

R F N I

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The Riel Family Welcomes the Arrival of Lawson Hawthorne Benesch!



New grandson brings Jeff and Carol to New Zealand

By Carol Benesch

Lauren and Dustin added a third boy to their household when Lawson Hawthorne was born on January 21st at 10:50 pm and weighing in at 7lbs.3ozs. Little Lawson took his time, but then to everyone's delight the handsome boy made his appearance as the first Kiwi born to the Benesch family. Big brothers Holden and Grayson welcomed their baby brother with open arms as did Grandma Alix.

Our plan was to leave Thurs, Feb. 2nd but some bad standby luck caused us to spend 2 extra days in LA. The time wasn't wasted however, as we got to spend time with



nephew Brett and his lovely girlfriend, Carinda, we also took a drive to Thousand Oaks to visit Jeff's mom and sister, Audrey and Debby.

Saturday night we finally got on an Air New Zealand Flight and the next thing you know (if you can call 13 hours of travel the next thing you know), Dustin was picking us up at the airport in Auckland. Our week in New Zealand was fantastic! Every day, we spent time at a different park or beach all up and down the coastline of the North island. Among the many activities, we saw the Auckland zoo and our first Kiwi bird, we body surfed at Orewa Bay, we hiked to waterfalls in inland reserves and saw spectacular tide pools and sea caves. We loved sharing the discoveries of crabs, fish, fresh water eels, sea stars, sea anemones, and many different birds found only in New Zealand with the kids. Baby Lawson was a real trooper (and pooper!)

Our last night we had a fantastic home cooked meal by Dustin and celebrated Grayson's 2nd birthday under a full moon. The highlight was a custom chocolate train cake made by Grammy Carol.

We had a great time sharing meals and taking long walks with Dustin, Lauren, Holden, Grayson and Little Lawson. Lauren and her 2-week-old were real sports, coming along with us on all our great adventures. I'm guessing Lawson had to be the youngest visitor to brave the steep trails of Omeru Reserve and to see the Waitangi Falls, and Lauren probably the only person to hike them 2 weeks after giving birth! The time went by quickly and we are sad to say goodbye but know we will be back again soon for some more adventures and good times!!







Riels at the Arizona Renaissance Festival



By Katy Riel



This weekend was the opening of the Arizona Renaissance Festival so Mom and I decided to make the trip out there. When we told Brian we were coming he took the day off so he and Drew could join us. The fairgrounds cover more than 30 acres and all the shops there have permanent structures so it is quite different from the pop up fairs we usually attend in Escondido. Brian and Drew have never attended a fair before so I am not sure they knew what they were getting into. I found that to be truer that I thought when they learned that they would have to help Mom and I with our corsets. They did good for their first go around.

Once we got in we were at kind of a loss at where to start as there is so much to see and do. From shows that should not be family friendly (but somehow at fair they are) to shops, and all the food you could ask for, it makes planning your day a little tough. We started



with a show by The Angeles, Heroines in Disguise, in which one of my good friends is the Yellow Angele Esther. I didn't tell her I was coming so it was exciting to surprise her and see the look on her face. With it being the first day of the fair there were a few bumps in the show, but it didn't fail to make us all smile and laugh. After that we got mom's hair braided then walked around taking it all in. Even the boys had fun going through the maze.

One thing I was looking forward to was getting my second Twisted Spider. They are small glass beaded spiders that you can affix to your costume and carry around with you as a pet. I got my first one two years ago and I decided that he needed a friend. Frank and Cecile will now be able to enjoy fairs together. If all of that sounds a bit crazy, well it is, but it's a fair thing. We had a good time but cut the afternoon a bit short, well because corsets are not comfortable in general but the heat makes it even worse.

The Arizona Renaissance Festival runs until the first weekend in April and I am planning on going back again. If you think any of this sounds fun or worth a look for yourself, the Escondido Fair is coming up the last weekend in April and the first weekend of May. I encourage you all to come out and play!



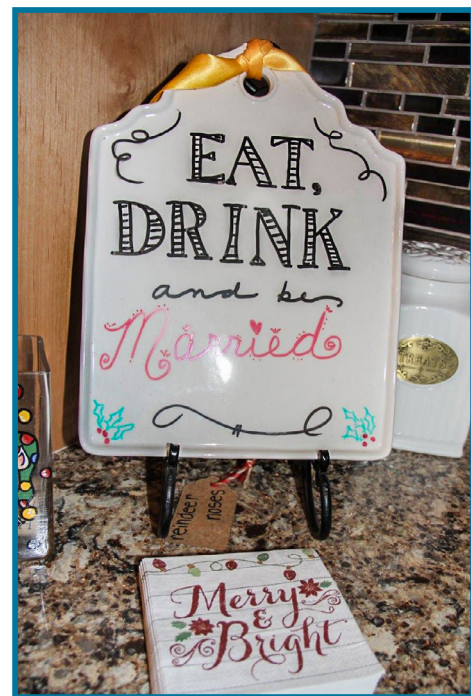


Surprise Wedding Shower for Bridget and Bryce

By Listy Gillingham

Christmas Eve is usually a day to celebrate with good food and family fun, but the Riel family decided to add a new twist by surprising Bridget and Bryce with a wedding shower. We took advantage of having the New Yorkers in town and the fact that Bryce was off golfing with the boys to bring the girls together at Bob and Listy's house to recognize the big event with a few presents, friends, a mimosa or two, and good food.

Unfortunately, the major party planner, Francie was stuck





in the Scripps Green Spa (SGS) for special treatment yet her presence was felt by everyone. The occasion started off with family and friends arriving and being greeted with a sign that read the following Holiday Greeting: "Eat, Drink, and be Married!" We all ate together in the dining room and then headed to the family room to open presents.



Francie was called and watched via a FACEBOOK's video chat. She got to "ohh and ahh" with us as Bridget opened every gift. Bridget was most appreciative of her new family and friends coming together during the hectic holidays to take a moment and share it with her in a very sincere way. We are thrilled to have her join our family and can't wait to join her in the wedding celebration to come this June!



Francie's Updates



Hey Everybody, January 19, 2017

I cannot believe that I am finally sitting at my home computer. It feels amazing to have on my comfy robe and slippers, to have control of the heater, and to have a refrigerator full of foods I think are tasty! In the last month and 4 days, I have only been home for 3 and 1/2 of those. It has been a bit tough but we are moving ahead in the battle and that is what I need to focus on.

Yesterday the insurance company finally okayed me for the transplant. This meant that I could do the 1st phase, the neupogen shots, as an outpatient. We were also looking at the possibility of me doing the shots at home, but since the transplant got okayed at the same time, it makes more sense for me to go to hospital since they will be drawing blood as well. But thanks Nikki and the rest of you volunteers to give me the shots at home, I really appreciate your willingness! Here is what the Neupogen will do for me:

Neupogen -Generic Name: Filgrastim
Other Names: G-CSF, Granulocyte

Colony Stimulating Factor

Drug Type:

Neupogen is a biologic response modifier. It is classified as a colony stimulating factor. (For more detail, see "How Neupogen Works" section below).

What Neupogen Is Used For:

- Neupogen is used to stimulate the production of granulocytes (a type of white blood cell) in patients undergoing therapy that will cause low white blood cell counts. Neupogen is used to prevent infection and neutropenic (low white blood cells) fevers caused by chemotherapy.
- Neupogen is a support medication. It does not treat cancer.

I will be returning to Scripps Green Hospital for these shots at least through Monday. On Monday they will be testing my blood to see if there are enough stem cells to initiate a collection. There needs to be at least enough stem cells for two transplants. If it looks like it is a go, then they will start harvesting that day.

I visited the pheresis room where they will have my blood run through a machine that will draw out the stem cells and return the rest of the blood back to me. It will take about 4 hours and may continue for several days until they feel they have enough. (I would hate to be the guy counting all those millions of stem cells hahah) Here is a rundown of what they will be doing:

Autologous Stem Cell Transplant or Bone Marrow Transplant

*Carolyn Vachani RN, MSN, AOCN & Lara Bonner Millar, MD
The Abramson Cancer Center of the University of Pennsylvania Last Modified: April 8, 2016*

What is bone marrow?

Bone marrow is a spongy substance found inside our large bones, such as the femur (thigh), hip, and ribs. It is made up of cells called hematopoietic stem cells. It is these cells that are given (transplanted) to the patient during a stem cell transplant. (NOTE: These stem cells are different than those we hear about in the news for research use- those are called embryonic stem cells.) Hematopoietic stem cells are "baby" cells that grow up to become either white blood cells, red blood cells and platelets. You may hear them called blood forming stem cells. The bone marrow acts as a greenhouse for these cells, growing them and storing them until they are needed. What do we need them for?

- White blood cells (also called leukocytes) are the body's infection fighting cells.
- Red blood cells (also called erythrocytes) carry oxygen from the lungs to the rest of the body and return carbon dioxide to the lungs as waste.
- Platelets (also called thrombocytes) help the body form blood clots to control bleeding.

What does autologous mean?

Autologous means structures or cells derived from you and your body. For example, if our patient Jack is to have a stem cell transplant, we will get those stem cells from Jack himself. Many people think a transplant has to be something taken from a donor, but that would be called an allogeneic transplant (which is discussed in a separate article). In an autologous transplant, Jack the patient "donates" his cells to himself.

What types of cancer is this therapy used for?

Autologous transplants are used to treat a number of different cancers, including leukemias, myelodysplastic syndrome, multiple myeloma, Hodgkin's disease, non-Hodgkin's lymphoma, testicular cancer and neuroblastoma, among others.

How do we collect these cells?

When healthcare providers first started doing these procedures, the only way to get stem cells was directly from the bone marrow. This is where the term bone marrow transplant first originated. The patient would be taken to the operating room and put to sleep lying on his/her stomach. The doctors would put long needles into the hip bones and pull out the bone marrow in syringes in a procedure called bone marrow aspiration. The solution was then poured through a special column that pulled out only the stem cells, allowing any other cells (mature red and white blood cells and platelets) to be given back to the patient. In order to get the number of cells needed, the needles would need to be inserted many times. These cells were then frozen in a special preservative (called Dimethyl sulfoxide or DMSO) to protect them from "freezer burn" until they were used.

Healthcare providers soon found that giving the patient a medication called granulocyte colony stimulating factor, or G-CSF, (such as Neupogen) would stimulate the stem cells to be released from the bone marrow and into

the blood stream. Using a blood test, they could tell how many cells were circulating in the blood stream. Once the number was high enough, the patient would go to the pheresis department at the hospital to have the cells removed: this procedure is known as "apheresis."

The cells could be removed using either a catheter in the chest wall (Which is what I have) or 2 large intravenous (IV) catheters, one placed in each arm. Blood would be taken out of the patient, be circulated through the pheresis machine to remove the stem cells, and then the rest of the blood would be returned to the patient. The cells would be frozen in the same DMSO preservative as is used for bone marrow; cryopreservation is necessary because the cells must be harvested months in advance of the transplant treatment. During the collection, the patient may experience tingling or numbness around their lips. This is caused by a loss of calcium and can usually be resolved by eating some calcium tablets.

What do we mean by "transplant"?

In order to understand the stem cell transplant, you must first have an understanding of chemotherapy. Chemotherapy is a group of medications that work by killing rapidly-dividing cells in the body. Cancer cells tend to divide rapidly, but so do many healthy cells (i.e. cells in the gastrointestinal tract, hair follicles, and blood cells). If you bite the inside of your lip, there is a good chance the spot will be healed by the next day. This is because those cells divide rapidly. A patient can only receive so much chemotherapy before the medication causes too much damage to the healthy cells for the person to safely tolerate. For instance, if a patient experiences a lot of diarrhea with a medication, the doctor may decide to decrease the dose by some amount. Healthcare providers call this "dose-limiting toxicity." One important dose-limiting toxicity is low blood counts (low white blood cells, red blood cells and platelets). Researchers thought that for certain types of cancer, if they could give higher doses of chemotherapy, they would be better able to treat the cancer. The problem was, how could we overcome the dose-limiting toxicity of low blood counts?

They soon realized that they could give high doses of chemotherapy that would wipe out a patient's bone marrow, but then later "rescue" the bone marrow using the patient's own stem cells (which were collected earlier, before the chemotherapy). The patient would receive several days of intense chemotherapy aimed at killing any cancer cells in his/her body. The patient then rests for 1 or 2 days to allow the body time to process and clear out the chemotherapy, so the new cells are not damaged.

On the day of the "transplant", the patient is given some medications to prevent him/her from having any reactions to the DMSO preservative. The patient receives intravenous fluids to help the kidneys flush out any dead cells in the infusion. Blood pressure and heart rate are closely monitored. Once the patient has received the premedications, the frozen stem cells are thawed and given to the patient like a blood transfusion. Some centers thaw the cells in the lab where they are stored, while some thaw them in the patient's room just prior to infusing them into the bloodstream.

After infusing the stem cells, where do they go?

The cells are quite smart, (Oh please God let me have smart stem cells...) and they find their way back to the bone marrow space and get to work. Remember, when the stem cells arrive in the bone marrow, things are in bad shape - almost all of the old marrow cells have been killed ("ablated") by the chemo. The stem cells get right to work to start producing new white and red blood cells and platelets. It can take anywhere from 7 to 14 days for the stem cells to produce new cells, and for those new cells to mature enough to function.

What happens while we wait?

This waiting period, also called the "nadir," is usually the most difficult time for the patient. The blood cell counts are very low, putting the patient at risk for infections, bleeding, and severe fatigue. The patient does not have any white blood cells to fight infections, so fevers and the need for antibiotics are to be expected. All visitors and healthcare personnel must wash their

hands before entering the room. Anyone who is sick or lives with someone who is sick would be best to stay home and call on the phone. Low platelet counts can lead to bleeding, and platelet transfusions are common during this time. A low red blood cell count (called anemia) can also be distressing for the patient. The patient may look pale, feel very tired, and require red blood cell transfusions. Many patients say the worst side effect is the extreme fatigue - they feel more tired and wiped out than you can even imagine. Just getting out of bed is a chore. When able, short walks in the halls can actually increase their energy, but this is often easier said than done.

On top of the low blood counts, the patient must deal with the side effects of the chemotherapy they received. These include, diarrhea, nausea and/or vomiting, hair loss, fever, chills, decreased appetite, and mouth sores (called mucositis). Every patient is different and it is difficult to predict

which patients will have more side effects. The chemotherapy drugs used before the transplant can vary, and some medications are more likely to cause certain side effects than others.

What can a friend or family member do to help the patient during this time?

Be supportive, let the patient get a lot of rest, and understand that he or she just may not feel like eating much during this time. Make one family member the contact person for friends and family. Let the patient tell this contact person how he or she is feeling each day and whether or not he or she wants visitors or phone calls. It is important to respect the patient's wishes. Send a supportive note or a card. Depending on the protocol for the transplant, the patient may be in the hospital, at an apartment near the cancer center, or at home.

What is engraftment?

Engraftment is a term the doctors use to describe the point when the stem cells start doing their job and blood cell counts start to come up. The first number we look for is the neutrophil count, which is the type of white blood cell that is most important in fighting infection. Generally, once the neutrophil count gets above 500, the patient can come off antibiotics and, in many cases, can go home. The time until engraftment varies from patient to patient, but is typically between 7-12 days. The red blood cell and platelet counts can take several weeks to get back to a normal range, but the patient can usually go home once they are not regularly requiring blood or platelet transfusions.

How will the person feel once he or she is home?

This can vary greatly from person to person, depending on what has happened over the past few weeks. It can take people weeks, months, or even a year to feel like their "old self" again. Some patients report having no appetite, or food tasting like metal, for months after the transplant. This can be a difficult time, as family and friends may assume that the person is "better" since they are home and the transplant is over. They may expect the person to be back at work, to return to school, or to run a household. The patient should resume normal activities slowly and add on jobs or duties every couple of days. ---

There you have what I will be dealing with in the next couple of weeks. It is a little daunting to think about, but it is my journey, and I am ready to face it and move forward. I want to thank everyone for their concern and kind messages, it is what gives me the strength to move on. That said

it is time to send those party crashers out of my back yard and let the rest of you that are actually invited into my life to take over. Your prayers and kind thoughts will give me the power to get through this and get back to a place of good health.

This is not a permanent fix and it will not "cure" me the mutating gene that i carry will still create cancer in my body. But there are weapons we can use to keep them at bay. Perhaps an Allogeneic transplant will be the next step:

Allogeneic Transplant (Bone Marrow & Stem Cell) Carolyn Vachani RN, MSN, AOCN

*The Abramson Cancer Center of the University of Pennsylvania
Last Modified: April 4, 2016*

What is bone marrow?

Bone marrow is a spongy-like substance found inside our large bones, like the femur (leg), hip, and ribs. It is made up of cells called hematopoietic stem cells. It is these cells that are given (transplanted) to the patient during a transplant. These stem cells are different than those we hear about in the news - those are called embryonic stem cells and are obtained from a growing embryo, not an adult. Hematopoietic stem cells are "baby" cells that grow up to become white blood cells, red blood cells and platelets. The bone marrow acts as a greenhouse for these cells, growing them and storing them until they are needed. What do we need these cells for?

- White blood cells (also called leukocytes) are the body's infection-fighting cells.
- Red blood cells (also called erythrocytes) carry oxygen from the lungs to the rest of the body and return carbon dioxide to the lungs as waste.
- Platelets (also called thrombocytes) help the body form blood clots to control bleeding.

What does allogeneic mean?

Allogeneic means that the transplanted cells are coming from a donor – this may be a sibling, other relative, or someone unrelated to the patient (these cells can even come from umbilical cord blood). If the cells come from an identical twin of the patient, the transplant is called syngeneic and is essentially like an autologous transplant, because the cells are identical to the patients.

The cells must be "matched" to the patient, which is done by human leukocyte antigen (HLA) testing or HLA typing. The HLA type is made up of either 8 or 10 HLA markers: half are inherited from the mother, and half are inherited from the father. There are 2 of each of the markers, called A, B, C, DRB1, and DQ (which is not always used).

Doctors usually look first to a family member for a match. Siblings from the same parents have a 25% chance of being an identical match (all markers match, called an 8 out of 8 or 10 out of 10 match). If your sibling matches half of your HLA markers, it is called a haploidentical match (4 out of 8). If no siblings match, that patient's parents or children can be tested.

The match is "scored" based on the number of markers that match between the patient and donor's typing. The higher the number of matching HLA antigens, the better the match and the greater the chance that the patient's body will accept the donor's stem cells. In general, patients are less likely to develop a complication known as graft-versus-host disease (GVHD) if the stem cells of the donor and patient are closely matched.

About 70% of patients will not have a family member match and will need to enlist the help of the National Marrow Donor Program, which keeps the HLA typing records from donors around the world, and has access to millions of potential donors and over 600,000 cord blood units.

In cord blood transplants, a well-matched donor seems to be less important. These cells are matched using 6 antigens (A, B and DRB1) and a 4 out of 6 match is acceptable.

How do we collect bone marrow cells?

When doctors first started doing these procedures, the only way to get stem cells was directly from the bone marrow. This is where the term bone marrow transplant originated. For this, the donor is taken to the operating room and put to sleep lying on his or her stomach. The healthcare providers put long needles into the hip bones and pull out the bone marrow in syringes, using a procedure called bone marrow aspiration. This solution is then poured through a special column that is able to pull out the desired stem cells, allowing any other cells (mature red and white blood cells and platelets) to be reinfused into the donor. In order to get the number of cells needed, the needles need to be inserted many times, which is why the donor is put to sleep for the procedure. These cells are then frozen in a special preservative (called dimethyl sulfoxide or DMSO) to protect them from "freezer burn" until they are used. The donor still has plenty of cells to produce blood cells for him/herself.

A second method of collecting stem cells, called apheresis, is now the preferred method of collecting stem cells for allogeneic transplants. This method involves giving the donor a medication called a granulocyte colony stimulating factor, or G-CSF, which causes the stem cells to be released from the bone marrow and into the blood stream. Using a blood test, doctors can tell how many cells are circulating in the blood stream. Once the number is high enough, the donor goes to the pheresis department at the hospital to have the cells removed. The cells can be removed using either a catheter in the chest wall or 2 large intravenous (IV) catheters, one placed in each arm. Blood is taken out of the donor, circula ted through the pheresis machine to remove the stem cells, and then the rest of the blood is returned to the donor. The cells would be frozen in the same DMSO preservative used for bone marrow above. During the collection, the donor may experience tingling or numbness around the lips. This is caused by a loss of calcium and can usually be resolved by eating some calcium tablets.

Lastly, these cells can be taken from umbilical cord blood. The umbilical cord is typically discarded after a baby is born, but the blood in the cord is rich in hematopoietic stem cells that can be used in allogeneic transplant. One drawback to cord blood cells is that there are fewer cells than are typically used in transplant. For this reason, cord blood is primarily used in children and smaller sized adults. Cord blood can take longer to engraft (see more on engraftment below) and therefore may lead to an increase risk of infection. However, cord blood transplants appear to have lower rates of graft versus host disease. Your transp lant team can discuss the specifics of your situation in greater detail.

What diseases are treated with an allogeneic transplant?

Leukemias, lymphomas, multiple myeloma, severe aplastic anemia, and sickle cell disease, among others.

What is the "preparative regimen"?

You may hear providers talk about the preparative regimen. This is the course of chemotherapy, with or without radiation that is given before the cells are transplanted into the patient. This regimen is given to prepare your body to receive the donor's cells. It is necessary to give this chemotherapy for a few reasons:

- To destroy the patient's marrow and immune system so that it does not attack the donor's cells, causing them to fail to "take" and work.
- To destroy any remaining cancer cells in the patient's body.

There are two types of preparative regimens, myeloablative (or standard intensity) and non- myeloablative regimens (low intensity or "mini" transplant). Standard intensity regimens use high doses of chemotherapy with or without radiation that completely destroys the patient's bone marrow. Non- myeloablative regimens use lower doses of chemotherapy with or without radiation and are often used in patients who cannot undergo the standard intensity transplant or, in some cases, patients who are in remission. Your care team will determine which type best fits for your disease and baseline health.

Why do a transplant?

This answer varies depending on the disease being treated. If the disease affects the bone marrow, as in leukemias and aplastic anemia, then the hope is to cure the patient by replacing the diseased marrow with the healthy marrow of the donor. In some cases, the hope is to administer much higher doses of chemotherapy to treat the cancer, which would also kill the patient's bone marrow. Giving the patient the donor's marrow after this marrow-killing (marrow-ablating) chemotherapy serves to "rescue" the patient with healthy bone marrow. One effect that doctors see as a very important part of all allogeneic transplants is called the "graft versus tumor effect". Basically, this is the effect that the donor's immune system (which is part of the marrow that the donor donated) has on the recipient patient's cancer cells. The hope is that the healthy donor immune system can attack any stray cancer cells in the patient that survived the preparative regimen. (This is the part that is most important to me)!!!!!!

When does the bone marrow (or stem cells) get infused?

After the preparative regimen is complete, the patient is given a day or two to "rest". In reality, the your providers are waiting for the chemotherapy to be cleared from the patient's system so it will not damage the donor cells. The cells are infused into a vein, similar to the way in which a blood transfusion is given. The cells are quite smart, and they find their way back to the bone marrow space and get to work. Remember, when they arrive in the bone marrow, things are in bad shape – most of the blood cells have been killed by the chemo. The stem cells get right to work producing new white and red blood cells and platelets. It can take anywhere from 7 to 14 days for these stem cells to produce new cells and for those cells to become mature enough to function properly.

What is engraftment?

Engraftment is a term the healthcare providers use to de-

scribe the point when the stem cells start doing their job and blood cell counts start to rise. The first number we look for is the neutrophil count, which is a type of white blood cell that is especially important in fighting bacterial infection. Generally, once the neutrophil count remains above 500, the patient can stop preventive antibiotics. The time until engraftment varies from patient to patient, and can be anywhere from 10-20 days. The red blood cell and platelet counts can take several weeks to get back to a normal range.

What are the potential complications of this treatment?

The patient can have side effects caused by the preparative regimen (chemotherapy and/or radiation), such as infertility, and damage to the liver, kidneys, lungs, and/or heart. Complications related to the transplant itself can vary depending on the medications used, but include mucositis (sores in the mouth and throat), diarrhea, nausea/vomiting, poor appetite, and fatigue. The patient can also have complications because of the destruction of the bone marrow leading to low blood counts. These include bleeding due to low platelet counts, infections due to low white blood cell counts, and fatigue due to low red blood cell counts.

In addition to these problems, there are a few complications that are specific to allogeneic transplants. These are graft versus host disease, graft rejection or failure, pulmonary (lung) complications, and liver problems (veno-occlusive disease of the liver).

In graft versus host disease (GVHD), the "graft" refers to the transplanted (donor's) stem cells and the "host" refers to the patient. GVHD occurs when the donor's cells attack the patient's body. GVHD can affect the skin (rash), intestinal tract (diarrhea) and liver (elevated liver blood tests and decreased liver function) in varying degrees, depending on how severe the GVHD is. It can occur anytime after transplant and is grouped into acute GVHD (first 100 days after transplant) or chronic GVHD (starting 3-6 months after transplant). Almost all allogeneic transplant patients have some degree of this complication, which can range from very mild to very severe.

GVHD is treated with medications that suppress the patient's new immune system (the donor's immune system), including steroids and cyclosporine. Antithymocyte globulin (Atgam) may also be used to remove the white blood cells that cause GVHD (called T-cells).

We mentioned previously the value of the "graft versus tumor effect", which allows the donor cells to attack any remaining cancer cells. This is a good part of GVHD, so we must be careful not to completely eliminate GVHD, or else

we will lose the benefit of the graft versus tumor effect. It is a fine line between the unwanted and the wanted effects, so healthcare providers need to carefully manage this balance.

Graft rejection can occur if there are immune system cells left in the patient after the preparative regimen. These "native" cells then attack the donor's cells because they recognize them as foreign to the body. This can be prevented most of the time by making sure the preparative regimen is sufficiently strong to kill any native immune cells. Graft failure occurs when the donor's cells fail to start working (producing new blood cells). Healthcare providers usually consider a diagnosis of graft failure if engraftment has not occurred by 42 days after transplant. This complication is rare, occurring in about 5% of patients, and the only treatment is to receive another transplant.

Pulmonary complications are generally caused by pneumonia and can be very serious in these patients. Veno-occlusive disease (VOD) of the liver is a complication that can present with jaundice, enlarged liver, or swelling of the abdomen and can lead to liver failure. VOD can be

very serious, and can even be fatal. Patients are monitored very closely for all of these concerns and will remain in the hospital for several weeks, at minimum.



What happens when the patient is discharged?

Transplant centers vary in how they handle the time for discharge. Once an outpatient, the patient will need to visit the clinic often, maybe even daily. Most centers require patients to stay near the hospital for the first 100 days after transplant. Even though the blood cells have started to perform, it will be months to a year before the patient will have a "normal" immune system. The patient needs to be very careful to avoid infection (avoiding crowds, washing hands frequently, wearing a mask in public places). The patient's energy level will not be like his or her "old self" for quite some time (some say years), so friends and family must understand that just because the transplant is over, the patient will not be back to normal. Transplant centers give detailed instructions to families who will be having the transplant patient staying at their home. These include help with domestic chores, childcare, pet care, and other daily household errands. The National Marrow Donor Program has some great resources for preparing the home for a transplant recipient. This can be a lot of work but it is a great way for friends and family to help out.

What is a mini-allo or reduced intensity transplant?

A reduced intensity transplant is an allogeneic transplant that uses a less intense preparative regimen before the donor cells are infused. The use of lower doses of anticancer medications and radiation eliminates some, but not all, of the patient's bone marrow. Unlike traditional transplant, cells from both the donor and the patient may exist in the patient's body for some time after a mini-allo. When cells from both the donor and patient are present, it is called "mixed chimerism". Eventually, the cells will all be from the donor (called "full chimerism").

Once the cells from the donor begin to engraft, they can cause the graft-versus-tumor (GVT) effect that works to destroy the cancer cells that were not eliminated by the chemotherapy and/or radiation. This treatment is not appropriate for all cancers treated by allogeneic transplant.

OK I know that you have had enough of the science lesson for today, but many people are asking about this procedure so I thought I would add it in.

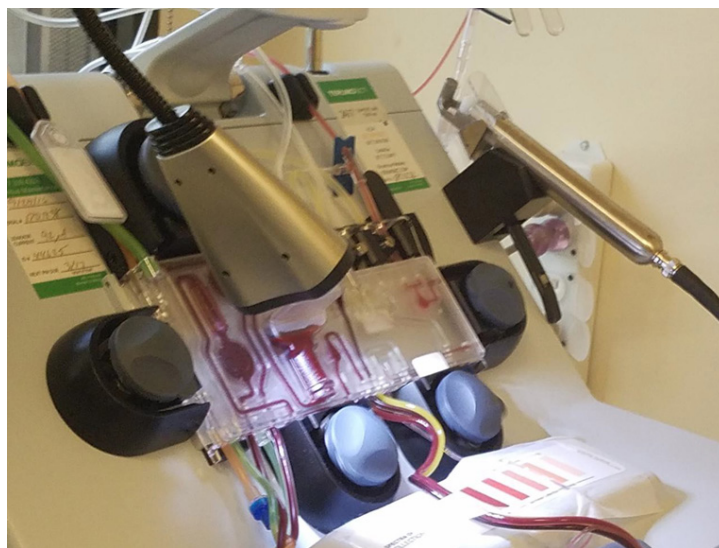
Enough of all of that. The most important thing to remember is that today I am home with my adorable Lyle and I feel good. My brilliant Super Power Team of Doctors are working overtime and so far my body has responded well.

The Cytotoxin that I received before Christmas took my cancer down to

a place where I am even able to consider these treatments. I am sure that all of your prayers have expedited my current condition, but I would like to believe what Birdy says, That when Bruce left this world and all the pain he was in, that he took my cancer with him.

Hey Everybody, January 29th, 2017

As you probably remember from the last update, I have been receiving the Neupogen shots to build up my white blood cells. That magic little shot did its job, and last Tuesday and Wednesday my stem cells were harvested in the apheresis room. I was able to collect 4.4 million (Whooppee!!!!), with 2 million needed for each transplant, so I now have 2 transplants worth of stem cells safely frozen away for my future use. Here is a picture of the pheresis machine that pulls out my blood, sifts out the white cells, then returns it back to me.



pretty fancy machinery doing amazing things!!!!

That first transplant is coming up soon as I am checking back in to Scripps Green Resort and Spa on Tuesday, January 31st for my long awaited transplant. As a reminder, here is a section of the info from last update of what will be occurring:

They soon realized that they could give high doses of chemotherapy that would wipe out a patient's bone marrow, but then later "rescue" the bone marrow using the patient's own stem cells (which were collected earlier, before the chemotherapy). The patient would receive several days of intense chemotherapy aimed at killing any cancer cells in

his/her body. The patient then rests for 1 or 2 days to allow the body time to process and clear out the chemotherapy, so the new cells are not damaged.

On the day of the “transplant”, the patient is given some medications to prevent him/her from having any reactions to the DMSO preservative. The patient receives intravenous fluids to help the kidneys flush out any dead cells in the infusion. Blood pressure and heart rate are closely monitored. Once the patient has received the premedications, the frozen stem cells are thawed and given to the patient like a blood transfusion. Some centers thaw the cells in the lab where they are stored, while some thaw them in the patient’s room just prior to infusing them into the bloodstream.

After infusing the stem cells, where do they go?

The cells are quite smart, (Oh please God let me have smart stem cells...) and they find their way back to the bone marrow space and get to work.

Remember, when the stem cells arrive in the bone marrow, things are in bad shape - almost all of the old marrow cells have been killed (“ablated”) by the chemo. The stem cells get right to work to start producing new white and red blood cells and platelets. It can take anywhere from 7 to 14 days .

This waiting period, also called the “nadir,” is usually the most difficult time for the patient. The blood cell counts are very low, putting the patient at risk for infections, bleeding, and severe fatigue. The patient does not have any white blood cells to fight infections, so fevers and the need for antibiotics are to be expected. All visitors and healthcare personnel must wash their hands before entering the room. Anyone who is sick or lives with someone who is sick would be best to stay home and call on the phone. Low platelet counts can lead to bleeding, and platelet transfusions are common during this time. A low red blood cell count (called anemia) can also be distressing for the patient.

The patient may look pale, feel very tired, and require red blood cell transfusions. Many patients say the worst side effect is the extreme fatigue - they feel more tired and wiped out than you can even imagine. Just getting out of bed is a chore. When able, short walks in the halls can actually increase their energy, but this is often easier said than done.

On top of the low blood counts, the patient must deal with the side effects of the chemotherapy they received. These include, diarrhea, nausea and/or vomiting, hair loss, fever, chills, decreased appetite, and mouth sores (called mucositis). Every patient is different and it is difficult to predict

which patients will have more side effects. The chemotherapy drugs used before the transplant can vary, and some medications are more likely to cause certain side effects than others.

What can a friend or family member do to help the patient during this time?

Be supportive, let the patient get a lot of rest, and understand that he or she just may not feel like eating much during this time. Make one family member the contact person for friends and family. Let the patient tell this contact person how he or she is feeling each day and whether or not he or she wants visitors or phone calls. It is important to respect the patient’s wishes. Send a supportive note or a card. Depending on the protocol for the transplant, the patient may be in the hospital, at an apartment near the cancer center, or at home.

What is engraftment?

Engraftment is a term the doctors use to describe the point when the stem cells start doing their job and blood cell counts start to come up. The first number we look for is the neutrophil count, which is the type of white blood cell that is most important in fighting infection. Generally, once the neutrophil count gets above 500, the patient can come off antibiotics and, in many cases, can go home. The time until engraftment varies from patient to patient, but is typically between 7-12 days. The red blood cell and platelet counts can take

several weeks to get back to a normal range, but the patient can usually go home once they are not regularly requiring blood or platelet transfusions.

How will the person feel once he or she is home?

This can vary greatly from person to person, depending on what has happened over the past few weeks. It can take people weeks, months, or even a year to feel like their “old self” again. Some patients report having no appetite, or food tasting like metal, for months after the transplant. This can be a difficult time, as family and friends may assume that the person is “better” since they are home and the transplant is over. They may expect the person to be back at work, to return to school, or to run a household. The patient should resume normal activities slowly and add on jobs or duties every couple of days.

Ok, so the part that jumps out at me in this info is he following sentence:

The patient would receive several days of intense chemotherapy aimed at killing any cancer cells in his/her body. This does not sound very good to me. This is the part I have been thinking about for the last 6 months. I am pretty sure

that anything strong enough to kill those cancer cells is strong enough to take a swipe at me too! So I am depending on all of you to wrap me in your thoughts and prayers which will give me the super powers I need to get through this. Together I am sure we can get past the most difficult part. Remember, I have Bryce and Bridget's wedding to attend in NYC come June 2nd, so I need to be feeling better number 1, and, more importantly, grow back some hair.

Fortunately, it appears to me that shorter haircuts have been popping up all over!!!



Now Glen Close was on Jimmy Fallon this week with some very short, super cute hair.

I am very grateful to see all of these very trendy short looks since I am not going to have too many choices early on. I only wish that it would come in silver like this, but luckily no matter how it comes back in, Leonor can fix it for me!

I have made many friends in my journey at Scripps, and I have been hearing through my special grapevine that a nice room is being selected for me. It may not be available the first few days but I am ready and willing to help push someone along to get where I need to be, hahahah (thanks Karen).

I have been trying to gain some weight, I know that sounds ridiculous, my apologies to all of you I've made fun of when you said you couldn't gain any, I just don't understand why I couldn't keep weight off before!!! I have tried milkshakes, cake, cheesecake, chocolate, and all kinds of fattening

foods and it just does not seem to be working, go figure! It just takes you back to that saying, be careful what you ask for!!! Lyle brings me lots of goodies to the hospital, loved the artichoke dip from BJ's that was especially nice, hahaha.

I have been very fortunate that I am still not very weak nor do I look sickly, I am grateful for that. Not being able to wear eye makeup has been tough, but I am hanging in there and trying not to whine too much.

Thanks to everyone who has sent me all the wonderful gifts, cards, texts and emails, I love hearing from all of you, you are keeping me strong and moving forward. We are now at the "nadir" and we will get through this too!!!! I will let you know how it goes as we head to the other side of this climb. Love to you all.

Hey Everybody February 3, 2017

I don't have a lot to tell since it has just been a few days since my last update, but I know a lot of you are wondering how the trans plant is going.

I checked in on the 31st, Tuesday, and got my first round of chemo by 2:00. It is called Melphalan and is most always used with a stem cell transplant. There are a lot of possible side effects, here is a time line for them:

Delayed effects:

Nadir: Meaning low point, nadir is the point in time between chemotherapy cycles in which you experience low blood counts.

Onset: 7 days

Nadir: 8-10 days (white blood cells), 27-32 days (platelets).

Recovery: 42-50 days

Ok, so this is going to have my attention for a while, but I hope to come out of it feeling better and healthier in the end. Here is the play by play so far:

Tuesday: first an infusion of anti nausea drugs, whoever discovered those is my new hero!!!! actual bag of chemo was so small it must be super deadly. For a half hour before, during and a half hour after I had to keep ice chips in my mouth to keep from getting blisters. Halfway through I switched to a popsicle for a bit, that was a nice change. So far I have none, but this is pretty nasty stuff and it may come back later to get me. But, I still feel great and that is comforting!

Wednesday: One more day of chemo and freezing my mouth, nice to know the mean and nasty stuff is behind me, hard to know how far it's tentacles will reach. I still feel pretty good, Carol and I spent most of the day not doing much. Lyle comes after work and we sampled the fare of the Scripps Color's Café, oh yum.

Thursday: This was the most interesting day for sure and is now considered my second birthday. The stem cells that

they removed from me last week were returned to home. First, I had a premed cocktail of Benadryl, Ativan and Tylenol. That was a guarantee that I would sleep through the whole thing. Then the bags of stem cells (2) were put into a bath of warm water before infusing them into me (thank you for that part!).



Here are my stem cells safely in the infusion bag, soon to be swimming to my bone marrow. I posted a short video of them moving through the IV on Facebook if you'd like to check it out.

Friday: Now here is the boring part. I have a lot of days to sit around and wait to get better. I don't feel as good as yesterday, and will probably be worse tomorrow, but eventually I will get better. My appetite is minimal but I am doing the best I can. My Doctor put me on fluids only until my appetite increases which makes it less stressful if I am not hungry.

Saturday/Sunday: Saturday was a replay of Friday a little bit worse. Took anti-nausea drugs most of the day and toughed it out. Still did a mile of walking on the treadmill, but come on, what else do I have to do? Tried to sleep through most of it. Today I definitely feel better. I still have fatigue but, hardly any nausea, I did my mile and 1/2 on the treadmill, and now I am getting ready for the Super Bowl. Gotta get

next to my good friend Kathleen and root for the Patriots, she gets my loyalty today!!!

I asked Doctor Andrey about the allogeneic transplant (the one using a donor) and he said it would optimally be 90 days after I am recovered from this one. That would put me right about time to push it out a couple weeks till after Bryce's wedding (June 2nd). That of course will depend on how mean my cancer decides to be. If it plays fair and doesn't get all crazy then that is the plan. Otherwise of course I will have it sooner. That will also depend on a sibling match first, then, if not, one from The National Bone Marrow Registry. My sis has been in the registry for probably 25 years, got called once, but was not a close enough match. I have been on it as well.

It's a good thing to do, you never know when you can help out someone in a tough situation.

That's a wrap for now, I am on the way to feeling better every day, and I am enjoying each one of them. Have a Good Super Bowl afternoon and may you all be happy at the end either because of the actual outcome or just because you spent a nice afternoon with people you love and enjoy!



So here I am finally on the other side of the transplant. Today is day 11 since my stem cells were returned to do their magic. Now my numbers should start coming up again, as they are. I am receiving platelets as we speak, they are still a little low but my neutrophils are rising daily so that is good news. Here is some info on what I have been through the past week and what I have to look forward to:

Stem Cell Transplant

If you received high-dose chemotherapy, the medication will cause all of your blood counts – white blood cell, red blood cell and platelet – to drop to very low levels (that is where I am right now).

A low white blood cell count puts you at greater risk for infections. You will receive prophylactic medications to prevent infections. It is essential that you practice good hygiene habits. The most effective measure is to wash your hands frequently, especially after using the bathroom and before you eat. You should also shower daily.

Your low red blood cell count will cause you to be very fatigued and possibly short of breath during activity. This is because you have fewer red blood cells to carry oxygen to the organs in your body. We will give you a transfusion of red blood cells (**I had one 3 nights ago**) if your count drops to a certain level. Keep in mind that this profound fatigue is common among transplant patients. Establishing reasonable expectations can help you deal with it more effectively. We will encourage you to stay out of bed and active as much as possible to minimize other complications.

Your platelet count will also be very low during this time period, putting you at risk for bleeding. You will need to avoid activities that can cause bleeding such as strenuous exercise, shaving (except with an electric razor), blowing your nose hard, or flossing your teeth. If your platelet count goes below a specified threshold, you will receive transfusions of platelets to minimize your risk for bleeding (**I have had 3 of these transfusions since I have been here**).

Other common complications and side effects from high-dose chemotherapy are gastrointestinal issues, including mouth sores (luckily none), taste changes (yes), nausea (definitely that), vomiting (some of that), lack of appetite and diarrhea (lucky for me my pain pills eliminated that). We will give you medication for these symptoms as they occur. During the time your blood counts are low you will need to follow a certain diet to minimize the risk of bacterial contamination. Your transplant nurse will help you with nutritional recommendations during this time.

Engraftment and Recovery

About 10 to 20 days following your transplant (today is day 11), we can begin to see signs that your stem cells are growing (engrafting) and beginning to produce blood cells. During this time, you may notice aching in your bones, especially your pelvis, lower back and thighs (hence the pain pills, haha).

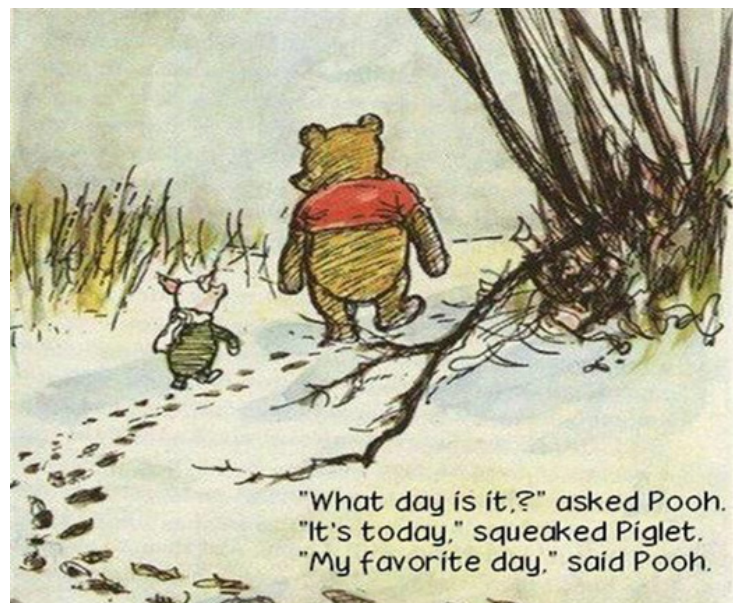
As your blood counts begin to rise, your white blood cells will start to fight and prevent infections. Fevers you had while your white blood count was low may get better now. You may no longer need to take antibiotics, and you should not need as many (or any) blood or platelet transfusions. You will notice that your other side effects will also start to get better (that sounds good to me!).

Re-establishing your life after transplant varies from patient to patient. However, the great majority of patients report that the quality of their lives is now the same or better than before the transplant.

Ok, so the last 5 days have not been great, I will spare you the gory details, but no worse than what some of you are suffering with the flu. We all need to have rough days from time to time so that we are appreciative of a day that is just a good one. Expecting extremely fabulous results, daily basis, leaves you open to disappointment.

I love the below sentiment sent to me by Marge Cushman. Winnie the Pooh always seems to have it nailed. It isn't difficult to have a good day, you just have to remember that you are having one!

I am almost up to the point where it is not so hazardous to my health to have visitors, I am out of the critical zone



and into the “low” end of danger to outside elements. No one like so to see those “c”s on your report card! I should be going home within the next 5 days or so where for the first time since mid December, I can resume somewhat of a normal life. I will probably be receiving chemo once a week again and after a month or so we will determine how much cancer is left behind. Then we will start searching from the National Bone Marrow registry for a donor that I could perhaps get an immune system via an allogeneic transplant

If you have an allogeneic stem cell transplant, you will stay on some of your antimicrobial medications even after discharge. You will also be monitored closely for graft vs. host disease which only occurs in patients who receive stem cells from a donor. This is a potentially serious complication. Your donor cells (the graft) see your cells (the host) as foreign and mount an attack against you, just as your immune system would normally attack an infection. You will be given medications to prevent or minimize this response and closely monitored. You will also have some additional long term restrictions that your transplant nurse coordinator will review with you.

Once you are stable, you will be transferred back to your primary oncologist for long term monitoring. This occurs in about 30 days after an autologous transplant. Allogeneic transplant patients have a longer recovery period and will be followed indefinitely by the transplant team.

Your primary oncologist or transplant physician will let you know about follow-up tests to measure the effects of the chemotherapy and the results of the transplant, such as blood tests, X-rays, scans or bone marrow biopsies. You will continue to have regular check-ups by primary oncologist and the transplant team to monitor your disease and check for any long-term side effects.

Progress during this time may seem slow. Keep in mind that long-term recovery may take a few months for an autologous transplant. Recovery for an allogeneic transplant can take a year or longer. Although you may feel frustrated at the seemingly slow rate of recovery, we encourage you to stay engaged in your life and seek out others who can share their experiences with you.

Patients tell us they coped by taking one day at a time and setting simple, realistic goals for themselves.

Brings me back to following Pooh’s advice, and remember that my favorite day is today.

XOXO Me

Breaking News – Another Mehan Has Joined the Family!



Addelyn Kate Mehan joined the world early in the morning of February 13. Born about 1:15am a month before

her due date and just over 5lbs. She is perfect and mom and dad were tired (and hungry) when we dropped off some dinner at about 2am. These fun pictures are from when she was introduced to her 3yr old sister Emily during a Welcome home party. More details in Next month’s edition.





We are back with our Filmmaker Spotlight Series for the ultra-talented group of artists showcasing their films at our February 18th Film Festival! First up, we have Brett Sorem, the incredible Writer/Director of the captivating short film "The Road Between." Here are his inspirational answers to our questions:

1) Why did you get into film in the first place?

I got into film originally because of skateboarding. I grew up in San Diego exploring the streets and filming skateboarding with friends. As I grew older and our skating skill progressed, our shot composition and understanding followed. I edited my first skate video on 2 VCR's using 3 buttons, STOP. PLAY. RECORD. After I got into high school we starting adding skits in-between skate parts, and that was the beginning of where my passion for storytelling stemmed from.

2) What do you plan to achieve as a filmmaker?

I am working towards refining my crafts. Ideally one day down the road I would love to be able to be respected enough throughout the industry, that others would be interested in the knowledge that I have gained throughout the years. I would love to be able to mentor and inspire young kids who are still discovering the person who they are becoming.

3) What inspired you to make this film?

I wanted to tell a story about a person who was put in a moral dilemma, and have that decision test the limits of right and wrong. It is also the first film that I have also written, and seeing the film through from conception to completion I knew was going to be a great experience.

4) What do you want to accomplish with your film being screened at this NFMLA event?

I want to be able to meet like minded driven people to collaborate with in the future, and expand my network. If you see me around, please don't hesitate to say hi! See you all at the event!

Come see Brett's film at our February 18th Film Festival in Downtown Los Angeles! Only \$15 for all films with open bar. TICKETS ARE GOING FAST! Get them here:

<https://goo.gl/tqDSXr>

