

Rita's Story

Survivor of DCIS (2001) and then Acute Lymphoblastic Leukemia (ALL) via a Bone Marrow Transplant in a clinical trial (Ni-Cord Project) at Duke Medical Center (4/2012 - 12/2012)

“Practice what you preach!” “Put your money where your mouth is!”

Did you ever say that to anyone? What do you think it means? Most of us think it means to- DO what you SAY and SAY what you mean.

I've been in fitness my whole life. In high school I participated in track & field and ran cross country. I got accepted to NYU and got a summer job at a local health club. I started teaching and personal training. I also met a young man from New York at this club. Little did this 17 year old girl know...this JOB and this young man, would help save her life over 2 decades later.



It was a Wed. morning late March 2012. I just taught my 2nd class of the day. Cycle class no less, hard but again, if I tell my class to push thru, I must too! I LOVE my members! Got home took a shower and did my self exam. Of course. From having breast cancer DCIS in 2001, I always did a self exam. I felt a lump under my right breast. I was very CONCERNED since my Doctor just did an exam weeks previously. I called him right away. He worked me in and after the exam, he decided I should get a biopsy asap. My Doctor assured me he would call as soon as he got my results.

Friday- Relay for Life in our home town: I was the Fitness Director at a local health club. That evening, I had events planned-picnic, a Zumba demo and planned to walk in the survivors walk as I did in previous years.

It's 10am,I get a call on my cell from my Doctor. I leave the club and run out to my car. I didn't want to upset anyone in the club in case it was bad news. I answer. He says " Well, I don't have good news for you. I am so sorry but it's lymphoma". My heart sank to the ground and I felt an overwhelming feeling of dread, doom, extreme grief. I start saying things like "What if I have a mastectomy?" He said, "I'm so sorry its already spread to your lymph nodes. PLEASE don't get on the internet looking for information. Just go be with your family, we will make an appointment for you and see an oncologist".

My thoughts are everywhere about everything- my kids, husband. My Job and I'm thinking...HOW do I walk in the survivors walk now? Am I still a survivor? What if I don't survive THIS? I took a big breath and said out loud "Please Lord, Please give me strength to get thru this". The tears come. I know I still have to go to the Relay. I have instructors who practiced for our demo and will need me tonight. I have to prepare for the picnic for our club members. And yet, my thoughts are back to-how am I going to tell my husband and my son's? They were going to come walk with me tonight. What am I doing??!! Is this really happening??!!

I tell my family I'm not feeling well. Don't come to the Relay. I'll just go to make sure everything is set up, help my instructors with the demo and come home. I'm going thru the motions there. Doing what I need to do, saying what I need to say..Trying hard not to have a panic attack, fall apart.. I force a smile and push thru.

I make it home. Make dinner, wait for Jim. He's home. Eats dinner. I try not to fall apart. I don't want to upset him and cause him stress. After dinner, he asks "So what did the Doctor say?" I tell him in a calm voice with no tears in my eyes. I see he is badly beaten by my words. Then he says to me, holding my face in his hands, "WE got this."

Jim and I immediately go into parenting mode, to protect our sons, we come up with a plan: share our life changing news and also share the hopeful possibilities of treatment. We sat them down. None of us shed any tears. But I knew when we told them "mom is sick", they had that same sickening feeling of doom. It was the day my son's lost their "smile".

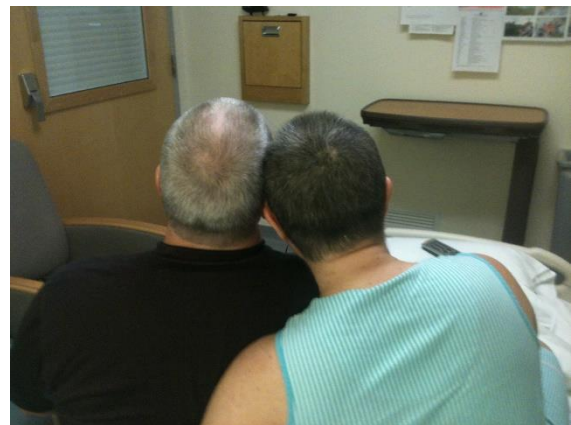
We saw our local oncologist about a week later. He had a plan and we agreed on treatment. I felt somewhat hopeful. Before we left, I had some bloodwork done.

About 7:30pm that night, the oncologist calls. I have a sick feeling in my gut. "Rita, you just don't have lymphoma you also have leukemia. You have to go to UVA asap!" That little feeling of hope, turned to utter despair. I ask him "How long am I going to be there?!! I have kids a job!" He says "You might be there a month or a year". A YEAR??!! Panicked, terrified, Jim and I stuff clothes into suitcases, called grandparents to stay with our boys...the phone rings again...it's the Doctor from the Emily Curic Cancer Center at UVA. He asks Jim, "Is your wife lethargic, bruised badly, in a lot of pain?" Jim replies "NO...she looks and feels fine, just tired." UVA Doctor says, "OK, no rush to get here. We will admit her on Monday".

Monday- we are at UVA. I'm sitting up in the bed with my arms crossed as 9 Doctor's and interns are looking at me. They ask "What are you doing here? You don't have a bruise on you and you look healthy?" I say "Right? What am I doing here??"

3 days of test of all kinds-lots of blood work, port put in my chest, scans, needle biopsy's, lumbar punctures, Then: YES. YOU have Acute Lymphoblastic Leukemia. Only about 40% curable. Treatment, the Linker Protocol- chemotherapy of all types, IV's, shots and pills.

Chemo treatment started that night, Vincristine was "her" name (my chemo drug) I remember her well. She was a special kind of Chemo that had to be gently coaxed in to me by syringe-the nurse would have to sit and push it into my veins. Vincristine was red. As the nurse, who was dressed in hazmat protective layers, push the syringe, I watched vincristine, slowly climb the IV line and entered by port in my chest- it felt like bubbles popping. I felt it popping all thru my chest, then down the sides of my stomach, down my hips, thighs and legs...my feet felt warm and flushed. One done, Jim gave me a fist pound. One done he said. Then we were silent. We didn't know how many "fist pounds" we had left to go. He is my rock.



Four months pass, we are in an apartment at UVA. Chemo weekly, some by IV, some by mouth, some by shots (in my stomach daily). When we could we traveled home. Our boys were still in high school-football, wrestling, home comings. I didn't want to miss any of it. It was hard on them. I felt like they mentally "checked out". It was hard even though we called and skyped nightly. Their smiles were gone. Then...

“Rita, I have some news for you. YOU are 98 % in remission. But your bone marrow is making the lymphoblastic cells...cancer cells. YOU need a bone marrow transplant”. RIGHT AT THIS MOMENT: I said...”LORD, your will be done”.

I’ve always been a spiritual person- always felt God’s presence in everything around me. I had prayed so hard from the time I got my Doctor’s call, all the way to this moment. But I was still trying to do it... MY WAY. Now I felt like I could no longer do it my way...even though I pushed thru...painful bone marrow punctures, the pain of cutting my hair with a pair of \$2 scissors we bought from Food Lion...the pain of seeing my son’s fearful faces...I prayed through all that but only right at this moment...did I say...”Thy will be done.” There was nothing more I “Humanly” could do.

Some people might say “She gave up.” Exactly the opposite. It was then that I HEARD GOD say, “Be still and know that I am GOD!” In the most devastating moment of our lives- as soon as I said those words out loud- I felt at peace. I could do no more. God’s got this!

From that moment on- a search was put in the world wide database for a match. My brothers were tested. My friends tested. A few days later, “Rita. I don’t have good news for you. We cannot locate a match for you. I’m sorry.” Again, I felt like I had been punched hard in the face. Battered, broken, bloody, “Lord your will be done” I said again. Then UVA Dr. says- “However, Duke is doing a clinical trial with new born babies’ cord blood. That is a good option, the only option.” I’m sobbing, “Maybe it will work, but what if it doesn’t??” UVA Doctor,” You know, we people, always want the best this or that...sometimes the MAYBE is what we need. Sometimes the MAYBE is what is GOOD for us.”

Jim and I are once again devastated there isn't a match. We search cancer centers for other treatment options: went to Sloan Kettering in NYC. They tell us that DUKE has a good plan. "We ONLY have ONE shot at this transplant". Jim says to Sloan. They say "YES. One shot".

We make an appointment with Duke. As we sit in the waiting room, I hear a woman say, "I'm 4 years old today!" My heart is so happy for her. I want to be 4 years post-transplant someday. Sitting there waiting to see the Doctor, I wasn't even 4 days post-transplant. So many sick people-mothers, father's, husband's...children. I realized WE were in that club. The "bad things happen to good people club". The "that happens to other people club." We did NOT choose CANCER. It chose me and effected my family and friends. What could we do but PRAY, gather a GREAT support team and take another step. "It's a good thing you are in good shape Rita. Your chance of surviving this has increased just because you aren't diabetic, have no heart disease etc." says Duke Doctor. And I thought all this time, I was just doing what I loved. Teaching. Teaching all these years prepared me for this battle. To keep it real, we do get the gloom and doom talk, the prepare your family talk as well. We cry, we are terrified but we PUSH THRU hopeful. I say to Duke, "I will do my part and be the best patient, you will do your part and GOD will do his part".

Sept.3rd Labor Day 2012- we check into Duke, 9200 Isolation ward.

When you don't know how long you will be at a cancer hospital you pack well! I brought our vacation pictures, my karate teddy bear, my Zumba, Les Mills body flow dvds, my Ipod. I chose a few uplifting, motivational songs to listen to while I got treatments. Packed my books, laptop and my own clothes. I changed out of my pajama's in the

morning and back into my regular clothes during the day. I had to choose wisely because I was attached to an IV pole and I did have to have blood work daily. I made it work for the nurses and for me. I also brought a calendar-crossed off each day. I wrote in " Dec.23rd- "patient discharge to home". THAT was my goal- to live...to go home 12/23.

Day one- Total Body radiation. 2 times a day. I am weak. Sitting in a wheel chair, waiting for radiation treatment. Jim and I see a lively, little 2 or 3 year old girl running about, laughing. She makes me smile. Then the tech calls me back. I lay on the table, curled up in fetal position as the techs make certain, I'm in proper form- they try to guard my eyes from radiation. ALL of my own bone marrow must be eradicated, whipped out so the new stem cells have a clean, healthy, cancer free "place" to grow.

Day two- more radiation. I'm burnt. I wipe my face with a wash cloth and I see its black with "soot". I get pushed down to radiation. Again, I see the little girl, running around, laughing and giggling. Jim and I look at each other. The nurse comes out, calls her by name carries her back to the radiation area. She has her treatment- nurses bring her back to her mom- in a portable crib-she is asleep. This little child had to be put to "sleep" so she could hold still for her radiation treatments. I shake my head and cry. It's one thing for a parent to go thru this- another for your child to go thru this. I pray..."LORD please comfort this little girl and her family".

Six total body radiation treatments, 2 more days of intense chemo...Cytosin. Bald head, burnt skin, barely breathing, IV pole attached for months, weak, barely alive. NOW! My bone marrow is finally ready to receive the stem cells.

"Happy birthday to you!" my nurse sings to me. Surprised her mundane, serene tone and mannerisms, I say "thank you" and watch as

she hangs my new stem cell on my IV pole and leaves. Duke performs about 496 transplants a year.. Only 9 others like me. I was #10. Last one accepted for the Ni-cord clinical trial. This was normal to my nurse, hanging stem cells. It's absolutely incredible. My stem cells looked like a bag of plasma. I quickly grab my ipod. I play uplifting, motivational, happy songs as tears gush from my eyes. I try to think positive thoughts. I say a prayer. I was going to make SURE I did my part to make these little stem cells...LOVE their new home...MY BODY.

My team of Doctors and nurses were watching for any allergic reactions to these foreign stem cells. This is an organ transplant much like kidney, heart or liver. Organ rejection is possible. Most likely graft VS host disease will arise. Essentially, by body rejects the stem cells. So yes, I was going to listen to music, practice my yoga breathe and be as calm as I could while these stem cells grow in my body. I had to do my part. Doctor's and nurses are doing their part. And GOD is doing his part. I had a GREAT team.

Jim, the young man from New York I met at the health club, would sit with me all day in his protective canary yellow suit, blue gloves and blue face mask. Poor guy typing away at his PC and talking in his blue tooth. He was still remotely working thru all of this. He kept me laughing. He was always good at that...still is. He motivated me to walk the hall ways at UVA and at Duke. I had to shuffle along like "Tim Conway chasing Mrs. Wiggin's". Jim would make me...make me touch the wall. If I didn't, he wouldn't count that as a lap walked. I wasn't always happy about that. But I did it. Jim was right. I had to push myself so hard and go thru so much pain to get the ultimate reward per-say—which was to GO HOME! We also went to the workout room and I rode on the nu-step. I loved that machine. Hard to exercise in a mask, gloves and gown but what ELSE did I have to do?? I'm so grateful for Jim. He is my everything.

At night, I would tell him to go get some rest at the apt. Jim had cared for me all day, worked remotely, spoke with doctors and nurses, helped me eat (hard when your mouth tastes like metallic, dirty coins) and made sure I had everything I needed for



a good night's rest. When Jim left, I had a routine- it took about 2 hours. 7pm to 9pm- brush teeth (had to be careful not to cause my tender gums to bleed, since I had no white blood cells, my blood would not clot), put lotion on my burnt body and changed. That took 2 hours. I was so slow and weak. I would tell the nurses I was going to sleep...pull the shades and darkened the room, play my iphone out loud so my yoga music filled the room. I would lay there and watch the colors blink, the machine beep, feel the burning in my body wondering how all of this...3 stacked high...all these fluids, medications, supplements, hanging there.. how was this stuff going inside of me? Amazing. The nurse comes in. She hears my music- "What are you doing?" she asks. I say- "I'm feeding my stem cells soothing music so they will sleep well and grow strong". She gives me a thumbs up. I smile.

2 week later, I'm engrafted! Stem cells doing good! They like me. I have some graph VS Host disease: stomach pains, acute diarrhea, extreme vomiting, hives, vertigo. YEP! All at once. NOT FUN! Doctors increase my intake of Prednisone to combat GVHD. My face is puffy and I feel like the Michelin man: NOT attractive for a personal trainer and fitness instructor...BUT I'M UPRIGHT and BREATHING. God says- "Yep...you don't look like yourself or feel like yourself but if you will keep trusting me- I have something much better for you." And HE DID.

Dec. 23rd 2012- "Rita, you did great switching from IV meds to pills...you can go home". Jim and I were scared to death. Scared of going home. What if something happened?? Were we too far from Duke?? But we were also elated to be home in time for Christmas.

Looking back

21 bags of blood from hero's who donated I'll never meet

Countless hero's cared for me! MY nurses and Doctors!

4 bone marrow punctures (Hand drilling in to my hip bone to extract by syringe bone marrow sample). I'll have holes in my hips forever!

2 spinal taps (lumbar puncture by needle and aspiration)

Over 30 nuprofen shots in my stomach daily

Countless PET scans, CAT scans, blood tests

Black fingernails and toe nails from treatments

Months of cramping toes and fingers, couldn't hold spoon or fork

Mouth tasted like crushed up aspirin or mouth full of coins, metal

Bald...twice. People staring, some running the other way

On a Walker for 4 mos. Now I know why the tennis balls are so important

Watching my husband gain 50 pounds taking care of me-eating what I could not eat, stressed from working all day and trying to care for me and our sons....and not exercising. He is my rock.

2 new born baby girls cord blood

1 miracle performed by 1 LORD

Dec.2012 to present

Because I got CANCER.. We were now a single income family with hefty medical bills to pay. My job was no longer available. I focused on getting strong so I could help my family –MAKE a living again. I did the one thing I knew I could do...help people get fit, feel encouraged and feel GOOD about themselves. So here is again where I heard God say..." What would you tell your friends, family or clients if they were in your shoes??" I replied- I would say "PUT your money where your mouth is. Practice what you preach! BEGIN again." I had to do what I had been preaching to my clients, friends and family.

SO, I said to myself

"GET UP!! Get moving. I don't care if you crawl to the kitchen from the couch. YOU will move your feet. Go ahead and cry, feel sorry for yourself, have pity party. Most people would AGREE with you if you wanted to quit, give up!! YES, you had a VERY BAD thing happen, you got kicked in the face while you were on your knees praying for one more day... but you are still HERE! And as long as you are HERE!! YOU will FIGHT!! DO YOU hear me! Now get up!!"

My feet hit the floor. Tears streaming down my face. I grab 3 pound dumbbells. I curl them up and down 6 times. I am tired. I am slow and weak. So pathetic, worthless, bald, crying, sobbing BUT I GOT UP!!

My boys would take me walking. One on each arm. We would do the “Tim Conway shuffle” (I love that show!) I was slow and we had a few laughs, of course, to get us thru the hard parts- “Mom, that leaf is walking faster than you” ... har har. They slowly got their SMILES back. My heart was happy. WE were all returning to “normal”. Our boring, every day, same old same old days. It is a privilege to DRIVE. Going to Kroger is such a GIFT! Rolling the windows down and feeling the wind in my face. AWESOME!

GOD

watches over you...me...all of us in every moment of our lives, HE never leaves us. There really is one set of footprints and it is “WHEN I CARRIED YOU.” When I was 17, I was supposed to go to NYU. God said no, I have something better for you. Here is Jim. You will find him useful later in your lives. Then when our boys were born, we donated their cord blood so someone else could have a second chance at life. AND 20 years later—it was me who needed cord blood from new born babies. GOD is watching over you...you have to be still..quiet your mind.. and listen.

Be a gracious receiver and a generous giver.

I am teaching and training again. I'm not at my ideal weight or strength level as a fitness instructor or personal trainer should be... YET. People who don't know me might laugh and think "Wow, she needs a trainer!" And in a way they would be right. We do want to see an accountant who is not bankrupt or a mechanic who doesn't just drive a car. However, I can relate to the hair dresser that has had cancer and lost her hair during chemo treatment. She is now bald, over weight due to prednisone (and other lifesaving meds). Her metabolism/ adrenal gland shut down due to radiation, chemo and steroids. Her body devastated and fighting hard to revive every cell in her body, so she could LIVE. ALL this and she is still a Professional Hair Stylist. Cancer doesn't steal our purpose. Mine is to teach and train..hair or no hair.

When LIFE is so HARD, it's EASY to dwell on the negative. It's easy to give up. It's easy to let what people think or say bring us down. We humans, all of us, have been a blessing or a curse to someone. No hate, just celebrate. It is also easy to have negative thoughts about ourselves. So form your "weapons of peace" and work towards JOY.

Weapons of Peace

As soon as you have a negative thought,
replace it with a beautiful one.

Surround yourself with beauty: Nature, animals, sunshine
Listen to beautiful music of ALL kinds and most of all DANCE and SING
Treat yourself gently. Your body, mind and soul have been thru much.
Remember, "Sometime helping means not being there". If you can't help someone at least do no harm. Move on. They might let you go, you might let them go. You are not meant for them.

Keep MOVING! Eat clean and drink water

Don't wait to be invited to a party! YOU start the PARTY!

And most importantly, surround yourself with compassionate, fun, loving, supportive group of friends with similar goals: to live healthier, happier, stronger, longer, helping and healing each other and to

ENJOY our journey together.

I am so humbled and grateful to have been in the company of so many strong warriors who fought cancer and have gone..much too soon.. to their heavenly home..including my mom recently. For my mom and for so many loved ones- WE will continue to LIVE. That's what they would want us to do. Let the tears come but let the smiles come as well.

Do your part! Do everything you have to, to find PEACE and JOY!

AND you can BEGIN again!

Even with tears in your eyes, you can push thru and begin again. We believe you can. Drop into one of our classes. We would love to meet you. Keep Kickin' my friends!