in my head.

So after Dr. McDonald and I discuss all the fun new things that are going on with my body (there's always something), I head over to the treatment room. I sit in my spot, which is the recliner closest to the bathroom. It's in the corner, sort of away from everyone else, but I can see the whole room. You know, never sit with your back to the door. Plus I can cheat and pull the mask down if no one is nearby me. And, you know, I should be concentrating on doing my homework instead of chatting. Believe it or not, I do have the self-control to do homework instead of talk. I just don't always exercise it.

The chemo nurses get me settled and once my labwork and the doctor's orders are in,

Dusty (the pharmacy tech) starts mixing my meds. He has a special little sterile room, with the
glove openings in the glass, like in the movies. Those drugs are super caustic, and really freakin'
expensive, so he doesn't get them ready until they're sure I'll be getting them. I'm lucky
because it doesn't matter what my blood counts are – I'll always get my chemo. I've seen other
patients have to go back home or get shots to try to get their counts up. It can throw off a whole
round of chemo. I'm still right on schedule.

So while Dusty is getting my meds ready, Derby sets me up with this bad boy:



This is my infusion machine. The IV bags hang at the top and the machine controls the flow of liquid. I have a big bag of saline that they use to flush my veins with in between each

med. They also mix the saline with the drugs that get pushed in by syringe. Each med is a different amount – some take 20 minutes. The big bag at the end takes an hour. I get steroids and antinausea drugs first. Then out come the big guns:

Adriamycin

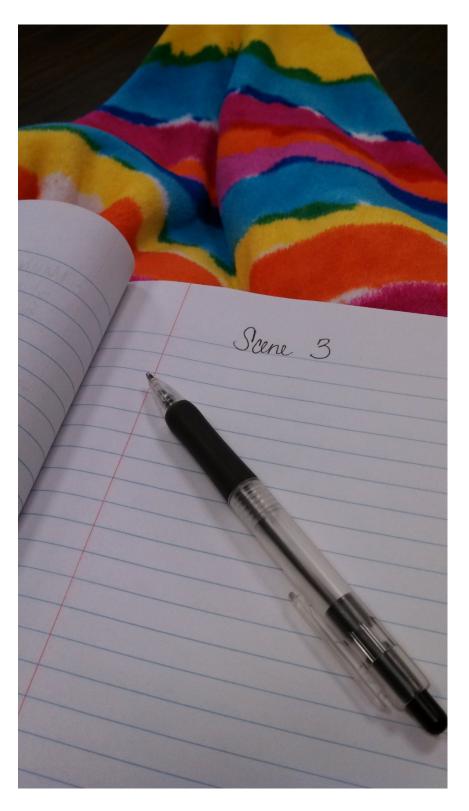
Bleomycin

Vinblastine

Dacarbazine

These four chemo drugs together are called ABVD therapy. It's been the first-line treatment for Hodgkin's lymphoma since about 2007. This particular therapy has better results for longer lifetimes of patients, since the toxicity is lower than what was previously used to treat Hodgkin's.

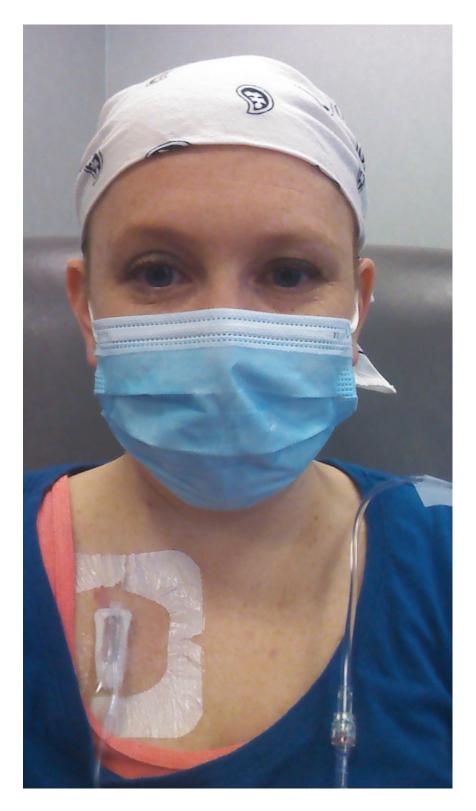
While I'm getting the drugs themselves, this is what I usually do:



I have playwriting class on Thursday nights, so I try to make sure my scenes are finished on Wednesdays. Then I can type them up and revise them on Thursdays. I still prefer to write

by hand first; it's part of my invention process. Every once in a while I can just sit down and start typing, but that's rare. I need the physical movement of pen on paper to get the ideas out. One thing I have definitely learned through all this is self-discipline. Creativity is a resource that can be tapped into, just like anything else. I don't wait for inspiration to strike anymore. I start writing because the work is due, and the work comes because I start writing.

About halfway through the big bag of Dacarbazine, I start getting pretty woozy and my characters start saying crazy things. That's when I pack it up for the day and either crochet or take a nap for the last half hour. They run a little more saline through, and then Derby untapes me and pops the needle out of my port. Usually I'm there from 9 am until about 1:30 or 2 for everything. Bobby picks me up and takes me home, where I crash on the couch for the rest of the day. His work has been awesome through all of this. He just works at the Resurgens location near my doctor's office every other Wednesday, and so far it's worked out great.



Here I am, sitting in my recliner. You can see where the needle is taped down so it won't come out. You can also see where the line is taped to my left shoulder so I won't accidentally

pull on it when I move around. The infusion machine unplugs from the wall and has a battery pack so I can walk around.

So that's a day at chemotherapy. I still have seven more treatments to go. I'll be finishing up at the end of June. In a couple more weeks, we'll do another PET scan to see how the cancer is reacting to treatment. I think it's working – the itching has gone way down and so has the swelling in the lymph nodes. Not to mention all the awesomeness you guys have been pumping me up with. I definitely believe that attitude has just as much to do with healing as medication.

April 17, 2014

I've been hesitant to write this post for a while now. I'm going to tell you guys the truth.

This is hard.

Cancer sucks.

It's a mind game and a body game, and sometimes it's really hard to win both of those battles at the same time, all while maintaining a semblance of normal life.

But that's exactly why I'm still teaching and going to grad school. I don't want to be at home on the couch, just thinking. It's easier to stay positive when I put all the negative possibilities out of my head and focus on the good things in my life.

The body game is not so easy to put out of my head. It's hard to ignore my stomach hurting all the time, or random body parts aching like they have arthritis, or the way I look in the mirror (fat around the middle and fuzzy on top!), or the extreme fatigue.

You know, it's funny, this hair business. My hair is super thin on top, but I have a light fuzz growing in. Everywhere else, though, the hair is falling out. Like everywhere. At least I don't have to shave anymore (one good thing!). But I don't have any nose hairs. So when my nose runs, it just falls right out onto my shirt. I keep tissues with me at all times because bloody snot just dripping out of nowhere is pretty gross. Thank goodness I teach middle schoolers — they're pros at gross. It barely even phases them.

I've also lost the fine peach fuzz I used to have on my face, so now (in addition to being puffy from the steroids) my face feels naked and shiny all the time. And I'm missing clumps of eyelashes, so I have to do an "eyelash combover" with my mascara. Hot, I know.

Some days it's easy to laugh all these things off and just be thankful that I'm still able to care for my kids, but other days each of these things feels like it might be the last straw.

That's why when people ask me how I'm doing, I try to always answer "I'm okay" or "Hanging in there!" Because I am hanging in there. Some days I'm barely hanging on with the tips of my fingers, but other days I've got a good strong grip.

Yesterday was chemo treatment #7 of 12, and the more treatments I go through, the more exhausted I get, and the harder it is to keep a firm grip. But I'm still hanging. I may be dangling by a thread by the time this is all over, but I have faith that I'll still be hanging around. I'll make it through, friends. Just keep those positive vibes coming. They really do help to lift me up.

May 3, 2014

There is so much that is ridiculously awful about undergoing cancer treatment, so much that I thought I'd never be able to endure, so much that has just become routine. But there are also some good things, things that I wouldn't have otherwise. Things like:

- -Driving with the window down. No hair to blow around in my face. This is what it must be like for guys!
- -Taking "twin selfies" with other bald people. I had no idea my brother and I looked so much alike. (Love you both, Matt and David!)
- -No shaving. Self-explanatory.
- -Insomnia = lots of middle of the night brainstorming for grad school projects.
- -My babies love to kiss and rub my fuzzy head at bedtime. It's oddly sweet.
- -Bonding with loved ones about chemo/cancer experiences. It's like a club you never want to be invited to join, but once you're in, you might as well make the best of it, 'cause it's for life!
- -Having complete confidence in a doctor. (That's you, Dr. McDonald! You seriously saved my life!)
- -Perspective...every day truly is a gift, and the small things are just that small things. No point in sweating them...I've got hot flashes for that!

May 16, 2014

Last Wednesday I had a PET scan to determine the success of my chemotherapy treatment so far.

Yesterday at my 9th chemo appointment, I got the PET report. I already knew its contents,

because my awesome doctor called me literally as soon as she got the results, which was last

Thursday. But hearing news over the phone and seeing them in black and white print, particularly to a writer, are vastly different things.

I sat in my chemo chair while I waited for my Activase (they call it the port Drano) to clear my port line and read every word of that report.

Just to give you an idea of how serious this was (which I've tended to downplay): nodular sclerosing Hodgkin's lymphoma stage 4, advanced disease involving lymph nodes on both sides of the diaphragm as well as the bone marrow. Meaning my previous PET scan was lit up like a Christmas tree. Now all the lights are off and nobody's home. Not even a kitchen light for the dog.

Previously noted abnormalities have resolved, in nearly all lymph areas and in all bone marrow areas.

Enlarged lymph nodes have significantly decreased in size.

Spleen is unremarkable. Gall bladder is unremarkable. Kidneys are unremarkable. Bowel is unremarkable. Bladder is unremarkable.

In other words, there has been a near complete response to chemotherapy. Praise God. Vindication. I have never been so happy to be unremarkable in my life.

I have to say, sitting there surrounded by other cancer warriors, some whose stories I know and some whose stories I don't, I couldn't help but tear up a little. I am going to walk out of there after round 12, healed. I cannot definitely say the same for those other men and women. I have an aggressive doctor who found my disease in the nick of time and wasted no time at all getting me the proper treatment. Thankfully, many of those other Wednesday patients have Dr. McDonald as well, though I'm sure all the physicians at Georgia Cancer Specialists are fantastic.

This wonderful news of my insides being unremarkable comes in conjunction with some other really great news; this past Saturday, at my drama students' final performance, I was presented with a beautiful bouquet of roses and Teacher of the Year! I was totally, completely surprised, not just because it's my first year at Master's Academy, but also because I just plain wasn't expecting it. I have truly enjoyed pouring myself into these kids and am looking forward to working with them again next year. I feel like I have really come into my own as a teacher (after only ten years) and am comfortable in my own skin in front of my classes. I have also discovered that I really have a heart for middle schoolers, and I've had a blast teaching English to them as well as teaching drama to the little ones. It was so rewarding (and humbling) to be recognized for the hard work I've done this year, not just because I've soldiered through and still showed up even throughout multiple surgeries and chemo treatments, but because I honestly feel like I've done a good job and really taught these kids things that they will remember. After all, that's what we hope for, right? To make a difference. To make our students' educational lives just a little bit easier in the future. To instill motivation, work ethic, and maybe even a little grammar. And fun. Fun is definitely important.

Speaking of fun, I have to tell you guys this story, even though I know my mom will be totally grossed out and fuss at me for it.

You guys know I'm really only about 12 at heart. I love to kid around and have fun at my appointments, because, well, if you can't laugh about the possibility of death, then what's the point of laughing about life?

So at the end, when the infusion nurse was taking the needle out of my port, she was showing a few of the medical techs how to do it. I was holding my nose, because if I can't smell the saline flush, it doesn't taste nearly as nasty. The pharmacy tech asked me why I was holding

my nose, and I told him it was so I wouldn't be able to taste it. Then, once the needle was out, I said, "Really I just farted. It'll hit you in a minute."

Best part of the day. All three of them cracked up. I didn't really fart, but wouldn't it have been hilarious if I had?



May 27, 2014

I lost a friend last week. I've been writing this post in my head for days, but I've been hesitant to commit to any words, because that would make it real. But it is real, whether I face it or not.

My dear friend Dana Freeman died last Sunday.

Dana and I shared a love for teaching, a passion for writing, the same Starbucks order, and a diagnosis of cancer. It is unfathomable to me that a person so full of life could be dead.

Dana was one of the friendliest people I've ever known. He was always smiling, always making cheesy jokes, always making new friends. Always positive. It never occurred to me that he would lose his fight. He was always "doing better," "doing well," "getting better." I can't help

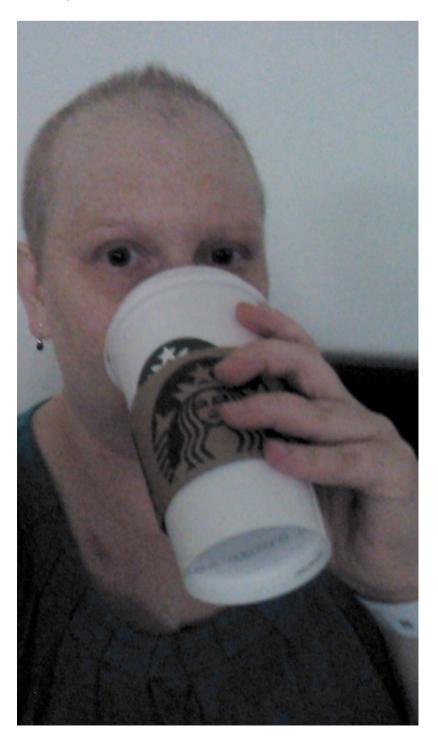
but wonder if it occurred to him that he might lose the fight. If I had not just gotten such a great scan, it would give me great pause about my own fight. It may just be that he wanted to focus on the positive. He didn't want anyone to feel sorry for him. He may have known all along that his time was limited and chosen to continue to live life without a shadow of fear. That sounds like my friend. He was brave. Most of all, though, I will remember him as being happy. I rarely saw him without a smile on his face.

I met Dana when I was the director of Sylvan Learning Center in Douglasville. He walked in one day and asked if I needed teachers. He was wearing a T-shirt with a smiley face on it. He was a retired teacher who also taught at other Sylvans, so he knew the programs. He became one of my most reliable teachers. He could teach science, reading, math...and he was always willing to help out. Stay an extra hour. Cover for someone else. Anything but the beginning readers. Dana loved to interact with the little kids, but he preferred to teach the ones he could really talk to, have discussions with. Make a difference for. And he did. Students often worked their schedules around the days Dana taught. He was a great teacher and a great employee. When Sylvan closed and I became a stay at home mom of two, Dana turned into a great friend. But he still always called me Boss.

I am sad and grieved at the loss of my friend, even though I know he wouldn't want me to be. It feels like the world is off-kilter somehow, like it's a little bit darker without Dana's unique brand of sunshine in it. I know that in time, things will right themselves. I will finish my treatment and become a cancer survivor. But it doesn't seem fair that Dana won't be in that club with me. It was something I had counted on. Now I will have to wait until my race is run until I see him again.

I have not told my kids about his passing yet. Even though I am a writer and words are my medium, I have no words to explain Dana's death without implicating the possibility of my own. Perhaps they are stronger and more resilient than I give them credit for. But I can't help wanting to shelter them. Childhood is such a magical time, and I'm not yet ready to cast a shadow over their sunshiny dispositions. Or maybe I'm just not ready to talk about it yet. Either way, not today. Today I will simply remember my friend and buy the person in line behind me at Starbucks a drink in his honor.

June 12, 2014



Today I am enjoying a post-echocardiogram reward for flashing an MA before 9 am (yes, Gina, I thought of you!) It has been a while since I've had any medical shenanigans, so I was overdue for a cheap medical thrill. And what better way to celebrate than with a decaf Americano?

Okay, I admit it...I also had a blueberry muffin. But it was totally still breakfast time. Never mind the fact that I had already had breakfast.

The echo was part of a routine set of pre- and post-treatment tests. Since I've only got one more chemotherapy to go (hooray!), I've started doing the post tests. My pulmonary function looked good (take that, Bleomycin!) and the ultrasound of my port looked good, so I expect nothing but stellar cardiac function. Adriamycin ain't got nothin' on me. Okay, the English teacher in me just cringed a little bit. But then the Georgia girl in me said there's nothing wrong with that there sentence. Never fear, Florida friends. I'm still mostly a Florida girl at heart. But the pasty white parts of me have gone over to the Georgia side of the state line. Anyway...my next test will be another PET scan after my final chemo, which I expect to be clear based on my most recent PET results. (Dangling modifier! Another nerd alert!) I must say, I'm not a fan of the PET. It's not the scan part, it's the needle full of radioactive stuff and the cup full of nasty fake Kool-aid stuff. Last time the nurse insisted on doing an IV instead of using my port, and let's just say that when your veins have turned to crap after nine months of constant poking, things can get ugly pretty quickly. Next time I'm going to see if I can get my port accessed ahead of time by the fabulous Tay at GCS (shout out to my girl!). That would make life much easier.

On a lighter note, I apparently had my hand on my phone for my entire seven-hour postchemo nap yesterday. Ahhh, there's nothing so blissful as uninterrupted drug-induced sleep, especially after a week of insomnia. But apparently I sleep-texted and called several people. So I apologize if you got a text full of gibberish or a voice mail of me snoring. When I woke up for my nighttime meds and a pre-bedtime episode of Downton Abbey (the one where William and Daisy got married...sniff, sniff), I had apparently been looking for Afghanistan on Google maps.

At least I didn't make any exorbitant electricity or credit card payments.

Also, can you guys see the tiny mohawk in the picture above? I've still got some malepattern baldness going on up front, but I've got fuzz growing in up top and in the back. I'm
trying to train it into a mohawk so I can avoid the awkward growing-back-in phase and go
straight to the how-badass-do-I-look phase. It's funny, in my dreams I still have really long hair,
so it's always a bit of a shock when I wake up and I'm bald. The only really bad part is walking
outside and instantly feeling like my scalp is on fire. Sunlight is not my friend these days. Just
one of the many fun side effects of all the drugs. And between the constant sweating from the
steroids, extra fat, and menopause, it's too damn hot to wear a hat! That's a song title from an
old musical, Mom...Kiss Me, Kate. Look it up:). By the way, menopause at 33...awesome.
Actually, it wouldn't be too bad if it weren't for the hot flashes. I'm used to the Crazy, and so is
Bobby. I've had the Crazy for quite some time. Like my whole life. I think it runs in the
family.;)

June 30, 2014

Most of you know that I am a klutz. I hurt myself a lot. I run into things, I stub my toes, and I trip and fall. Not great habits to have when one has minimal self-healing powers. But usually great for comic relief. A few months ago, I fell at work. Like totally busted it. It was raining, so I couldn't take my students outside for recess, and I decided to play follow the leader with them up and down the hallways. Slick hallways. We were pretending to be on a roller coaster when I somehow tripped over my own feet and went sliding, face-first, down the hallway floor. I

looked like I was on a slip-n-slide, only no water. Ouch. And of course I did this right in front of the director and a prospective parent. I sat up and turned around to see all of my students following suit, sliding on the floor. They loved it. They thought I did it on purpose. I needed to sit on the floor for a few minutes, so I took advantage of the fact that we were near the restrooms and sent them on a potty break. This is just one example of how my dorkiness sometimes gets misinterpreted as me being a cool teacher. I had bruises on my knees for a loooong time. The kids all seemed to survive the slide just fine, though I nixed all future rounds of roller coaster follow the leader. The next time we played spies and just sneaked around the building instead. Much safer.

I tell you this story because it is exactly what I seem to be doing with my life lately — going along just fine, doing my thing, when BAM! — I fall on my face and realize that I am not in control of my life. But I get back up. Sometimes with a little grace, sometimes with a little pain. A few weeks ago, I fell again. I was being stubborn and assumed I could carry my sleeping daughter up a wet staircase while wearing flip flops. Not my finest decision. (We all know what happens when we assume!) Thankfully, Fiona was fine, but I ended up spraining my ankle as my entrance into my in-laws' house for the weekend. Lots of ice, hobbling, x-rays, and an ankle brace later, I am doing okay. But again, I was reminded…every time I think I've got things under control, God shows me that I don't. Thankfully, I had my wonderful family there to pick me up and force me to take it easy. That is a difficult thing for me to do. It is hard for me to admit that I am not always strong, that I do not always have it all together, that sometimes this cancer thing gets the best of me.

Last week I had my last chemotherapy treatment. Number 12 of 12. Thank the Lord.

But I am not finished yet. My PET scan looked a lot like my last one – there is a spot near my

port that is still lighting up. This doesn't mean it's the Hodgkin's. It could be something else – inflammation from the port or a number of other things. What is does mean, though, is more investigation. I feel like I have stumbled again. Things didn't quite go according to my plan. But that's just it. It was my plan. There was no guarantee that things would go the way I wanted them to. They never do. And this is just a minor setback. The medicine worked. It eradicated 99% of the cancer from my body. Maybe even 100%. I just have to be patient and work with my doctor to figure out this last little puzzle. I have to trust that God is not finished with me yet. He wants me to get back up. He wants me to keep going. My story is not finished yet. There is more to tell, more to write, more to share. And trust me, I will share it. You have all been instrumental in helping me climb to my feet time and time again. I have no doubt that when this is all over, I will be standing strong. Not through my strength, but through His and through yours.

July 20, 2014

So I'm done with chemo. I completed my 12-treatment sentence of marching through the valley of the shadow of death while keeping my head above water and carrying two little people on my back and mostly refraining from screaming to the masses how much this whole process has sucked (I'm pretty sure I hit the maximum number of allowed metaphors in that sentence). Now what?

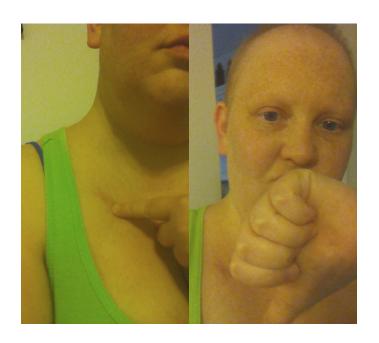
Now we wait.

If you are married to me or related to me or have ever stood in a line with me, you are already aware of one very basic fact about me: I hate waiting. A lot. Many of you have

expressed surprise or admiration about the fact that I continued to teach and attend grad school and shuttle small children around throughout this whole process, but really, I couldn't have just stayed home and hung around until my next treatment. Because that would have entailed waiting. Which I hate.

I've already done a post-treatment PET scan and it showed that my body is about 99% clear. What about the other 1%, you ask? Well, there were a few small spots near my port (right side of neck and clavicle) that are still lighting up on the PET. It could be a little bit of cancer left over. It could be inflammation from the port. It could be something else entirely. We can't know for sure without a tissue sample. That means biopsy, which means more surgery. But the spots are in a sort of tricky place to get to, which would mean fairly invasive surgery.

Bobby and I talked to my doctor and we all agree that the best first step is to take the port out. I've had a lot of trouble with it all along, and the general consensus is that my body wants it out. So out it will come. Unfortunately, due to the surgeon's schedule, that's not going to happen until the end of August. So guess what I get to do until then? I get to wait. Yay. Thankfully, I have picked up a little bit of patience along this journey. Not nearly enough for Bobby (the hero of all my stories), who has enough to spare for both of us, but enough to make it till the end of August. He will make sure that I maintain my sanity through the rest of this process. And of course I've got lesson plans and princess camp and four different school schedules to figure out and end of summer activities to keep me busy until the surgery. And what happens after the surgery, you ask? What do we do once the port comes out? We watch and wait, my friends. Watch and wait.



August 9, 2014

Well, there has been a change of plans. I will not be having my port taken out any time soon. My doctor presented my post-treatment PET scan at the tumor board (I'm such an interesting patient, I've been presented to the tumor board twice now!) and the board didn't think the few little spots I have left were too much of a concern. Something to keep an eye on, definitely, but not enough to warrant pulling out the port six months early. So for now, we will leave it in. I've been able to take Aleve now that I have an immune system again, so I've kept the soreness around that side of my neck at bay. Actually, it was getting much better and I had left off the Aleve for a few days when I had to go back for bloodwork and a port flush. Now it's been bothering me again, so I'm thinking my body is just saying, "leave me the hell alone!" I feel ya, body! Nine months of poking and prodding are plenty. Ain't nobody got time for all that.

Monday I go back to teaching, and I'm actually really looking forward to it. This past week was Open House, and I think I'm going to have a pretty good group of kids. My little

drama munchkins seem to be chomping at the bit to start acting, and my middle schoolers did very little whining when I talked about all the writing they would be doing. I can hardly ask for more! Hopefully I will be able to keep my own whining to a minimum when I start back to grad school in a week.

I'm a little concerned about having enough energy to keep up with everything I'm about to have going on, but mostly I'm just happy to be getting back into a routine. I've laid on the couch watching Pioneer Woman long enough. It's time to get back in gear – the energy will come back in time, along with my hair!

August 26, 2014



Check me out, friends! See that tiny little mohawk? I grew that all by myself! And those eyebrows, too! And even those tiny little lashes. I'm fuzzy all over again. It looks a little weird, and my skin doesn't feel all smooth like a baby's butt anymore, but I'll take it. The bald spots on my head are filling in and I actually had to use a razor the other day. On my legs, not my head. It's the little things, right?

So you know how I used to complain about how awful it was to not have nose hairs, especially coupled with frequent bloody noses? Well, thankfully, the bloody noses are gone with the Adriamycin, but I have found something worse that bald nostrils. Ingrown hairs. INSIDE my nose. How on earth does a girl exfoliate in there? She doesn't. So I put some Clearasil on a Q-tip and stuck it up there and that worked. Much better after a few days. But I hope my doctor doesn't read this – she probably wouldn't be very happy with me for sticking things up my nose. There's no good way to sterilize a Q-tip. Now you are all picturing me with a Q-tip up my nose, aren't you? My work here is done.

Seriously, though, this healing thing is harder than I thought it would be. You see, I still have to take it EASY. No strenuous working out yet (serious fatigue issues still), no long periods of time on my feet or sitting at my desk (swelling in my feet and legs – a fun new thing), and no staying up late doing homework (because I can't seem to function on less than 9 hours of sleep). I know, I know...I spent 6 months doing chemo, so it's going to take at least 6 months to get over it, but really...ain't nobody got time for that. I have lessons to plan (teaching The Hobbit right now – so excited!). I have a Master's thesis to write. I have lunches to pack. I have a crap-ton of weight to lose...man, I need a nap just thinking about all this stuff.

But there is good news – I do NOT have a blood clot. What?! Blood clot? Yeah, I know...I didn't say anything about this, so I'm sure my mom's getting mad at me right now (hi, mom), but the swelling in my feet was pretty bad. And it was worse on one side than the other, which can be indicative of a blood clot. So my doctor sent me for an ultrasound on both legs and another echo and everything seems fine. Just lots of extra lymph fluid. Maybe it's because I actually have white blood cells now. Maybe they all threw a party in my feet and had hangovers and puked lymph fluid everywhere...

On the plus side, I've now lost count of all the doctors and techs I've taken my clothes off for, so I think it's safe to say my modesty has gone out the window. If you went to college with me, you can stop laughing now. I really did have some, you know. Being a teacher made me a little bit prude-y. At least that's what Bobby says. But I have mooned (bone marrow biopsy) and flashed (mammograms and echocardiograms) and walked around pantsless (surgeries and leg ultrasounds) and worn low-cut shirts (easy port access) so much lately that I think he can no longer accuse me of being a prude. At least not at the doctor's office.

But I do still wear clothes to teach. You know, 'cause I like my job. And I want to keep it.

October 2, 2014

Hello, dear friends! I'm still here! The good news is I've been so busy with normal, everyday life that I haven't taken much time to sit down and write...scratch that – sit down and blog. I write every day because, well, I'm in grad school for a Master's in writing. Oh, and I teach writing. So there's that. But I've been composing blogs to you all in my head a lot lately, which means I need to sit down and get some of it out!

So here's what's been going on lately:

My monthly bloodwork has looked pretty good. Everything is back in the normal range except for my red blood cells. I'm still anemic, and a further blood study showed that my iron is really low. So now I'm on a supplement of iron and about a million other vitamins and minerals. Hopefully this will help boost my energy. If not, there's always the option of iron infusions if this doesn't work. Good thing I kept the port in.

Ah, yes, the port. The discomfort I was having around my port has gone away and all the other doctors and pathologists my doc talked to said we should leave it for now. So that's what we've done, and it's worked out fine. Besides, I'm not looking forward to another surgery, so I'm happy to put that one off for now.

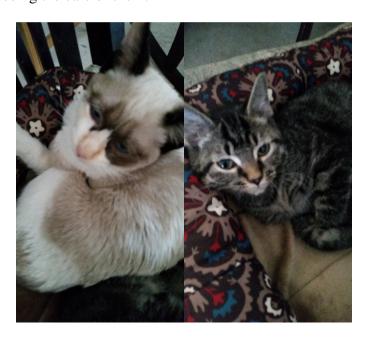
What about that small area that was still lighting up on the PET scan? Well, that's still there. There's a hard lump in the right side of my neck which is most likely a swollen lymph node. It could be reactive just because my body's still trying to get back to normal, or it could be a little bit of Hodgkin's still in there, or it could be nothing. I'm not terribly worried about it, because at this point there's nothing I can do about it anyway. We'll do another PET scan in December, and if it is something, we'll look at our options then. But I look at it this way: if having undiagnosed cancer for a few years didn't kill me, I don't think a couple of months with one swollen lymph node is going to make a difference. Besides, I wouldn't be able to do more chemo right now anyway. I maxed out at the end of June.

So how am I feeling? Emotionally, I'm doing fine. I'm happy to be back in the swing of things and soooo happy to be done with treatment. Physically, things have taken a bit longer, which is of course to be expected. A lot of the soreness and body aches have started to dissipate and I can get around much more easily, which is great. I still don't have a lot of energy and I've lost very little weight, but at least I've stopped gaining! Once I get some energy back, I'll be able to do more physically. I just have to be patient, which we all know is a weak point for me. Oh, and I have hair now! Like, a full head of hair. You can't see my scalp at all any more. I even got a compliment on my "haircut" from a stranger the other day. And I think it might be coming back blonde. Sort of a silvery blonde. It's still only about an inch long, so I can't tell for sure yet.

But yesterday I was able to go on a field trip with my daughter's pre-K class to Pettit

Creek Farms. I walked around and kept up with all the other mommies and was quite proud of
myself! I even stayed outdoors the whole time and for the most part didn't feel like the sun was
scorching my skin off. That must mean a lot of the chemicals are out of my body by now. I did
end up crashing on the couch for a couple of hours before class that night, but still, compared
with where I was four months ago, yesterday was nothing short of a miracle for me.

And speaking of miracles, we've added two new tiny ones to our family! This weekend we adopted two adorable kittens. Yes, I know, that seems like craziness, and maybe it is a little, but so far it's been really good for our family. The kids are learning responsibility by taking care of them, Paco is happy to have some little sisters (even if they are cats), and Bobby and I didn't realize just how much we've missed having cats in the house. Plus, they are two adorable little fluffballs of love that purr whenever they are picked up, even by an overzealous five-year-old! So I've decided that the benefits of two new somethings to love outweigh the responsibility of overseeing the care of them.



This is Lily and Violet. I told you they were cute!

November 10, 2014

Hello, dear friends. It's been a while. I'd love to tell you that it's because I've been out living my life and having a great time, but unfortunately things have been very busy because I've been running around to all my doctors again lately.

I have less than stellar news to share. My Hodgkin's lymphoma has returned. Or perhaps it never completely went away. I'm not sure.

Here's the timeline:

First, I did a red blood cell study because I was still anemic and lethargic. That showed that my RBC's were still too small and too few, and my iron was seriously low. After some trial and error with oral supplements, we decided that the best course of action would be for me to have iron infusions. I've done two so far, and I'll go back on Wednesday for a third. But that's not all that's happened.

The spot in my neck has grown, and two more spots in my left breast showed up. So I did a mammogram and an ultrasound. The breast surgeon said it didn't look like breast cancer, but it was definitely possible that it was the lymphoma again. My oncologist wanted biopsies. Frankly, so did I. I wanted some pathology to back up what I had suspected for a while now. On Tuesday I underwent a needle biopsy. Friday I got the pathology results and they were positive for lymphoma.

There are a few silver linings here: I don't have to have surgery on my neck, since we know now what it is. It's the same old thing, and not a new kind of cancer. That's all I got right now, but I'm sure there are more.

The bad news is that I will have to undergo treatment again. We will start out with chemo (a different type from last time) and then look at a stem cell transplant. Within the next week or so, I'll do another PET scan and a bone marrow biopsy. I'll also see my oncologist on Wednesday to go over the exact plan of treatment.

I've been open with you all throughout this journey so far, and I intend to include you on this next leg of the trip. I've had a much-needed break, but now it's once more unto the breach, dear friends. Many thanks for the love you always share with me. Know that it flows back to you a hundredfold.

December 2, 2014

The last time I wrote I dropped a big ol' bomb – hey, my cancer's back! – and then left it alone for a few weeks. Now that I've had time to process (and deal with all the crazy new meds), I'm ready to fill you all in on the game plan. Which, of course, has already changed. Because that's what plans do.

I started out a few weeks ago with another PET scan and bone marrow biopsy. For those of you who've heard the story of the first bone marrow biopsy (last November), I'm happy to report that I behaved much better this time around. Unfortunately, that means I got fewer drugs, so I remember the entire procedure. Not. Fun. The biopsy came back clean (no involvement in my marrow) but the PET showed significant disease on both sides of the diaphragm. So in a way we're back to square one.

Two weeks ago I started a new chemo, called ICE. It's three days in a row every other week. It's a "salvage chemo," which basically means damage control while preparing me for a

stem cell transplant. All involved parties have decided that the stem cell transplant is the way to go because it is the best chance to eradicate this disease once and for all. It is obviously aggressive based on how quickly and how extensively it came back. So we are going to be aggressive with it.

Today I was supposed to start my second round of salvage chemo, but my platelet counts are too low. My white counts have already bottomed out, but that won't stop treatment.

However, if my platelets bottom out, I'll need a blood transfusion, and that will prolong the transplant process. So we're going to wait a week and hope that my counts come back up. Then I can do chemo next Tuesday, Wednesday, Thursday, and another PET scan on Friday.

Tomorrow I will meet with the transplant people and find out more information about that whole process. Hopefully my body will start cooperating and we can get this show on the road.

I'll fill you all in once I know more about the transplant. Right now it all sounds very science-y and magical to me. I'm sure my adjectives will change significantly once I'm going through the process, but for now...how cool is it that they can do that?? Take out my stem cells, freeze them, kill all my marrow, thaw the stem cells, reinject them, and grow new clean marrow! That's right, people, I'm so cool I'm going to be the donor for my own transplant. Actually, I'm very thankful for that because it means I won't have to deal with graft vs. host disease.

So that's where we are. I'm at home right now, on isolation. I'm officially done working and going to school because my immune system is nonexistent and I have to be healthy for the transplant. I can't go to see A Christmas Carol or take the kids to see Santa or have visitors. But I can still drive them to school and wave to my mommy friends from the car. I can still feed them dinner and yell at them to quit wasting water and get out the shower. So even though a lot

of things suck right now, a lot more things are still good. I am here. I will continue to be here. And I am blessed.



December 21, 2014



Crazy, crazy, crazy. That is the only way to describe these past few weeks. It has been a roller coaster around here lately. But things are looking up now and we are moving forward with the transplant process. So here's what's been going on:

A couple of weeks ago, I passed out in the bathroom at home. I stood up to go wash my hands, and somehow ended up on the floor again. I think I was a little overheated and dehydrated. It hasn't happened again. Bobby heard the thud of me falling and came running. He looked at me lying on the floor and said, "What are doing? Get up!" I think the shock of finding me on the floor was a bit much for him at the time, but I absolutely love to tell this story when people talk about how sweet he is and what good care he takes of me. **Disclaimer: Bobby takes excellent care of me, and really can be quite sweet at times, but if you know anything about either one of us or our relationship, you'll know that sweetness is not a major characteristic of either of us. More like sarcasm.**

To his credit, he did try to help me up, but of course I was having none of that. I got up on my own and he promised he wouldn't tell anyone if I told the doctor. But now of course I'm telling you guys. After I told my doctor and got some fluids.

Then, when I was supposed to start my second round of chemo, my blood counts came back really low. Now I always do treatment regardless of my white blood cell counts (zero) or my neutrophils (also zero), but my platelets were really low, too. Like the number per unit I needed to be able to do treatment was 100 and mine were at 12. Like I talked my way out of a blood transfusion and promised to come back in a couple of days to get a transfusion if they hadn't come up. So my chemo nurse went over all the bleeding risks with me, and reminded me to be very careful, and took the needle out of my port. I was packing up my stuff to go when I

looked down and noticed my shirt was wet. I lifted my shirt and my chest was covered in blood. "Um, Derby?" I said. "I'm bleeding."

The tiny hole from the needle had bled out in the few minutes I had been getting my things together. Of course, all the nurses and techs rushed over to me to stop the bleeding and clean me up. I kept trying to put my bag down, since it was still on my lap, and finally one of the techs took pity on my and tossed it in another chair so I could have my hands free to get in their way.

Did you know that saline gets blood out? I guess that makes sense, since that's what they use to flush ports and IVs. Finally a worthwhile use for that nasty stuff. Thankfully it doesn't smell the way it tastes when they put it in my port, or I would have puked as well as bled all over everyone. So they watched me for a few minutes, and I was fine (though my platelets were probably down to 8 by that point) and I went home. When I came back a couple of days later, they were up to 31, so I didn't need a transfusion. And they were up enough the next week to do treatment.

Which leads me to the next fun thing. Now other than the platelet business, I hadn't had any trouble with treatment up to that point. (I'll spare you a description of some of the normal chemo side effects and just say everything went fine.) Round One was three days in a row, followed by one day of fluids. Tuesday is Isofomide, Mesna, Carboplatin, and Etoposide. Then Wednesday and Thursday are Isofomide, Mesna, and Etoposide. I'm probably spelling those drug names wrong, but I don't really care.

For Round Two, I had all the pre-meds, then the first three drugs. By that time I'd been there about 4 hours. They started the last drug, Etoposide. About 15 minutes into it, I started to feel weird. Like my head was fuzzy. By this time I was the only patient left. "Derby? I feel kinda

funny..." And then I couldn't talk anymore. My throat closed up and I was gasping for air. My whole body felt like it was on fire and the nurses said I had turned bright red. Derby ran over to me, stopped the med, and then went for the Epi-pen. She jabbed that sucker so hard into my leg and held it there to make sure the meds got in...let's just say I would never want to get into a fight with her. I'm pretty sure Derby could totally kick my ass if she wanted to. Thankfully she's actually one of the nicest people I've ever met. Anyway, I digress. (I still have the bruise on my leg.) The tech ran for a doctor and the other nurse took my vitals, which were surprisingly not bad considering my recent lack of oxygen. The PA gave me some more meds, and then they all sat around and stared at me for a while. I had to call Bobby to come pick me up, and his 45 minute drive from work somehow magically turned into 20 minutes. Then he got to sit there and stare at me for a while. Finally, as I continued to breathe normally and turned back to my usual pasty white, they let me go home. But we left off the Etoposide for the rest of the week.

Needless to say, I've developed a bit of a reputation as a troublemaker at my doctor's office. Not really, but I've noticed that all the people who work there tend to swing by at one time or another while I'm there to see if anything interesting is going to happen. I'd settle for boring from here on out.

Finally, I had another PET scan on Wednesday morning. I think this was my 6th one in the span of a year. I got my results later that same day. (This is what happens when you don't behave yourself as a patient – you go to the front of the line so they can get rid of you.) Really I think the transplant doctor called in a STAT read. Here's the awesome part – the scan was completely clear!!! I responded so well to treatment that I don't have to do the third round we had originally planned for this upcoming week. But we will still do the stem cell transplant because the likelihood of my disease returning is so high.

Tomorrow I will go up to Northside and spend the day doing all the necessary tests to get clearance for the transplant. I will also see my transplant doctor again. And then I will have an entire week with no needles!

It's the little things, folks. But needles or no needles, God is good. After all the craziness that has ensued lately, I am still hanging in there and moving forward. Onward, march!



January 5, 2015

Hello friends! I hope your holidays were merry and bright. I was able to see lots of family, which was a blessing, since this people person is about to head into several months of not being around people!

The stem cell transplant process is now in full swing. I have already completed the first two phases: testing absolutely everything (I passed) and patient education (I learned). Bobby and I are very happy with the Northside Blood and Marrow Transplant Group so far. They're

well-organized, friendly, helpful, and they get things done quickly. Not to mention they are the number one group in the nation for this type of transplant. Good thing we live so close to Atlanta! Everything will be done on an outpatient basis, which means I get to sleep in my own bed at night and will only be admitted to the hospital for an infection or other complication. Here's what I've done so far...

Step One: Testing. That was a really long day. It started out with a bone marrow biopsy...in office. With no anesthesia, pain meds, or Xanax. Just a Lidocaine injection. That's a post for another day. Then we did an echo, an EKG, a brain CT scan, a pulmonary function test, lots of blood work, and met with the nurse, the psychologist, and the blood services group.

Step Two: Education. Another long day, but it didn't start out with anyone shoving giant needles into my backside and removing pieces of bone and vials of marrow, so it wasn't as bad. I had PT and OT evaluations, then we met with the nurse, the midlevel (nurse practitioner), and the doctor. And the clinical research people. And the blood services rep. And the pharmacist. Lots of info. Brain stuffed.

Tomorrow, I'll start with Step Three: Mobilization and Collection. Tomorrow morning I'll get a central venous catheter placed in my chest. It has three lumens, so they'll be able to do multiple things at the same time. With my port, you can only put in one needle. After tomorrow, I'll be able to, say, get fluids and have blood taken at the same time. Very convenient, but I'm not looking forward to looking like an alien with three tentacles sticking out of my chest. Though I guess it doesn't matter much, since after tomorrow I'll only be able to go to Northside and my home for the next three months. Seriously, guys, no Super Target or Starbucks for THREE MONTHS. Sure, people can bring me Starbucks. But you can't put a Target in your cupholder and bring it home!

Anyway, after I get my central line, I'll start mobilization chemo, which will move my stem cells from my bone marrow into my peripheral blood stream. This will involve IV chemo (Cytoxan), then twice-daily Neupogen injections. They're going to teach me how to give them to myself so I don't have to drive all the way to Northside just for a shot. Although some days I will have to go in for labwork. Once my labs show that I have enough stem cells in my bloodstream, we'll start collection. They'll take my blood out, run it through a machine that separates out the stem cells, and put it back in. Then they do some magical science-y stuff to the stem cells to make sure they only have good ones and cryogenically freeze them. It can take up to four days to get enough stem cells for the transplant.

Step Four is High-Dose Chemo and Transplant. After they collect my stem cells, they'll do a test dose of Busulfan, another chemo drug. Then I'll take it orally for a few days. Then I'll do two days of extremely high doses of chemo, which should kill all remaining stray cancer cells in my body. However, it will also kill my bone marrow and most of my white blood cells and platelets. Which leads us to the transplant itself. The last step is to re-infuse my stem cells back into my blood stream. They will migrate into my bones and rebuild my marrow. So essentially, I will be saving my own life after the doctors try to kill me. Okay, not exactly, but I like to think of it that way because it feels very superhero. And superheroes are a big deal in my house. :)

After the transplant, I will go to Northside every day for about a month so they can check my levels and make sure I'm doing okay. Then it moves to every other day, then every third day, etc. After 100 days, I should be released back to my oncologist. And if I'm doing okay at that point, I should be able to go back to work next fall! Hooray for a normal life! Something to look forward to.

So that's the whole plan. I'll be spending a lot of time just sitting around hooked up to IV's for a while, so hopefully I'll have the energy to keep writing to you all. I'll try to update again after this week and let you know how mobilization is going!

Love and light to you all.

January 10, 2015

Now you guys know I prefer to be matter of fact about most of this cancer stuff I've been going through, but this is one subject that gets me all blubbery every time I talk to someone about it.

So please excuse the mushiness of this post. I promise to return to my usual humor and oversharing with the next post.

When my transplant doctors told us that I would need someone devoted to my care 24/7 for about three months plus someone else devoted to our children's care, Bobby and I were a bit overwhelmed. How in the world were we going to manage this? He needed to continue working in order to provide for us. We are both very independent people and asking for help is not easy for either of us. We felt like we'd already asked for so much help with the previous two rounds of chemo over the past year.

And that is when we were overwhelmed by our village. The people who love us and our children. The people in our lives who understand what it means to be the hands and feet of Christ to others. The people who just want to help out a little for whatever reason, whether it be a need to pay it forward, gratefulness for their own health, love for my babies, whatever. These people have all wrapped their arms around us and made this journey so much smoother and less stressful for us.

Bobby's mother has come to stay with us and take care of the kids for a few months.

They love having Grandmama here and I love that we have someone we all know, trust, and love to take the kids to school, pick them up, and make sure they are clean, warm, and fed.

My mommy friends have been a huge help with playdates and taking the kids to birthday parties and other places I can't take them. Elliott and Fiona have been able to maintain their normal lives throughout all this.

And then there's my church ladies. Actually, it's a group of men and women from St. Teresa's who have formed a committee called "Kristi's Angels." And they have definitely been angels to me. They have devoted entire days of their lives to make meals, be here early in the morning so that Bobby can get to work on time, drive me to Northside and sit with me while I get chemo or blood work, and bring me home and stay with me until Bobby gets home from work. It's been wonderful so far, being able to spend time with people, chat, and get to know them better. It's also been humbling to accept help when I can't really offer anything in return other than my sincere gratitude.

My friends and family have gotten in on the action too, making meals, sending us gift cards, becoming one of my "Angels," taking the kids, sending cards, calling to check on me...like I said, it's been incredibly overwhelming. I can't thank all of you enough for the support, the prayers, the million different ways each of you has shown your love to my family. Each of you has contributed to my recovery in a meaningful way, and I credit my village just as much as my doctors, my nurses, and my Maker for the strength to walk the path that has been laid before me.

Here are a few of these wonderful people: Betty and I, laughing at Elliott's insistence on a 20-minute photo shoot of us, Pat and I, headed home from Northside after a successful day of

chemo and Neupogen self-injection education, and Tiffany, my beautiful and sweet infusion nurse.





So much love and thanks to all of you. We know that we can never repay the gifts you have given us, and we are learning maybe that is part of the lesson we are supposed to learn from this. I am paying it forward by sharing my story in the hopes that others going through rough times will find comfort, laughter, and maybe even a little strength and inspiration from the

knowledge that they are not alone, no matter how rough the road they are walking. Angels are all around us.

January 19, 2015

So I have a new swear word: neupogen. New-puh-jinn. Picture me saying it with a snarl in my voice, spitting each syllable out like a bitter taste, every time you read it. No long, sweet, Southern, drawn-out vowels in this word. Neupogen. I hate that shit.



What exactly is neupogen, you ask? It's a drug used to mobilize my stem cells. It makes my stem cells move out of my bone marrow and into my peripheral blood system (my blood stream). I give myself an injection of it twice a day. But that's not the bad part. I've quickly grown used to the daily injections. They're subcutaneous, on my lower belly, with a fairly small needle. I actually kind of prefer giving the shot to myself (especially rather than Bobby giving it to me – pretty sure he'd suddenly develop an interest in playing darts). No. What I hate about the neupogen is the side effect.



Actually, there are three major side effects of neupogen: nausea, fever, and bone pain. I've had very little of the first two. It's the last one that's driving me nuts. There's an everpresent, generalized ouchiness that I can totally deal with. What's driving me nuts is the way I'll get a sudden, sharp, crippling kind of pain whenever I move. And I mean crippling literally – I walk around like Quasimodo for a minute every time I stand up. It's kind of like being sore from a bone marrow biopsy every day. 'Cause, you know, they drill a hole in your bone when they do that. Only imagine they are drilling holes all over. And because of what the drug does, my bones hurt every time my blood pressure or heart rate changes. Which is of course every time I stand up or sit down. And this is not one of those "you feel better after you get moving" kind of deals. So that's frustrating. Which is why I say my new curse word is NEUPOGEN. Neupogen

neupogen neupogen. Thankfully, though, I probably only have to keep taking it this week, and then I'll be done with it until after the transplant. Then I'll get to enjoy it some more.

Just imagine if it caught on as a swear word though..."Stay in your lane, you stupid son of a neupogen!" "Neupogen, Kristi, I told you not to eat all of my chocolate!" "Don't you look at me like that, I brought you into this neupogen world, and I can neupogen take you out of it!" Okay, maybe not. But now you all know how much it sucks on behalf of chemo patients everywhere.

Well, now I feel much better, having vented! Except in my shoulder. My shoulder still hurts. And my teeth. But I'll forget all about my shoulder when I stand up to walk around and get that awesome whooshing of blood out of my spine. (That's a technical term, by the way. Whooshing. Totally happens.)

Anybody want to put on a production of "The Hunchback of Notre Dame?" I'll let someone else be Esmerelda, 'cause I've totally got Quasimodo in the bag!



February 20, 2015

Hello dear friends. I'm still here! It has been a pretty rough month and to be honest, I haven't felt like blogging much. Every time I've gotten my laptop out, I've put it right back. But I'm feeling much better now and wanted to update you on what's been going on. I plan to go back and write posts about each of the events that have happened, but for now I'm just going to give a basic run-down.

After the Neupogen, I did stem cell collection, which was probably the coolest of all this stuff. They hooked me up to a machine that took my blood out, separated out the stem cells, then put the rest of my blood back in. Because I'm a rock star, I only had to do collection for two days. I got about 7 million stem cells, which was well over the minimum amount I needed.



After collection, I did the high-dose chemo. I took Busulfan orally (52 little pills a day) for about a week, and then I did two days of IV Cytoxan. The high-dose chemo is the point of no return. It kills all the cancer cells as well as all of my bone marrow and white blood cells. No bone marrow means no ability to create more blood cells, hence the stem cell transplant, which "rescues" me from the high-dose chemo.



I had a day of just fluids after the Cytoxan, and then on Thursday, February 5th, I had my transplant. Everyone on the transplant floor tells you "Happy Birthday" when they see you, because they know it's the day you're getting a new lease on life. They thaw your stem cells out and slowly push them into your IV via syringe. I had seven full syringes, which were pushed in over about an hour's time. The preservative they put in the stem cells is gross; it burned my throat and made me cough, and it also made me smell for a day or two. Some of the nurses said it smells like creamed corn and some said it smells like garlic. One of the midlevels said it smells like a fart to her. At any rate, every single medical personnel I came into contact with for the next two days immediately asked if I had just had my transplant. "Why yes, yes I did. What does it smell like to you?" The funny thing was that I couldn't smell it at all, but I could taste it in the back of my throat. Tasted kind of like throw-up. But no complaints here, I'll deal with the puke taste if it means my stem cells will survive!



So now I am on 21 days of coming to the clinic every. single. day. Every day I get 2 liters of IV fluids, which takes 6 hours to infuse. I also get blood work done and then get platelets or blood or potassium or whatever my CBC panel says I need. On day 6, I spiked a fever of 101.7, so I had to go to the hospital, back to the BMT unit on the 4th floor at Northside. I spent a few days in the hospital, getting antibiotics, blood, and platelets, and then they let me out on Friday afternoon. That weekend the mouth and throat sores got really bad, and I nearly had to go back in, but thanks to Boost and a pill cutter, I was able to get calories in and my meds down. I'm doing much better now. Yesterday I even was able to eat some junk food and walk around the clinic several times.



Today is day 15, so I only have one more week of going every day. This week I haven't needed anything but fluids, so hopefully next week I will be able to go to three days a week. It would be really nice to sleep in occasionally! I'm still bald, and still exhausted, but starting to feel a bit more human. I'm so grateful that this treatment is available to me, and that I've made it through without any major issues. And of course I'm thankful for my awesome village-you guys have been a huge factor in helping me pull through this!



March 11, 2015

Well, I have an update. This may sound bad to many of you, but it is actually better than I expected. I have had another relapse. Just before I started my high-dose chemo, I felt a few lumps in my left breast, in the same area as the last time I relapsed. So we biopsied them (seriously fun times...or not...remind me to tell you all about it later) and they came back positive for Hodgkin's. Then we did the high-dose chemo and hoped for the best. The spots went down, but they have come back with a vengeance. I call them my "stubborn spots," among other things. I also call them my "not-a-tumors," because they are actually enlarged lymph nodes, but they feel like tumors. We couldn't do anything about the stubborn spots for a while because I was still recovering from the high-dose chemo and the transplant and any further treatment...well, let's just say it would have had the opposite of the intended effect if we had done any treatment while my counts were so low. So now I have passed day 30, my counts are up, and on Monday I did a PET scan.

Today I got the results of the scan. There are 6 nodes in my left breast (several under the muscle – no wonder that junk hurts!) and 1 on the right side of my neck that are showing cancerous activity. Basically that means those are the areas where the Hodgkin's cells are right now. So in a way, it's a good thing that it hasn't spread to the rest of my body like it did last time. That means we did have some results with the stem cell transplant. We just didn't have a "complete response." Fan-tastic. What do we do now?

Well, now we start treatment again. I am going to try a relatively new chemo drug called Brentuximab. It was approved by the FDA for use with Hodgkin's in 2012 and the big study that

was done showed pretty positive results. This is a smarter chemo drug. It targets the cancer cells specifically. This means it won't try to kill me as much as the other chemo drugs did, because it can tell the difference between good cells and bad cells. Most of the front-line chemo drugs just kill all the cells, which is why there are such horrible side effects from them.

Now this doesn't mean it's going to be a walk in the park. There will still be side effects. But seeing as how I'm still dealing with stuff (like my skin turning gray and then peeling off) from the chemo that was over a month ago, I'll be happy if it's not much more than the usual (hair loss, fatigue, tummy issues). I've also decided that it's a good thing my head is not all crazy-shaped, because I will still be bald for a while. Honestly, I don't really remember that well what it's like to have hair. Or take a shower, for that matter. I still have my central line, so I have to saran wrap it and take a bath still. Not terribly relaxing. Well, this post has turned into venting, so I think I'll wrap it up.

No worries, friends. I am still confident that I will beat this. There are more back-up plans, like radiation and other drugs. We will fight on together. It's just going to take some more time.

April 7, 2015

Tomorrow will be my second round of this new chemo drug, brentuximab. I get an IV infusion of it every three weeks. This one has been a bit rough. It's the first chemo I've done that really made me nauseated. I've spent the better part of the past three weeks throwing up and eating very little. But Monday we doubled my Zofran dose and I also got an anti-nausea patch to wear. SO much better. I've vomited much less and have been eating much better. Hopefully this

means I will be less dehydrated and won't have to spend quite so much time at clinic getting fluids and electrolytes. At any rate, I feel better. That's worth a lot.

On Monday morning, I also got my central line catheter removed. I still have my port to use for chemo and IV fluids, but now my risk of infection is much lower without three lumens hanging out of my chest. I will probably have to have another one placed, but not for a while.

So the plan moving forward is to do about 3 rounds of brentuximab and then radiation if necessary. We will keep trying chemo drugs until we find one that works on these stubborn spots. Once we get rid of the stubborn spots, we will look at doing an allogenic stem cell transplant to ensure that the cancer doesn't return. I'll share more info about that process as I get it. That's it for now – not a whole lot going on except watching and waiting. Thanks for the many prayers and kind thoughts – they are helping!

April 15, 2015

Hello lovelies!

I feel like I've re-entered the land of the living. I've been released from the BMT docs at Northside back to my regular oncologist for a couple of months. I will do a few more rounds of brentuximab with Dr. McDonald and her crew, and then radiation if necessary. Once we get rid of these stubborn spots, I'll do an allogeneic stem cell transplant to make sure the cancer doesn't return. Allogeneic means I'll have an outside donor. Right now we're testing my brothers and looking through the registry for a match. I'm hoping this takes a while because I need some time to wrap my brain around another transplant.

But back to my release. I had my central line catheter removed from my chest. I'm allowed to drive again. I can have grown-up, non-sick visitors. I still can't go anywhere public, but I can eat whatever I want! This means I can have salad again! And I have had salad every single day since being released to a regular diet. No, salad every day for a week and a half straight is not the wisest choice, but I don't care! Lettuce! I never knew just how much I loved plain old iceberg lettuce. It tastes like freedom. It really does. Freedom covered in ranch dressing.

My taste buds are still all messed up, so I still don't like anything sweet at all, but I've gotten used to not eating chocolate or drinking sweet tea. I do feel a little un-Southern, but that's not necessarily a bad thing. ;) For now, I'm a happy camper to have some more freedom.

Today I went to Dr. McDonald's office for a quick check-up, and it was really wonderful to see all of my GCS family. Lots of hugs, even though I'm not supposed to! And only a 20 minute drive to the doctor! Needless to say, today is a good day. It's really important to have those every once in a while, and I was definitely due for one. Hopefully all of you are having a good day, too!