







Easter at the Gillingham's

By Listy Gillingham

Easter Sunday proved to be another great family gathering as the sun was shining and the kids came ready to swim and hunt a few eggs. Francie sponsored the party and was quick to bring extra snacks, decorations, and drinks. We started the party with plenty of mini cousins playing in the game room while the parents chatted and munched on some snacks. We then opened the food feast allowing everyone a chance to make a sandwich and try some of the other delicacies made by others.

The pool was then opened and though it might have been a chilly 75ish degrees in the water (close to 80 outside), there were plenty of kids who were brave enough to jump in and enjoy a wet day. Luckily, the

Jacuzzi was also open and plenty warm to help those moments when a few goose bumps began to develop. The new deck built by Bob proved to be a great haven to watch the swimmers and the new porch cover also provided nice shade to keep everyone cool and comfy for most of the afternoon.

And of course, we could not end an Easter Celebration without a famous Riel Easter Egg Hunt. Eggs were hidden in the game room and family room which kept all the grands hopping as they ran around and were able to fill their baskets with at least a dozen eggs each. Special thanks to everyone who brought food and beverages to make the event fun and memorable.

We had 100% attendance from the Riel Sisters and wondered what happened to all of the brothers? Good thing we had a few innocent bystanders to represent the males and a nice balance of grandkids to keep it fun. Special thanks to Brett, Corinda, Curtis, Lauren, and Cora for making the longest trek to come over. We were also happy to have Ana and her crew and Chavvya with Noah and Maddie!

























RFNL May 2017 Page 4



Hey Everybody,

April 21st, 2017

Lots of news all pretty good today you can tell by the smile on my face!!! I am a very happy girl, so much to share I will try to get it all down for you!

As you all know from previous postings I have been waiting for the results of the blood tests to see if my boys are a match for my pending transplant.

Unfortunately, my stem cell coordinator checked their markers first, not thinking I guess that we already knew they were a half match because they are my kids, and didn't get them checked for blood types which is really what I needed to know!

We were able to call the blood bank where Brett was a blood donor and the good news is we were able to get his blood type instantly. The bad news is, it

doesn't match mine, but if Alan ever needs a donor, he is all set!!! Brett and Alan are both A+ and I am O+.

Bryce was tested on Friday and by Tuesday we should know if his blood type matches mine. If they should both be so obstinate that neither of them matches than we will use one of them anyway, it just takes longer for the stem cells to engraft, which is not good but my choices here are not that great either. Unfortunately, this is a risky procedure, that really has only a 30% chance of

being successful but it is the only chance I have of acquiring a new immune system.

That said, the plans called for me receiving the transplant 3 months after the stem cell transplant I gave to myself on February 2nd. Because Bryce's' wedding was one month after the new target stem cell transplant, my chances of going to the wedding dropped to none. Even though it was very difficult I accepted this as part of the deal, and moved forward. Now back then, 8 weeks ago, when I agreed to skip the wedding I also was not in such good shape. From the effects of the transplant, my blood labs were not so great, I was low in most everything, and very susceptible to infection which of course is part of the reason for me to not even consider traveling.

Just 5 weeks ago I had a bone marrow biopsy. The results were a resounding no cancer in the area they checked, at least for now. The light chain readings from my blood labs were at a very low .11. Also, Indicative of no cancer. Just last week I had the light chains tested again and still they are at .11. That is very good news, coupled with the facts that my white blood cells are in the black, and everything else is on an upward climb. Life is good, I am moving up and past this danger zone, at least for now.

Since my transplant coordinator has not even applied for insurance authorization yet, there is no way I will be getting that transplant on the 2nd of May. It is pretty darn near impossible. So, let's say we move that date to mid-May, which could be possible. That is only 2 weeks away from Bryce's wedding. 2 WEEKS!!!!! I say, even if things are going to go downhill so fast that those two weeks are going to make such a big difference, I'm a goner anyway. So, I told my Dr. Hutchins that

I was not going to miss my son's wedding. She agreed that at this time it is looking less risky and that she is in agreement with my decision. YAY!!!!!!!!

All things considered, the most important prognosticator is, I feel amazing. I feel so good that there is no fatigue left in me anymore. All my prayer warriors are doing their thing, and it is working.

But. it would be reckless for me to think that the cancer will not be returning, as a matter of fact, Dr. Hutchins informed me that the one place the chemo I am taking is not getting to, is my spinal column. So far, there are no neurological indicators that the cancer is growing there, but it is still something that has to be considered. Since my cancer originates in my blood, it is pretty much everywhere once it gets growing.

So far, the Cytoxin is keeping it at bay, but in the manner of keeping ahead of this thing, I am going to start receiving my chemo in my spinal column as well via a spinal tap. Oh goody, doesn't that sound like fun???? I will probably get 4-6 infusions a week apart, I can hardly wait, hahaha But to get to go to see Bridget and Bryce get married I am willing to take on almost anything. I am doing my part and you guys are doing yours, and so far, all is good.

Got some sad news this last week though, Jim McShane, husband to GiGi, my childhood friend Cindy's sister lost his battle with Cancer and passed along to what I hope is a better and more peaceful existence. Jim, you inspired me with your smile and grace and I was lucky to know you. Thanks for your braveness and your sense of humor, you will never be forgotten!

We are all only here on earth for a brief moment in time. Let's make it count. Live each day like you mean it and let everyone know how special they are to you. Tony, keep your battle going, I know there are some tough days, but you have what it takes to keep going. And Dr. Lundy, your kind words to me give me strength, thanks for letting me know the impact I have made on you. It was the most special of gifts. I love you all and especially those of you who have taken time to share yourselves with me. Thanks to all!

Bryce is coming to town to see me this Tuesday and I will let you know if he is a match or not. Either way, I will be moving forward with one of my children giving me life with their stem cells. I am so appreciative and lucky to have them to so unselfishly share this with me. Everyone have a great day and may only happiness come your way!

Lots to tell on this fine day in May, Got some good news and some not so good news. Sounds like the start of a letter everyone could send today, right?

Well so far all of my blood labs are great, I am in a nice remission for now so that is good. One of my Doctors, Dr. Mahindra, suggested that I do some Intrathecal infusion of a chemo called Methotrexate alternating with one called Cytarabine. This is because the chemo I am taking orally does not travel to the spinal cord, so to be on the safe side he wanted me to do 4 infusions, one per week.

While we were getting this set up I started to have some nerve pain in my lower extremities that had caused me some worry. Because of my concern, Dr. Hutchins decided to run a new blood panel even though I just had one done on Monday. this time we are looking for different indicators of problems with the spine.

Lactate Dehydrogenase test may be ordered, along with other tests such as a when a health practitioner suspects that a disease or condition is causing some degree of cellular or tissue damage. My total was 388 units with the normal range being 313 to 618 so that looks pretty good.

We are also checking the light chains again which have been showing no cancer returning to my blood yet. Results will come in early next week.

Here is what the procedure was like:

Intrathecal Chemotherapy (IT Chemo)

The cerebrospinal space is the area surrounding the spine and brain, which contains cerebrospinal fluid. Cerebrospinal fluid (CSF) is a colorless fluid, produced in the ventricles of the brain, which acts as a buffer around the brain and spinal cord, to keep them safe from injury.

Intrathecal (IT) chemotherapy is used to treat cancers that have entered into the CSF. When a cancer has gotten into the CSF, it may be called CNS (central nervous system) involvement. Chemotherapy given intravenously and/or by mouth are typically not able to cross into the CSF, and therefore, are unable to treat these cancer cells. Giving chemotherapy directly into the CSF allows the medication to reach the cancer cells and minimizes the potential systemic (overall) side effects that intravenous chemotherapy can cause.

IT chemotherapy can be used to treat or to prevent cancer in the CSF. IT chemotherapy may be administered as part of a chemotherapy regimen or on an as needed basis. IT chemotherapy may not have been part of your original chemotherapy plan, but added because cancer cells are found in your CSF. Symptoms of cancer in the CSF include a change in the person's ability to think and speak, difficulty swallowing, headaches, seizures and changes in vision. (Luckily I had none of these) To determine if cancer cells are present in the CSF, a procedure called a lumbar puncture is done.

Intrathecal chemotherapy is administered during a procedure called a lumbar puncture. Prior to having IT chemotherapy, you will have your lab work done. You need to have a sufficient platelet count (Mine is pretty damn good for someone on chemo 143 with 155 being normal) to ensure that your blood will clot at the site after the procedure. Your provider will also talk to you about medications that you take or allergies you have that could affect the procedure.

Administration of IT chemotherapy through a lumbar puncture

A lumbar puncture is a sterile procedure in which a needle is placed into the cerebrospinal space in between two bones (vertebrae) in your spine. The needle may be used to withdraw (remove) CSF and/or to administer the chemotherapy through a syringe, attached to the needle, directly into your CSF. It can be an uncomfortable procedure, (YES, haha) but you should not feel pain. A numbing medication will be used where the needle is inserted. The numbing medication may burn and you may feel a pinch at the site where it is being injected. A lumbar puncture can be anxiety provoking and some patients require an anti-anxiety medication (YES) prior to the procedure. You also will want to go to the bathroom prior to the procedure since you will have to remain still during the procedure.

- Your provider will position you in a way that your spine is stretched out to create space between the bones in the back. Opening this space makes the cerebrospinal space more accessible. You will be instructed to either lie on your side in a fetal position in bed or you will sit on the edge of your bed and rest your chest, arms and head on a tray or chair that has been placed in front of you, with your feet dangling off the bed. (none of the above, on stomach on a very comfortable table with feet extended against a table at bottom)
- Once you are in a comfortable position your provider will feel your back to determine the best place to insert the lumbar puncture needle. It is important to remain still during this time unless you are instructed to move. Once your provider has determined where to insert the needle, he or she will mark the spot with either a marker, a pen or with a piece of plastic making an indentation into the skin.

- Your doctor will put on sterile gloves. The area is cleaned with a topical soap to prevent any germs from being introduced into the CSF. You will have a sterile drape placed on your back to cover the area not being affected by the lumbar puncture.
- Next, your provider will use a needle to give some anesthetic (numbing) medication in the area that the LP is being done. You may feel some burning or pressure for a few seconds before the numbing occurs. Your provider will touch the area and ask if you can feel it to ensure adequate numbness.
- A long, thin needle is then used to enter the cerebrospinal space through the location that was previously marked and numbed. You may feel pressure but you should not feel pain. It is important for you to stay as still as possible. If you need to move you must notify your provider first If you are feeling pain it is important to notify your provider. (Since I felt 2 electrical shocks from my waist to my toes and my leg spasmed off the table, it was a little too late to inform my Physician) Once in the needle is in the appropriate space, CSF is collected into test tubes. Your chemotherapy is then infused through this needle directly into the CSF. The whole procedure typically takes about 30 minutes.
- Once the procedure is complete, the needle is removed and either gauze secured with tape or another type of dressing is placed over the area. You will then be instructed to lie flat for 30-60 minutes.

Honestly it wasn't too bad, and I only have to go 4 times once a week... or so I thought, now comes the bad news. There were some Myeloma cells present in the Cerebrospinal fluid. Not what I wanted to hear. Now I will be having 8 of these procedures, 2 per week and some radiation thrown in just because I haven't had any yet and we want to make sure I get to try everything!!

I also will be having a PET scan to compare to my last one and an MRI of my brain that takes 2 days to give, with 2 hours in the MRI each day. Oh goody!!!!

I'm not sure I could pick a better itinerary. And we're having our house tented on Wednesday and Thursday too. At least my Lylie is checking us into the Estancia hotel in La Jolla so we can have a few days by the pool in this lovely May Gray weather!

Here is a little recap of what they were looking for:

Multiple Myeloma of the Spine

Understanding how this blood cancer affects your spinal bones

Multiple myeloma is a blood cancer that originates in plasma cells. Plasma cells live in the bone marrow in the center of your bones and are a type of white blood cell, which means they are a key player in attacking germs and other harmful invaders that enter your body. However, when

plasma cells become cancerous, their typical protective properties no longer work. This causes a host of problems, some of which impact your spine.

The disease usually occurs in bone marrow with the most activity, which includes marrow in the back and pelvic bones. When plasma cells develop into myeloma cells, they can produce a cancerous (malignant) tumor called a plasmacytoma. Plasmacytoma may occur as one solitary tumor, but multiple myeloma means more than one tumor exists.



Multiple myeloma is the third most common blood cancer in the United States, according to the Multiple Myeloma Research Foundation. It typically occurs in people older than age 50, and is more common in men and African Americans. This blood cancer can impact many areas of your body, but this article focuses on how multiple myeloma can affect your spine.

Understanding How Multiple Myeloma Damages Spinal Bones

One of the main features of multiple myeloma is that the malignant cells produce a large amount of abnormal antibodies in the blood called M proteins. These M proteins don't benefit the body, and they crowd out the healthy plasma cells that are beneficial. When the cancerous cells begin outnumbering the healthy cells, bone damage and other symptoms (https://www.spineuniverse.com/resource-center/spinal-cancer/symptoms-multiple-myeloma-spine)occur.

Here's how multiple myeloma can cause problems for your spine:

Multiple myeloma proteins prevent the cells that help keep your bones strong from working properly. Healthy bones regularly go through a break-down-then-build-up cycle to keep them strong. This process is called remodeling. The two types of cells responsible for remodeling are called osteoclasts (which break down old bone) and osteoblasts (which build new bone).

Myeloma cell growth interferes with the way osteoclasts and osteoblasts normally work together because they signal the osteoclasts to speed up the dissolving of bone. At the same time, the myeloma cells overpower the osteoblasts, preventing the formation of new bone. As a result,

your spinal bones become soft and weak, making them painful and susceptible to fractures and osteoporosis. Additionally, the increased breaking down of bone can cause spinal cord compression and hypercalcemia (too much calcium in the blood). (That I do not have right now)

Concluding Comments

Multiple myeloma can impact many areas of the body, and it can cause significant problems in the spine. This blood cancer can cause back pain, osteoporosis, spinal fractures, and spinal cord compression—all of which have a huge influence over your quality of life.

Although multiple myeloma does not yet have a cure, patients have many treatment options. If you have multiple myeloma, your specialist will create a personalized treatment plan to help you successfully manage the symptoms.



Ok I am sure you are all wondering do I still get to go to the wedding. As of now that answer is yes. Our plan is to go ahead with the treatments and then do the transplant after the wedding. We are not too sure how I am going to feel after the latest additions of all these new poisons. Brett will have to come in from Los Angeles for 5 days to give me his gift of life. At least we will get to hang out together, ha ha.

But I intend to come through it all with flying colors I am going to open up that can of Whoopass again and go to work. I am learning so many new things and have the support of so many, what could go wrong, ha ha ha?

As you can imagine yesterday was not a very good day for my Lylie either. He is such a trooper and takes such good care of me. Tomorrow is his birthday, so much has happened since we celebrated his 60th last year with so many of you! I would like you to make sure that those of you who know him give him a big shout out on Facebook, send him texts and emails and let him know how great he is. I could not get through this without him!!!

Thanks again to all, Carol for keeping up with all my medical appts. and being my "twin" and Co-Mother of the Groom, don't know what I'd do without you either. Thanks for that Vanilla Shake last night for dinner, it was delicious!!

To all my prayer warriors, you can move onto my spine for this month, maybe it was feeling neglected, ha ha ha. Thanks for your unwavering support you send my way!

Aside from that, I have been very busy picking out furniture for the new house, window coverings, back yard landscape and all kinds of fun things. We should be moving in around the end of May beginning of June. Very exciting stuff ahead.

Here is a sneak little peek of me in the dress for the wedding, that's all for now Love you Large!!!!

Me

Sorry my last update was a little confusing, I have so much going on right now that it is difficult to get it all figured out. So, I am going to do some clarifying and some new news.

I have been asked how the sale of my house went, I forget that was still up in the air for all of you. We got 11 offers after the first weekend of our open house. The first buyer fell through but the second one seems to be working out. We sold the house for about \$30,000 over the asking price and we should be through escrow by the end of the month. (knock on wood!)

Our new house should be available for move in around the last week of this month. Lyle and I have been making a pretty big dent in our shopping budget buying all new furniture. It has been pretty fun. We had our last Taco Tuesday at the Greyling House last week with Bryce coming from New York and Brett and Carinda surprising me by driving down from Los Angeles just for the day. It was a pretty special one if I do say so myself. I have added in some pictures, thanks Brad for the awesome black and whites you took!!





There was a little confusion also over the transplant details. Neither one of the boys are my blood type, but being my sons, they both carry half of my DNA. That is the important part. Many people share my O+ blood type but finding a DNA match is next to impossible, since my ancestry is clouded by several varieties! A half DNA match is not as good as a perfect one, but at least they are young and that is important as well. Their immune systems will be stronger than my 64-year-old one and may give me a better shot at fighting my Cancer. Doctor Mason, my transplant specialist says that the blood type issue is not impossible, tricky, but doable.

So, since Brett lives closer, we will be using his stem cells as soon as I get back from Bryce and Bridget's wedding. There is only a 30% chance that his immune system will take over for mine, but it is a better chance than the one I am facing right now. That is an immune system with a mutating gene that continues to make Myeloma cells. And if this one doesn't work out we may try it again.

Now, as I am sure you remember from a few days ago, they have found myeloma cells in my spinal cord. Chemo taken orally or by IV does not go into the spinal cord and though I was not showing any symptoms of neurological



impairment, they still decided to go in and use a lumbar puncture to #1 take out some spinal fluid to check and #2 insert some chemo to prevent or kill off any cells that are there. Finding them there which was a little disheartening, but part of the battle I face.

The good news is I had the MRI done last Saturday and the results showed no tumors in my brain or spine. Now that was some awesome news and certainly a step in the right direction. Though I am still going to have to have the chemo inserted into my spine 2x a week for 8 treatments, at least the radiation should be off the table.

I also got the light chain results from my blood test on Friday and it did in fact show a slight rise in elevation which is not a sign I am looking for, but Dr. Hutchins explained that when I had my transplant in February, we pretty much killed off all the lambda chains in my white blood cells. When you have myeloma, the good cells are taken over by the bad ones, but even someone with no cancer has some Lambda and Kappa free light chains in their blood. My rise was from .16 to .18 which is pretty minimal. So, for now we are not going to worry about that. I am still on target for the transplant.

So as of today, I am still planning on going to the wedding, and having the transplant when I return. Brett will be my donor and Bryce will be my cheerleader. I still am going







to have a PET scan done in the near future and have a bit ahead of me to deal with, but today is a great day!!!!! Keep me in your thoughts and prayers, as I will do for you.

Taco Tuesday coming to new house soon! you are all invited...

OXXOX

me



Curtis is honored by his students!

For Curtis' birthday I think we both got the best gift of all. His school does a survey of teachers with the seniors and he was mentioned quite a bit. It's just so wonderful to see that my son is making an impact as a teacher. This is a profession that is near and dear to my heart and so to see him follow in my footsteps is so very cool! Love, Birdy

Graduation Survey 2017 (2017 - 2017) - St. John Bosco High School Question: Which teachers or staff members would you like to thank and why? (editor's note: there are just a sampling on the many more comments by the school's graduating class of 2017)

"Mr. Hartman was the best teacher I had in high school and had the privilege of being in high school and had the privilege of being in high school and had the privilege of being in high school and had the privilege of being in high school year, and AP Comparhar AP Art History junior year, and AP Comparative Government and Politics as well as Psylonder School year. He taught me and my chology Senior Year. He taught me and my chology Senior Year. He taught me and was a friend as well as a teacher." and life and was a friend as well as a teacher.

"Mr. Hartman - I would like to thank him because he is all around a very good teacher, he is capable of allowing a very relaxed mood within his class whilst at the same time is capable of teaching the material. The mood in which is held within his room whether it is during a period or at break is always very positive."

"Thank you, Mr. Hartman, for being one of my favorite teachers. I can honestly talk to you about anything and you would give me great insight. Being your student these past two years, I have been able to learn anything from life lessons, to understanding why Duchamp should be considered an artist and all the way to video games and Kpop. I am very grateful for all the talks and class time that we have spent together. Good luck on your journey to becoming a doctor in education."

"Mr. Hartman, his class was always fun and learning at the same time. It made it easier to learn and remember things."

"Mr. Hartman, because he taught passionately and taught many different things he was knowledgeable of. He was a realistic teacher who had attainable expectations of me that engaged me in the classroom."

"Mr. Hartman - offered a new and unique approach to teaching, putting tons of responsibility on the student, and simulating a college environment."

"Mr. Hartman: He has taught me so much, not only about Psychology and AP Comparative Government and Politics, but also about life and about myself. I cannot thank him enough for always believing in me and encouraging me; it truly helped me in my high school career. He is one of the most exceptional teachers and people I have ever met."

"Mr. Hartman - offered a new and unique approach to teaching, putting tons of responsibility on the student, and simulating a college environment."

"I would like to thank Mr. Hartman for being somebody I could talk to about anything and being the best teacher I have ever had in my life. He has shown me so many things and explained each of them in a way I could

understand. I see the world in a very differ-

ent way than before I had him. If not for him

I don't think I would be the man I am today."

"There are a lot. If I could choose two I would pick Mr. Fernando, and Mr. Hartman. I am so glad I attended their classes, because not only was it enjoyable being there, but they actually taught how to write. I do not know if this is actually going to be read to them or its just to the administrator reading this evaluation, but I would like to thank those two teachers for helping me understand the writing process just a little more than I did a few years ago. I will go on in life remembering them as two people that really changed my life for the better."

"I would like to thank Mr. Hartman for making class interesting by teaching us random facts about life and making them humorous. I felt he would tell us the plain truth about colleges and what to expect. Thanks to him, I have an idea of what I should know before my freshman in college."

"Mr. Hartman because he has made my learning process much more enjoyable, while at the same time still exercising my skills and knowledge in writing papers, which in the long run has helped improve my thinking process throughout the past 4 years."

"Mr. Hartman for teaching me more than just Politics. He was a very respectable voice on any topic especially the college application and decision process."

"I would like to thank Mr. Hartman and Mr. Cordero. These teachers have taught me much more than what was required in the classroom. They were always open to talk to about anything."

"Mr. Curtis Hartman- For being an all around fun teacher and showing me that school doesn't have to be all work. He embodied the home, the school, and the playground of the SJB motto."

EAMILY SHORTS









OK, by now you might have guessed by looking at the pictures above someone might have bought a new RV. Well yes it's true, Karla and I have ordered a new, 38', diesel pusher, Tiffin Phaeton RV. It will be delivered in early August, just in time for our trip to see the total eclipse of the sun (we are going to view it in Nebraska). We still have our old one but will be trading it in once we return from our vacation which starts May 10th and returning by June 6th.

Our old RV has served us well but it is 11 years old with over 60,000 miles on it (which is a lot for a gas powered RV) and things are starting to need repair. We have therefore decided to upgrade rather than repair. This new RV with its 380HP diesel engine, is capable 500,000 miles or more and should be the last one we will ever own. We can hardly wait for its delivery!

Carol and Francie spent the morning with Grandma YaYa a few weeks ago, tagging along on the walk to the Balboa Park fountain and back. Then celebrating a well-deserved lunch on the roof patio for Merrill Gardens. It always a good day when the sun is shining and you are with your family.