

TINA SIERRA'S CHRONIC MYELOGENOUS LEUKEMIA JOURNEY



Well OK, here's the long version ... you asked for it! YOU GOT IT. I've been putting this off because how do you put into words my almost 6 years journey of leukemia treatment? I will try in hopes that I can offer hope and encouragement to anyone in need along with info in case someone needs that as well. Plus my lessons along the way!

December 2001. I was 42. It started when I wasn't feeling well for a couple months. I was very sluggish, not eating well among other things. I told myself that after the holidays if I still wasn't better I'd go see the doctor. I sat in her office and explained the above. She quickly tried to reassure me that I had a terrible year after losing my dad and enduring a bitter divorce that took a year and a half, and that was all. I INSISTED that she run some tests before just putting me on anti-depressants. I went for blood work that day. That night I went to sleep and was wakened by a call at 2:00am from one of the Dr's in the group. The lab had just contacted him to get me to come in right then as my blood work was crazy bad. Normally your white blood count is between 3,000 – 10,000. Mine was 320,000 and they knew immediately that I had cancer ... either an aggressive tumor or leukemia.

Lesson #1 Ladies, listen to your own intuition and speak up to get the medical attention and information that you deserve. If I had waited like she said I would most likely be in heaven now. She called that day to apologize.

I was sent to an oncologist/hematologist from the ER who spoke to Rick and me. Thank God by that time in my life, I had this wonderful man with me that God had sent months before. The Dr said that he thought I had CML (Chronic Myelogenous Leukemia... definition below) based on the blood work but a bone marrow biopsy would confirm it. If it was that, guess what?! There was a brand new miracle drug called Gleevec that I'd take to get me into remission. Imagine? Just some orange pills, no "chemo". FYI ... Bone Marrow Biopsies are tough to have. They go into the hip/pelvis with a big ass needle/drill (I've never seen it ... won't look!) after a shot of lidocaine to

numb the area. The pain/pressure involved depends on the technician doing it. You're sore for a week or 2 afterwards ... kinda like getting kicked by a horse?!

Well, I had my first of many bone marrow biopsies, (BMB), right then. Instead of being afraid, I got into my "faith zone", trusting in the Lord to be with me. The Dr had me get onto my side so that he could take the sample from my hip. The examining table was against the wall so that when my arm extended, my hand was resting on the wall. I had the vision of Jesus' hand on the other side of the wall with our fingers touching. I was totally calm in His hands. The nurse even commented to me, "You've got someone there with you, don't you?" He's been with me every step of my journey. It would take a week for the results. I was put on a chemo pill that day to kill off some of those crazy white cells and stayed on it only a few weeks. I wasn't all that sick but could not eat. I lost 15lbs. in less than 3 weeks.

Explanation of CML from a website is below. Only 5,000 people a year are diagnosed with it. There are many types of leukemia. Chronic Myelogenous Leukemia (CML) is a cancer of the blood and bone marrow. All blood cells are made by stem cells in the bone marrow, which is the spongy tissue inside your bones. There are 3 types of blood cells: red cells, which carry oxygen to all the tissues in the body; white cells, which fight infection; and platelets, which allow the blood to clot to help stop bleeding when a blood vessel is damaged. In CML, the stem cells in the bone marrow make too many white blood cells, some of which never mature. These immature white blood cells collect in the bone marrow and blood. Eventually, the extra white blood cells crowd out the healthy red cells and platelets and interfere with the functioning of other organs. This causes the symptoms of CML.

I got started on the Gleevec February, 2002 and Rick & I felt very optimistic. Of course, family members were petrified (especially my mom and 3 daughters who were 6, 11, & 22 years old). The drug was so new that we only knew what was reported from the clinical trials.

Lesson #2 Professionals suggested complete honesty in telling kids, no matter the ages. Ya know what? I swore that I would ALWAYS tell them the truth NO MATTER WHAT and that was easier on them. They didn't ever think I was hiding anything. Don't we tend to think of all the worse possible things when you're left "in the dark"?

Praise God, I responded to the Gleevec and within several weeks, my blood work started looking more normal. The side effects started right away. Nausea, terrible diarrhea which lasted 1 year then stopped, bone pain, swelling, brain fog, period problems and muscle cramps. Gleevec, which was approved for the U.S. prescription drug market in May 2001, after just three years in clinical trials, is sometimes referred to in the media as a "magic bullet" because it is thought to target only the enzymes in your body that allow cancerous cells to grow, not your normal healthy cells. Traditional chemo drugs are "generalists;" that is, they can affect (hurt) all the cells in your body, not just the cancerous ones. Side effects include nausea, fatigue, bone pain, muscle cramps, diarrhea, loss of skin pigmentation, low platelets, low white counts, rash, and

others. Gleevec has been tried on many cancers and now is used for a rare type of stomach tumor. (G.I.S.T.) Our sister director Maureen Eisenhart's sister, Kathleen, was also helped with Gleevec and doing well! PTL!!

My cousin told me about a young woman with CML who had a website all about the above. I contacted her and met with a few others on this new Gleevec. We were like pioneers. They talked about a new upcoming cancer vaccine clinical trial and who would like to go to hear the talk at UCONN Health Center? Well, I wanted to go, just to hang out with them, my newfound friends, comrades. Believe it or not, I was the one out of the group who signed up for the trial and took part in the 12 week study of a new cancer vaccine for CML patients. It was safe and made sense. If the Gleevec did not work, I'd have a little back up.

What a great experience it was except for the Bone Marrow Biopsies before, half way thru and after! I could write an entire other story about the people and patients and professionals that Rick & I connected with. One young guy and his wife came from Missouri for the trial only to find out there was no funding for housing. By the way, they had lost everything when he got sick and was fired from a six figure job. Rick had them live at his apartment those 12 weeks, plus the last 3 weeks with their 3 small children! We became life long friends. He is well today after a successful bone marrow transplant following a relapse.

Lesson #3 & #4 My Dr did not know much about the trial and depended on me to keep him informed. In other words, do not depend on your Dr's to know it all and YOU be open to learn and research. Be your own advocate or have a loved one do it. I believe that besides God's grace & Gleevec, the vaccine may be also why I've done so well. It was only a phase 1 study and I got no info on it. It HAS been very successful on many other cancers. Trials go 4 phases and it could take years to get drugs released to the public and tons of government dollars in which much more is needed. You can find them at www.clinicaltrials.gov. They need more participants as well .

The other lesson is our MK business and the amazing benefits that we should never take for granted. You can't fire YOU. The positive attitude we've *learned* to have can be, and I believe is , life saving. The joy I got from the MK and working with my people even when I was quite sick helped me more than I can say.

OK, so get this! Rick & I get married right after the trial and while in the Bahamas on our honeymoon we got the greatest news ever! My last Bone Marrow Biopsy came back negative for the first time, October, 2002.

Another part of my journey once I was in remission was to have my now healthy stem cells collected and stored in case I needed a bone marrow transplant (now called stem cell transplant) since neither of my brothers were a match for me, nor were there any potential unrelated donors listed on the national registry. It was a fight with Dr's and insurance companies but I did it. We also raised thousands of dollars to host a bone marrow drive. (BIG thanks to the generous Danforth Directors and others). It is not free to get people tested. There is a huge need for donors, so get ready for it now ...

LESSON #5 You never know when someone you know and love will need donated blood or marrow to live. Please be willing to learn and listen when you hear or see a need. You see, for marrow, only 30% of patients have a relative that matches them. The other 70% must depend on a stranger that has been put on the donor list and can donate their life-saving cells to save those lives and cure them. Here's the website: www.marrow.org

Donors are put under brief anesthesia so no pain for taking the little bit of marrow and blood needed. Another way to donate is taking blood from the arm veins after taking medications to speed up stem cell production. It's not as bad as you'd think plus you could SAVE A LIFE! SIGN UP!

Cord blood transplants are now very promising and info is on that site as well. My daughter, Amy, has had 2 babies now and has banked both of their cord blood for the future. Some hospitals, not enough, are capable to take cord blood donations. It is a must for the future to expand on this!

Fast forward: New 3-5 year studies show Gleevec really is a miracle drug. 92% of us are still in remission compared to 23% survival rate with the old treatment, which had much worse side effects. The not so good news is everyone who goes off Gleevec relapses. So, I gotta take keeping it. January, 2008 marked 6 years since my diagnosis. More molecular target drugs have been released since then and you'll hear more and more exciting advances in cancer research.

LESSON #6 There's always someone worse off than you. I've learned to reach out and help others by volunteering with the leukemia society as a first connection volunteer, offering hope & encouragement to newly diagnosed people, and also with the American Cancer Society's "Road to Recovery" Program driving cancer patients that do not have rides to treatment. Guess what? THEY sometimes have better attitudes than healthy people and will lift you up. It takes so little time for such huge rewards of the soul:

www.americancancersociety.org

Lots of the side effects have gotten better with me in time. One side effect not listed but all Gleevec patients complain about is "brain fog" or "chemo brain". Most (including me) go on an antidepressant to help it. Don't even JOKE about having a bad memory, right, Pat?! IT'S BAD, BAD. SrDirector Theresa Northway says I remind her of the movie "50 First Dates". She has quite the sense of humor! Well as time has passed, I've gone through ups and some bad downs. It turns out, newsflash, Gleevec + SSRI's (some antidepressants) do not mix. My Dr did not know this either but sent me to a "head" specialist. Since summertime, I am working my way out of a fog again. Basically, it felt like **everything** was an effort and I had to force myself to do what I **had** to do. What a DRAG! Ask Theresa! She has been my true friend for 20 years and has been my confidante. She's the only one that has heard my real fears and knows my difficult days. She knows what to say in her loving but tough way how to help me and she does.

LESSON #7 I've learned to take personal responsibility to find a way to feel the best I can. Don't settle for less. Eat right and exercise! Establish a "new normal" for yourself. I tried to get back to "normal" for a long time and got frustrated and depressed. Even though you may never get back to way you were, the new you will emerge so be grateful for it and strive for the best new you. There are many fantastic professionals out there and new medicines that can make all the difference in the world! As you can maybe tell, I've BEEN feeling better and better. We're trying different antidepressants and I'm hoping and praying that I'm gonna STAY good! When I was feeling my worst in June, 2007, not knowing why, I told the Dr, I'm lowering my dose of Gleevec! With his approval (not that I needed it!) I went from 400mg a day to 300mg. Instead of a 3 month ultra-sensitive blood test I'd go for one every 6 weeks that looks for any leukemia cells. After waiting a week for the results we got the good news. Still zero!! NO BAD CELLS FOUND!

I shared the latest good news with Pat and she asked me to share my story. Going again for my last 6 wk test, Cindy, the girl at the lab I see every time in the cancer center, tells me that there's a new and even more sensitive test available for me IF I want to have it. PANIC! Now on this lower dose, do I really want to go to a MORE sensitive test?? I never want to go back to 400mg as I feel less nausea now. Of course I do and of course I was STILL AT ZERO! Yipeee! I am now awaiting the test results of a new, **new** test to maybe see how much Gleevec is in my system. You know I want to go even lower than 300 ... 200mg, then someday none. I'm claiming myself cured, ladies.

LESSON #8 Read and view the DVD on The Secret. It's really all about God in essence, and the reality of a positive attitude and spirit. Finally, thank you so much to all of you who have prayed for me! Thanks to all who WILL pray for me as I continue my journey. BIG thanks to all who read this whole, long sordid story!

HUGE THANKS to all who act and get on the marrow donor list!

LOVING THANKS to PAT who loves and cares for us ALL and made me write this!!

With lots of love, hope and faith,
Tina Sierra

PS: I finally got the results of the Gleevec levels in my blood and it is great news! My level is that of someone who is on 400 – 600mg and there may be room to go lower with the Gleevec. The expert advised me to continue re-testing, which I will do, just to be sure.

I am so, SO grateful!!

FROM PAT: I wanted to add to Tina's Mary Kay story. In November 2007 she celebrated her 25th Mary Kay anniversary ... and by Seminar 2008 got her 102nd Star on her ladder and has been on Queen's Court of Sales EIGHT times. She has earned the use of 11 career cars, 3 of them Premier Club.