RFNL

Catch The News

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The Countdown Begins!

Wisdom cannot be taught or learned it can only be acquired.

By Rich Riel

On Friday, June 23, at the Gillingham mansion in La Mesa an event of little importance to the world, but to me one of life's golden moments occurred. I shared this moment with my wife, family, friends and soon to be extended family. With the official announcement of my only son's engagement to be married I have been rewarded with another milestone in my life.

In every life, there are moments that transcend reality. They are the moments that live with you forever. Those moments make you who you are, and shape what you will do. If life is an Easter egg hunt, these golden moments are the chocolate rabbits. They raise existence above the plain of the physical universe to an existential plateau where the vista transcends reality. It separates our lives from simply living to being alive.

My life began almost seventy years ago. I was blessed to be born of Frank and Edith Riel who found each other as a result of an improbable meeting across a world torn apart by war. Frank Riel was a singularly unusual man who had the good fortune to fall in love with a woman who is the epitome of motherhood. Together this exceptional couple created eight individuals who are themselves, distinctively different, yet bound together as a family. If mom is the perfect mother, then dad was the perfect father. If perfection begets perfection I will leave it to the reader to draw their own conclusions as to the Riel family.

When you are young the most annoying thing you hear from people older than you is, "when I was young." The older you get the more ironic is this situation. I report this event from the perspective of an age I never envisioned achieving. Many of my observations are colored by the perception of a life that now expects to live long enough to be a grandfather.

More than a hundred years ago Mark Twain wrote, "When I was a boy of fourteen, my father was so ignorant I could hardly stand to have the old man around. But when I got to be twenty-one, I was astonished at how much the old man had learned in seven years." That bit of wisdom sums up my relationship with my father and I hope with my son.

The most important thing any man can do is be a father. The better you do your job as a father; the better your life gets as you get older. Frank James Riel was the gold standard, his grandson is my legacy. Frank Riel was the most influential man in my life. As a child, one is not in a position to judge how good their parents were. It is only after you become a parent yourself; can you begin to understand how good your parents really are. When I knew I was going to be a father, I prevailed on my long-suffering wife to name our son, Frank James Joseph Riel. I honored my father and Liz's father by that name.

Friday night was a celebration of why men are fathers. My brothers and sisters gave a party to honor the promises made by Samantha Rene Davis and Frank James Joseph (JJ) Riel to marry on April 28th, 2018. In attendance were, besides my brothers and sisters, the Davis family and many friends. Roy and Karin Davis, together with their sons, Tyler, Joshua, and Nico, were introduced and are now a part of the Riel clan. Roy Davis as a father, with his wife Karin, honors us all with their blessing and approval of the up-

coming marriage of their only daughter to my only son. My son now has, besides his child hood friend Shane Barber and his wife Ashley, three brothers. My wife and I share our family with Roy and Karin.

In my toast to the last-born Riel of the second generation, I said," There are moments in your life that are with you until death. These moments define who and what you are. They are as personal as your fingerprints and as private as your spirit. My first such moment came when I graduated from the Citadel, my father's Alma Mater. The school itself is rich in tradition and one of the traditions is a father hands his son his diploma on graduation day. That day in May 1969, when I saluted my father and took my diploma lives with me every moment of my life. The next such day was October 21, 1978, when I was in All Hallows Catholic Church marrying the love of my life and soul mate Elizabeth(Liz). Twelve years later a little past noon, Sept 1, 1990, in a Kaiser Hospital delivery room I watched my son take his first breath. Twenty-one years later I watched him graduate from San Diego State University. Tonight, I celebrate his intention to marry a woman I think is too good for him. I am blessed to be in the company of all who share this moment with me. To Frank and Sam, may you know the joy I share with all of us in celebrating your upcoming marriage." As my father Frank Riel would have said if he was reporting this event, "A good time was had by all."

An Engagement Party - a Year in the Making

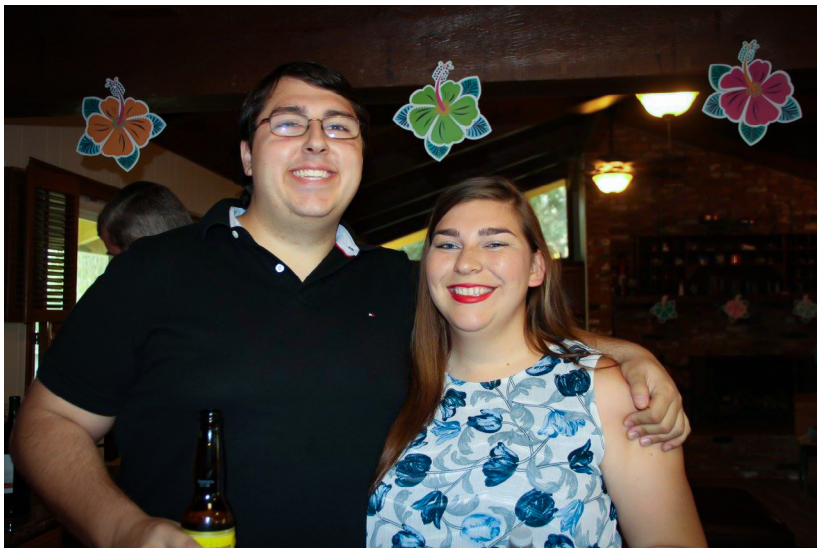
A little over a year ago Frank announced his intention to marry his longtime sweetheart Samantha Davis, in the spring of 2018. This, of course, put the Riel sisters into action and it was quickly decided that Listy and Bob would host this very special event.

Now I am not even going to pretend that it would take a year to plan this event seeing as we have had plenty of practice in giving engagement parties. But still each one is unique and there were lots of things to do to prepare for this party. Top of the list was "The Song." Fortunately, Bob had a year to get it just right! Then there were the practice sessions… two time a week for 8 months… would you believe once a week for a month? … With apologies to agent Smart (look up the movie "Get Smart" or the show with the same name if you don't get the reference)… How about 5 minutes just before it was sung?

Still, it turned out perfect (well for the Riel Singers it was about as good as it gets) and you can watch a video of it by clicking here. Richard even had the music for the song "Margaritaville" and this helped tremendously.

After the Riel Singers closed out the song, it was time for the presentation of the traditional engagement gift (a silver ice bucket engraved with their names on it). It was nicely wrapped and when Frank opened it he declared it to be a beautiful urn! Close… and it could be used that way but Sam quickly pointed out a few uses that it would be more suitable for.

It was a very fun evening and we all enjoyed meeting the Davis side of the family along with many of their friends. We are really looking forward to next April when we can all celebrate the marriage of Frank and Samantha! Until then just keep singing….



Frank and Sam's Song

Sung to the tune of "Margaritaville"

Talking bout wedding cake
Wanting to par-take,
All of those guests are ready to dance
Here comes the DJ
All of our songs played
Frank and Sam, hey it's truly romance

Waiting a year or more for a wedding day
Searching for lost time, make her a bride
Some people claim that there's a Riel to blame
But we know, Frank will abide.

We don't know the reason
We've been waiting all season
Nothing to show but this sparkly new ring
But it's a real beauty
Cost him much booty
Now we know it wasn't a fling.

Waiting a year or more for a wedding day
Searching for lost time, make her a bride
Some people claim that there's a Riel to blame
But we know, Frank will not hide..

She works at the Y now
He's got CVS know how
Both work real hard at their jobs all day long,
But they do love Disney
It's there they they feel free
And being together helps them hang on.

Waiting a year or more for a wedding day
Searching for lost time, make her a bride
Some people claim that there's a Riel to blame
But we know, he will abide.

Yes, some people claim that there's a Riel to blame
Yet we know, it's the Davis' side.

Francie's Updates

Hey Everybody, June 22nd, 2017

It's a good thing I did not send it this on Monday, it was not a good day for me and I was not in my best of spirits. It seems like I had this idea of looking down the road and thinking that maybe the outcome of all of this was not going to be so bleak and that maybe there was a cure for me. But the truth of the matter is, the way to get by living with cancer is to really enjoy the day you are in and not try to count how many you are going to get. As Dr. Hutchins likes to say, the only cure for cancer is dying of something else.

It seems as though the nastiest, meanest, toughest Myeloma cells in my body are a little irritated with the fight I have been putting up. So, they have gathered together, the strongest and most determined to keep me in a bad place, and they have hunkered down in my spine to cause some trouble from behind the walls of their castle. Cancer is very smart and very resilient, much like cockroaches are, and are constantly searching for ways to survive.

So, here's the agenda for those bastards. As most of you know, the plan has been to get my cancer into a remission so that I can have Brett's harvested stem cells transplanted into my blood, hopefully leaving a bit of his immune system behind for me to fight my cancer with.

As part of the treatment, after they kill off all my good and bad cells, to use some low dose radiation to finish off what is left over before they give me Brett's younger and healthier ones. My no holds barred Doctor Mahindrah's suggested that I do a Craniospinal Irradiation first.

http://ozradonc.wikidot.com/me:craniospinal

Even though certain tests have shown next to no myeloma cells, it just means we pulled from a spot that did not have a proliferation of them. He said you are dreaming if you think they are not there. Unfortunately, one of a list of many serious side effects is impaired mental reasoning. I am already stupid enough from the chemo, I do not need to get any stupider. It is a hard decision to make but I think I would rather die than have diminished mental capacity.

My thought process is what makes me special and I am not ready for that type of risk, especially because I feel so good everywhere else. This is a very unique situation, because there is no protocol. Generally, when someone gets cancer in their brain or spinal cord they are not in good enough condition to even consider a transplant. It was a very disheartening thought for me and put me in a place closest to depression I have come to yet. But it did not last long. I went back to the words from the song in RENT about living with AIDS when they asked, but how do you feel today. And he said great!!! There's no day but today and that is where I am going to reside from here on out.

So that said, we are putting off the transplant for a month and trying some different chemos, one is experimental and we are trying to get a compassionate release of it. It is still in phase one of testing but, what the heck, let's give it a try. It is called Marizomib I will continue with the two new ones I started last month, Bendamustine and Pomalyst.

Myeloma Morning:
Marizomib, And Bone Cell Precursors As Possible Disease Markers

With Multiple Myeloma becoming a cancer that is less rare, there is a lot of new research for more effective and specific targeting chemos. In fact, there are almost 20 items in the list of new myeloma research at the end of today's report.

We obviously have to pace ourselves a bit with such a long list of new research. So we are going to start today by reviewing two of those studies with you. We'll then share with you summaries of some of the other studies in Myeloma Mornings to be published over the weekend and early next week.

Also in today's report, we have some myeloma business news to discuss. A number of companies that develop and sell myeloma treatments issued quarterly earnings releases yesterday.

The new research articles that we'll be summarizing in this report include:

1. A study of marizomib (NPI-0052, salinosporamide A) by Australian researchers

2. A study by researchers in China, who investigate using osteoblast and osteoclast precursor cells as potential myeloma-related biomarkers.

Marizomib Phase 1 Clinical Trial Results

We start today's look at recent myeloma research with a study by Australian researchers. (Go Aussies) They report results of a Phase 1 trial investigating marizomib as a potential new treatment for multiple myeloma and several other cancers.

Marizomib is in the same class of drugs, known as proteasome inhibitors, as Velcade (bortezomib), Kyprolis (carfilzomib), and Ninlaro. (I have used Velcade, had the eye issue from that one, and used Kyprolis for a sort time before last transplant) The marizomib trial discussed in the new Australian study included 86 patients with various forms advanced solid tumors and blood-related cancers; 35 of the trial participants had relapsed / refractory multiple myeloma.

The objective of this trial was very similar to that of a Phase 1 marizomib trial conducted in the United States. As we mentioned in a previous edition Myeloma Morning, the goal of the U.S. trial was to determine the recommended dose for a Phase 2 trial of marizomib. Thus, numerous dose levels – and different dose schedules – were tested in both the U.S. and Australian studies.

However, all myeloma patients in the Australian study received the same dose schedule (twice weekly for two weeks in a three-week treatment cycle). All but one of the myeloma patients in the Australian study also received 20 mg of oral or intravenous dexamethasone on the day of their marizomib infusions, plus another dose of dexamethasone either the day before or the day after the marizomib infusion.

The myeloma patients in the trial were heavily pretreated, having received a median of seven prior treatment regimens. The majority of patients (80 percent) had previously received Velcade, and 20 percent were refractory to Velcade.

In medicine, refractory describes a disease or condition which does not respond to attempted forms of treatment. A cancer is said to be refractory when it does not respond to (or is resistant to) cancer treatment. Refractory cancer is also known as resistant cancer.

Patients completed a median of two treatment cycles. The main reason for treatment discontinuation was progressive disease (73 percent).

Of the 27 myeloma patients evaluable for response, one achieved a very good partial response and three had a partial response. In addition, four myeloma patients reached a minimal response and 12 had stable disease.

The most common treatment-related side effects for the dosing schedule the myeloma patients received were fatigue (37 percent) and nausea (23 percent). The researchers observed central nervous system-related side effects when marizomib was infused quickly (10 minutes), so the infusion time was extended to two hours to minimize the side effects.

The researchers state that "marizomib was generally well tolerated and demonstrated activity in heavily pre-treated relapse/refractory multiple myeloma patients, providing a rational platform for combinatorial studies in the future. This study determined the dose of marizomib to be explored in a Phase 2 trial in patients with multiple myeloma to be 0.5 mg/m2

on days 1, 4, 8, and 11 in 3-week cycles, infused over 2 hours in combination with dexamethasone given on the day before and day of marizomib dosing."

The researchers point out that this is the same recommended dose developed during U.S. marizomib trial. It also is the marizomib doing being used in a trial investigating marizomib in combination with Pomalyst (Coincidentally, I'll be using that too, hahah it crosses into the spinal cord and I started taking it last month.) (pomalidomide, Imnovid) and dexamethasone (I'm taking this too) in relapsed multiple myeloma patients.

Circulating Osteoblast And Osteoclast Precursors As Disease Markers

The second new research study that we'd like to review today is by researchers based in China. It concerns osteoblasts and osteoclasts – the cells involved in the maintenance and repair of bones (abstract).
For help in interpreting the Chinese study and its potential implications, we turned to Dr. Michaela Reagan, a myeloma researcher at the University of Maine and the Maine Medical Center Research Insitute. Dr. Reagan has a particular interest in the interaction between multiple myeloma cells and their surrounding bone environment.

Here is what Dr. Reagan told us about the study:
"One of the most devastating aspects of multiple myeloma is the accompanying bone disease. We have long known that bone cells, including the bone-forming osteoblasts and bone-degrading osteoclasts, function abnormally in the bones of myeloma patients.

"In a recent report from Dr. Shao's laboratory at the Tianjin Medical University General Hospital, China, the researchers look at the cells that become bone cells, rather than the bone cells themselves. By examining these "precursor cells", or cells that then mature into bone cells, the authors identified a new aspect to myeloma bone disease.

"Specifically, they found that the numbers of these precursor cells may be abnormal in multiple myeloma patients. Newly diagnosed multiple myeloma patients in the study tended to have fewer osteoblast precursors circulating in their blood compared to healthy (control) patients.

"Similarly, the same newly diagnosed myeloma patients tended to have more osteoclast precursor cells circulating in their blood compared to healthy patients.

"My analysis of the statistics used for the authors' analysis suggests, however, that these findings are not yet significant. Perhaps with data from more than 36 patients, this finding will prove correct, but due to the analysis conducted here, it cannot be concluded as of yet.

"Still, the implications of this work are that looking at circulating osteoblast and osteoclast precursors may be a novel biomarker, or a predictive marker used to study the disease course, for patients. This could be a new way to help doctors monitor bone disease or myeloma disease progression."

Now for the other two, Bendamustine is a once a month infusion, had no real side effects to it last month so we are going to give it a go again because of its ability to cross into the spinal cord.

How Bendamustine Works:

Cancerous tumors are characterized by cell division, which is no longer controlled as it is in normal tissue. "Normal" cells stop dividing when they come into contact with like cells, a mechanism known as contact inhibition. Cancerous cells lose this ability. Cancer cells no longer have the normal checks and balances in place that control and limit cell division. The process of cell division, whether normal or cancerous cells, is through the cell cycle. The cell cycle goes from the resting phase, through active growing phases, and then to mitosis (division).

The ability of chemotherapy to kill cancer cells depends on its ability to halt cell division. Usually, the drugs work by damaging the RNA or DNA that tells the cell how to copy itself in division. If the cells are unable to divide, they die. The faster the cells are dividing, the more likely it is that chemotherapy will kill the cells, causing the tumor to shrink. They also induce cell suicide (self-death or apoptosis).

Chemotherapy drugs that affect cells only when they are dividing are called cell-cycle specific. Chemotherapy drugs that affect cells when they are at rest are called cell-cycle non-specific. The scheduling of chemotherapy is set based on the type of cells, rate at which they divide, and the time at which a given drug is likely to be effective. This is why chemotherapy is typically given in cycles.

Chemotherapy is most effective at killing cells that are rapidly dividing. Unfortunately, chemotherapy does not know the difference between the cancerous cells and the normal cells. The "normal" cells will grow back and be healthy but in the meantime, side effects occur. The "normal" cells most commonly affected by chemotherapy are the blood cells, the cells in the mouth, stomach and bowel, and the hair follicles; resulting in low blood counts, mouth sores, nausea, diarrhea, and/or hair loss. Different drugs may affect different parts of the body. (I did not really experience anything last month, except lower blood cell counts from this we will keep our fingers crossed)

Bendamustine is classified as an alkylating agent. Alkylating agents are most active in the resting phase of the cell-cycle. There are several types of alkylating agents. Bendamustine is a nitrogen mustard derivative and is active against resting as well as dividing cells.

And lastly Pomalyst, an oral chemo taken daily for 21 days then off for a week. Knocked down my white and red blood cells a bit, my platelets and some other things I need to survive, but not too bad, I'm still here.

How Pomalyst Works:

Pomalyst®'s exact mechanism of action on cancer cells is not clear. It may act by inhibiting the growth of new blood vessels (angiogenesis) in tumors, enhancing the status of the immune system, or decreasing cytokine and growth factor production.

In normal tissue, new blood vessels are formed during tissue growth and repair (i.e. a healing wound), and during the development of baby during pregnancy. Blood vessels carry oxygen and nutrients to tissue that are necessary for growth and survival. In cancer, tumors need blood vessels in order to grow and spread. Through a complex process, endothelial cells (which line the blood vessels) are able to divide and grow and create new blood vessels. This process is called angiogenesis and it occurs in both healthy tissue and in cancerous tissue.

Additionally, Pomalyst® is known to have various effects on the immune system (immunomodulatory agent), which may contribute to its therapeutic effect. Pomalyst® may also alter the production and activity of cytokines (growth factors) involved in the growth and survival of certain cancer cells. There may be an effect on the genes that direct the cell's growth and activity particularly those associated with cytokines (growth factors), apoptosis (cell death), and metabolism. Pomalyst® enhances T cell- and natural killer cell-mediated immunity. Additionally, Pomalyst® has an effect on lenalidomide-resistant multiple myeloma.

I will still do the intrathecal spinal lumbar taps with chemo but just bi weekly instead of twice a week and we are going to switch those up too. We're coming after you myeloma, there is no escaping us now. Wherever you are hiding my prayer warriors are coming after you too, so look out!!!!!!

And finally, as if I am not putting enough different medicines in my body, we are going to throw in a little Neulasta to try to build it up a bit.

Neulasta
Generic name: Pegfilgrastim
Other names: G-CSF, Granlocyte - Colony Stimulating Factor

How This Drug Works:

Colony-Stimulating Factors:
In the body's bone marrow (the soft, sponge-like material found inside bones) blood cells are produced. There are three major types of blood cells; white blood cells, which fight infection; red blood cells, which carry oxygen to and remove waste products from organs and tissues; and platelets, which enable the blood to clot. Cancer treatments such as chemotherapy and radiation therapy can effect these cells which put a person at risk for developing infections, anemia and bleeding problems. Colony-stimulating factors are substances that stimulate the production of blood cells and promote their ability to function. They do not directly affect tumors but through their role in stimulating blood cells they can be helpful as support of the persons immune system during cancer treatment.

Pegfilgrastim is a growth factor that stimulates the production, maturation and activation of neutrophils. Pegfilgrastim also stimulates the release of neutrophils (a type of white blood cell) from the bone marrow. In patients receiving chemotherapy, pegfilgrastim can accelerate the recovery of neutrophils, reducing the neutropenic phase (the time in which people are susceptible to infections). Pegfilgrastim is a long-acting version of filgrastim.

Pegfilgrastim is filgrastim with a substance called polyethylene glycol (PEG) attached to it. The attachment process is called pegylation, and is used to allow active substances (the filgrastim) to stay in the body longer before they are broken down and eliminated.

I always love these little reminders:
Contact your health care provider immediately, day or night, if you should experience any of the following symptoms:

- Fever of 100.4° F (38° C), chills, sore throat (possible signs of infection)
- Shortness of breath
- Rapid heart beat
- Bleeding that does not stop after a few minutes
- Any new rashes on your skin
- Or your husband puts a stop to your online spending

And of course my favorite, sleep robbing, energy providing steroid, Dexamethazone, that encourages all the other drugs to play nice together.

Trade Names: Decadron, Dexasone, Diodex, Hexadrol, Maxidex Other Names: dexamethasone sodium phosphate, dexamethasone acetate
Chemocare.com uses generic names in all descriptions of drugs. Decadron is the trade name for dexamethasone. Dexasone and diodex or hexadrol are other names for dexamethasone. In some cases, health care professionals may use the trade name decadron or other names dexasone or diodex or hexadrol when referring to the generic drug name dexamethasone.

Drug type: Dexamethasone has many uses in the treatment of cancer. It is classified as a glucocorticosteroid.
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What Dexamethasone Is Used For:

- As an anti-inflammatory medication. Dexamethasone relieves inflammation in various parts of the body. It is used specifically to decrease swelling (edema), associated with tumors of the spine and brain, and to treat eye inflammation.
- To treat or prevent allergic reactions.
- As treatment of certain kinds of autoimmune diseases, skin conditions, asthma and other lung conditions.
- As treatment for a variety of cancers, such as leukemia, lymphoma, and multiple myeloma.
- To treat nausea and vomiting associated with some chemotherapy drugs.
- Used to stimulate appetite in cancer patients with severe appetite problems.
- Also used to replace steroids in conditions of adrenal insufficiency (low production of needed steroids produced by the adrenal glands).

Last week, my brother Ed and Sister-in-love Jan attended a cancer survivors celebration at Scripps hospital where my Dr. Hutchins did some Ballroom dancing with a surviving cancer patient she met at the Hospital.

http://www.kusi.com/Clip/13402520/cancer-survivors- day#.WT1OUgwrtGg.facebook

She has been inspired by Stephen and myself to create a Foundation to fight Blood related Cancers, so people can dance to donate instead of necessarily running or just walking. She has some pretty big plans and is getting a lot of attention from the right people, will keep you posted on her generous journey as well.

With all of this on the table, we are going to move the transplant date forward at least a month. If I get the transplant without my spine being in remission, I will not be able to take any chemo for a month or so and that has proven not such a good thing for me.

So, in the meantime, I will do what I love doing, fixing up my new home, (I promise, more to come on that in a week or so!), having lunch and walking with my friends, and running into many of you at the Salon. And by the way, speaking of the Final Cut, Leonor and I are turning the Inspiration Lounge over to Jaimie Olvera, a Design Artist for Joico and longtime friend. He will be turning it into a space for himself and some other Hair Designers bringing in a new energy to our home on Balboa Ave. I am so happy to have him there, and it is great for Leo and I to downsize our space a bit. Thanks Jaimie for joining us, can't wait to have your creative influence a part of our home!!!

One thing I have learned this week is how important it is for all of us to live in today. We have no control over the future, but every day when we get up in the morning we get to decide what kind of a day we are going to have, because we can see the good parts of it instead of the stupid driver who is always in front of me. There are so many great things we miss out on because we are so obsessed with what's coming along. Seize the moment as they say, find your place of joy even if it is that lull in time before you buy that awesome new dress and the credit card bill gets there, hahahahah.

That is my goal for now, and it has raised the heaviness from my heart I allowed in earlier this week. Today is the day I live for…

Love you all

Me

July 6th, 2017

Hey Everyone,

Hope you all had a wonderful 4th of July, Lyle and I went up to see Brett in Los Angeles and watched 4 hours of Fireworks above the city from Brett's front porch, after attending Tory and Amanda Weisz's wedding on July 2nd at the La Costa Omni Resort in San Diego. It was a beautiful wedding that Michelle and Wayne put on and it was so fun to see our fire sprinkler friends from east of here, the Will's, the Rees's and the Bateman's. Again, a wedding that my Doctor's told me I wouldn't be going to. But some one higher up then 3 North in Scripps Green seems to be scheduling for me.

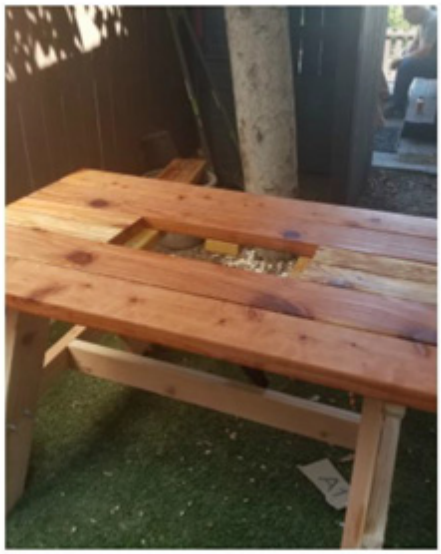
It seems that over and over I am getting to attend events that I was going to miss due to my future return to the "Spa" at Scripps Green in La Jolla. Wayne and his brother Byron are now partners with Lyle at Western Fire Protection and along with the rest of their family, it was so great to be at Tory's wedding.

I felt pretty good for the most part but the nerve pain continues to be something I have to struggle with and am hoping that once I get to the transplant and am not getting the spinal shots in my back so frequently, that the pain will diminish and I will go back to my normal self, whatever that is, hahahah.

The weather could not have been any nicer and the scenery at La Costa overlooking the golf course was spectacular for sure.

We took the train up to see Brett and Carinda, and had a great time barbecuing with many of our L. A. friends. Brett and Carinda, along with some help from Alan and Lyle, built a beautiful picnic table to serve up our food on. There was even an opening for the copper wine holder in the center, and between the food and the Fireworks it was a great way to spend a warm summer evening!

There were many trips to Home Depot where the guys were looking at tools and Carinda and I were all about the plants!!!



Ok, enough about the fun stuff, let's get back to the serious business of what's going on with my cancer. I was not in a very good place as I am sure many of you noticed, last update, there are times when the overall picture gets a little dim and I cannot always stay in my happy place. Here is the story. I cannot get the transplant until there is no cancer in my bone marrow or in my spinal cord, period. If there is cancer, I need to do chemo, if I am taking chemo, I will kill off Brett's stem cells, which sort of defeats the purpose. As I told you last update, I was switching to a new chemo in my spinal cord, DepoCyt. Here is a little info on how it works:

DepoCyt ™
Generic name: Cytarabine Liposomal
Trade name: DepoCytTM
Other name: Liposomal Ara-C

Chemocare.com uses generic names in all descriptions of drugs. DepoCyt is the trade name for Cytarabine Liposomal. Liposomal Ara-C is another name for DepoCyt. In some cases, health care professionals may use the trade name DepoCyt or other name Liposomal Ara-C when referring to the generic drug name Cytarabine Liposomal.

Drug type: DepoCyt is a sustained-release form of Cytarabine Liposomal. It is an anti-cancer ("antineoplastic" or "cytotoxic") chemotherapy drug. This medication is classified as an "antimetabolite." (For more detail, see "How this drug works" section below).

What This Drug Is Used For:

- Liposomal cytarabine is used to treat lymphomatous meningitis (lymphoma found in the lining of the brain and spinal cord).

Note: If a drug has been approved for one use, physicians may elect to use this same drug for other problems if they believe it may be helpful.

How This Drug Is Given:

- Liposomal cytarabine is given is by intraventricular or intrathecal infusion. This method is used when drugs need to reach the cerebrospinal fluid (CSF) the fluid that is surrounding the brain and spinal cord, the drug is infused directly into the spinal fluid. The body's blood-brain barrier does not allow many chemotherapy drugs given systemically (through the whole body) to get to the CSF. There are two ways chemotherapy can be given to the CSF:
- Lumbar puncture (Intrathecal). Chemotherapy can be given through a lumbar puncture (spinal tap). In this case a small amount of chemotherapy is injected during the lumbar puncture, directly into the CSF. Once the drug is administered the catheter is removed. (this is how I am receiving it)

- Ommaya reservoir (Intraventricular). The ommaya reservoir is a small dome-shaped device with an attached catheter. It is placed into the subcutaneous tissue (the layer of tissue between the skin and the muscle) on the scalp. The catheter is threaded into the lateral (outer) ventricle of the brain. The nurse or doctor, who is specially trained on this method of giving chemotherapy, will insert a small needle through the skin on the scalp into the ommaya reservoir to inject the chemotherapy.

- The amount of liposomal cytarabine that you receive depends on many factors, including the type of cancer you have, your height and weight, your general health, any other health problems you may have. Your doctor will determine your dose, how it should be given and the schedule.

Side Effects:

Important things to remember about the side effects of cytarabine:

- Most people do not experience all of the side effects listed.
- Side effects are often predictable in terms of their onset and duration.
- Side effects are almost always reversible and will go away after treatment is complete.
- There are many options to help minimize or prevent side effects.
- There is no relationship between the presence or severity of side effects and the effectiveness of the medication.

The following side effects are common (occurring in greater than 30%) for patients taking liposomal cytarabine:

- Inflammation of the sac surrounding the brain and spinal cord. This can cause neck pain, neck rigidity, headache, fever, nausea, vomiting, and back pain. Steroids are given before and for 5 days after the injection to prevent or lessen this reaction.

These side effects are less common side effects (occurring in about 10-29%) of patients receiving liposomal cytarabine:

- Headache
- Confusion (see central neurotoxicity), (unfortunately, I am experiencing some of this. Thus the reason it is taking me 4 days to write this update. It is very frustrating that I can hardly remember what I have just written!)
- Weakness (I am experiencing weakness but I still have lots of energy which is a good thing)
- Excessive sleepiness (see central neurotoxicity)
- Nausea and vomiting
- Fever

Not all side effects are listed above, some that are rare (occurring in less than 10% of patients) are not listed here. However, you should always inform your health care provider if you experience any unusual symptoms.

Here is some more info if you are interested. http://chemocare.com/chemotherapy/drug-info/depoCyt.aspx

We were hoping to get in on a new drug that is in the early stages of testing I told you about called Marizomib, but it was not available. The nice and somewhat famous MD/PHD, myeloma expert, Dr. Amit Agarwai was very impressed and interested in my treatment and has encouraged Dr. Hutchins to write a journal article about the combinations that they have been using to treat my cancer. It's nice to know that my team is leading the pack on new ways to battle this disease.

So far I am in a nice strong remission in my bone marrow according to the tests I have taken since my last transplant. The myeloma cells that have shown up in my spinal cord have diminished, but seem to be still lingering a bit. The last CSF test was the largest amount of spinal fluid that we have been able to get so far (12 cc's) and it showed no cells present. If the test I take this coming Wednesday shows the same result, we will schedule the transplant for 2 weeks after my last chemo capsule which will be this coming Thursday the 13th.

I am not going to consider the alternative right now because that is not where I am planning on going. We'll worry about that later. As it seems to be happening, that will keep me out of the hospital till after my Birthday on the 21st, so I may have to have an open house here for those nearby to drop in for a visit. Bryce, Bridget, Carinda and Brett will all be here to celebrate, and right now, that is what I am focusing on. I am a lucky Mom to have them all coming to see me.

Dr. Hutchins is becoming very involved in the Lymphoma Leukemia Society and is a candidate for Society woman of the year. She will be very active this next year and I am going to be working on her team as well. We need to get more people aware of the difficulty of blood related cancers and get more interest in the fund raising end of more cancers that need help from all of us. Multiple Myeloma is becoming more and more prevalent as the baby boomers hit their 60's, here is a little info on my disease.

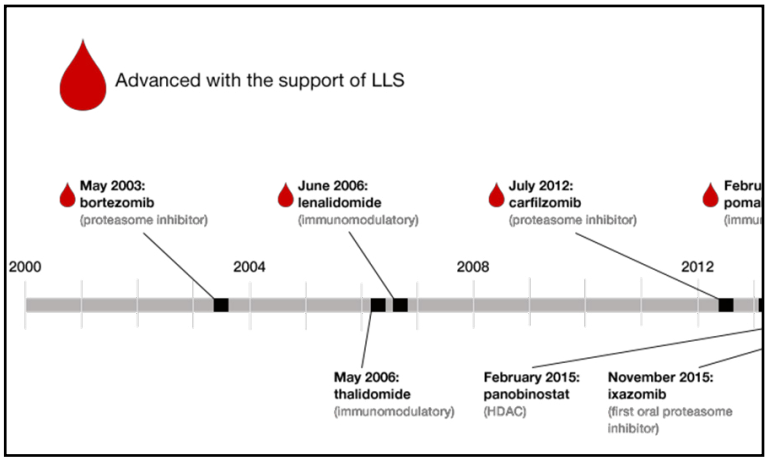
Myeloma: Past, Present, Future Past

Prior to 2003, there were few options for patients with myeloma. From 2003-2008, the landscape for patients with myeloma began to change with a flurry of groundbreaking new drug approvals, many of which were supported by research investment from LLS. The new therapies extended survival rates from less than three years to seven or more for some patients. The next wave of new therapies occurred between 2012 and 2015, with six new FDA approved therapies. Doctors anticipate these newer drugs will extend life to ten years and beyond.

Present
Researchers are now focused on optimizing the existing drugs while continuing to seek new therapies and cures. LLS is playing a key role in supporting research to not only identify the most effective combinations but to discover more novel therapies. LLS is currently funding more than 26 active grants and four projects through our Therapy Acceleration Program.

Future
Myeloma remains an incurable disease. We are working to change that. LLS is supporting research focused on better understanding the underlying drivers of myeloma so that more effective targeted therapies can be developed. We are also supporting work aimed at preventing precursor diseases from developing into full-blown myeloma, through vaccines and investigational targeted therapies. And the emerging science of immunotherapy is showing promise for patents with myeloma as well. We are committed to increasing our investment even further over the next five years.

Breakthroughs in Myeloma Treatments



Definitions:
Proteasome inhibitor: inhibits the proteasome enzyme that regulates cell activity

Immunomodulatory: stimulates the immune system to fight the cancer

Monoclonal antibody: Helps the immune system find the cancer cells

Histone deacytalase (HDAC): targets a class of enzymes involved in gene expression

"BET" inhibitors: target a class of proteins that play a role in myeloma

Immune checkpoint inhibitors: unleash the immune system by targeting the proteins that block the immune system's activity

Chimeric Antigen Receptor T-Cell Immunotherapy (CAR-T): using genetically engineered immune T cells to target the cancer

Vaccine: stimulate the patient's immune system through combined use of peptides (small proteins) and adjuvants (substance that enhances the body's immune response)

The other chemo I am taking daily is called Pomalyst, here is the down low on that one:

Generic name: Pomalidomide

Pomalyst® is the trade name for the generic chemotherapy drug pomalidomide. In some cases, health care professionals may use the generic drug name pomalidomide when referring to the trade name drug Pomalyst®.

Drug type: Pomalyst® is classified as an "immunomodulatory agent with antineoplastic activity," and an "anti-angiogenic agent." (For more detail, see "How this drug works" section below).

What Pomalyst Is Used For:
- For treatment of multiple myeloma who have received at least two prior therapies including lenalidomide and bortezomib and have demonstrated disease progression on or within 60 days of the last therapy.

Note: If a drug has been approved for one use, physicians may elect to use this same drug for other problems if they believe it may be helpful.

How Pomalyst Is Given:
- As a capsule by mouth. Capsules should be stored in a cool, dry place and protected from light.

- Swallow capsules whole with water 1 time per day, at about the same time.

- Do not break, chew or open the capsules. Do not open the Pomalyst® capsules or handle them any more than needed. If you touch a broken capsule or the medicine in the capsule, wash your hands right away with soap or water.

- Pomalyst® can be taken with or without food.

- If you miss a dose of Pomalyst®, and it has been less than 12 hours since your regular time, take it as soon as you remember. If it has been more than 12 hours, skip your next dose. Do not take 2 doses at the same time.

- In order to receive this drug, there are strict guidelines that you must follow. You will be required to participate in a special program called the Risk Evaluation and Mitigation Strategy (REMS) Program. You will be asked to fill out a questionnaire before you receive the medication, and every month, while you are taking the drug. Only certain pharmacists and doctors may prescribe or dispense this medication. Patients must sign a Patient-Prescriber agreement and comply with the REMS requirements.

- Do not share Pomalyst® with others.

- You should not smoke cigarettes while taking Pomalyst®. Smoking cigarettes during treatment may effect how well Pomalyst® works.

The amount of Pomalyst® you will receive depends on many factors, including your general health or other health problems, and the type of cancer or condition being treated. Your doctor will determine your dosage and schedule.

Side Effects:

Important things to remember about the side effects of Pomalyst®:

- Most people do not experience all of the side effects listed.

- Side effects are often predictable in terms of their onset and duration.

- Side effects are almost always reversible and will go away after treatment is complete.

- There are many options to help minimize or prevent side effects

There is no relationship between the presence or severity of side effects and the effectiveness of the medication.

The following side effects are common (occurring in greater than 30%) for patients taking Pomalyst®:

- Severe life-threatening human birth defects.
- Fatigue
- Weakness
- Low white blood cell count
- Anemia
- Constipation
- Nausea
- Diarrhea
- Shortness of breath
- Upper respiratory infections
- Back pain
- Fever

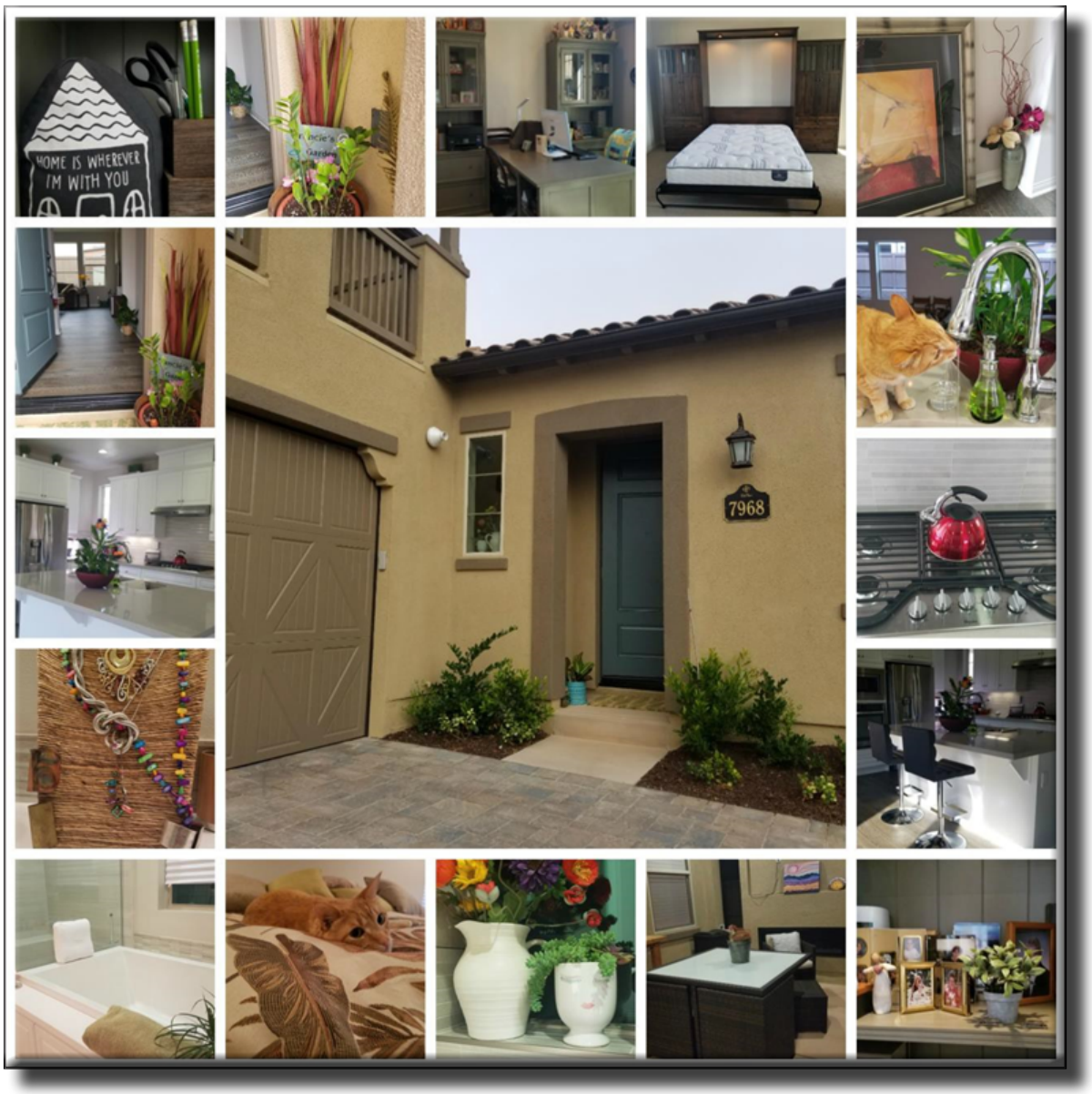
These side effects are less common side effects (occurring in about 10-29%) of patients receiving Pomalyst® :

- Neuropathy (numbness and tingling)
- Dizziness
- Confusion

A serious but rare side effect of Pomalyst® is blood clots forming in the legs or lung. Call your provider right way if you experience shortness of breath, chest pain or arm or leg swelling.

Pomalyst® is not to be taken during pregnancy. This type of medication has can cause severe life-threatening birth defects.

The new house is coming along great we had ceiling fans put in today, they look really nice and keep the AC circulating nicely. We are still waiting for quite a bit of furniture but that makes it seem like Christmas each week when new things arrive. The hiking trails around here are really nice and I am enjoying my new neighbors. They have a very nice community group that you can get help from if you need it. This definitely was a smart move for us and we are having fun getting it all together. I am hoping that after the transplant Brett's immune system will take over for mine and that things will be looking a little more positive for me. I will be on anti- rejection drugs for about 6 months, Oh goody, more new things for me to try.



There is a nice gym here to work out in so I am trying to keep in good shape, I have managed to gain some weight so that when I am in the hospital I will have some leeway to keep in a healthy place.

Sorry this update is so erratic, my thought process is not as good as it used to be, but I will keep hanging in there and trying to make sense of it all.

Going to see Mitch tomorrow, we started out together doing hair shows so many years ago it will be so fun to see him, congrats to Damien for being named Hairstylist of the year, and to Dilek and Benson for your nominations, I am proud to have been able to learn from the best! Love you all, will try to get my thoughts together better next time,

July 13, 2017

Great news, spinal cord came back cancer free for the second time, transplant to occur in approximately 2 weeks thanks for all the thoughts and prayers!!!!! Also, In case you did not see this in the newspaper in your cities here is more good info on treatment for me.

Gene therapy for cancer nears FDA approval 'This is the beginning of something big,' says expert

By DENISE GRADY

A Food and Drug Administration panel opened a new era in medicine on Wednesday, unanimously recommending that the agency approve the first treatment that genetically alters a patient's own cells to fight cancer, transforming them into what scientists call "a living drug" that powerfully bolsters the immune system to shut down the disease.

If the FDA accepts the recommendation, which is likely, the treatment will be the first gene therapy to reach the market. Others are expected:
Researchers and drug companies have been engaged in intense competition for decades to reach this milestone. Novartis is now poised to be the first. Its treatment is for a type of leukemia, and it is working on similar types of treatments in hundreds of patients for another form of the disease, as well as multiple myeloma and an aggressive brain tumor.

To use the technique, a separate treatment must be created for each patient — their cells removed at an approved medical center, frozen, shipped to a Novartis plant for thawing and processing, frozen again and shipped back to the treatment center. A single dose of the resulting product has brought long remissions, and possibly cures, to scores of patients in studies who faced death because every other treatment had failed. The panel recommended approving the treatment for B-cell acute lymphoblastic leukemia that has resisted treatment, or relapsed, in children and young adults ages 3 to 25.

One of those patients, Emily Whitehead, now 12 and the first child given the altered cells, was at the meeting of the panel with her parents to advocate approval of the drug that saved her life. In 2012, as a 6-year-old, she was treated in a study at the Children's Hospital of Philadelphia. Severe side effects — raging fever, crashing blood pressure, lung congestion — nearly killed her. But she emerged cancer-free, and has remained so.

"We believe that when this treatment is approved it will save thousands of children's lives around the world," Emily's father, Tom Whitehead, told the panel. "I hope that someday all of you on the advisory committee can tell your families for generations that you were part of the process that ended the use of toxic treatments like chemotherapy and radiation as standard treatment, and turned blood cancers into a treatable disease that even after relapse most people survive."

The main evidence that Novartis presented to the FDA came from a study of 63 patients who received the treatment from April 2015 to August 2016. Fifty-two of them, or 82.5 percent, went into remission — a high rate for such a severe disease. Eleven others died.

"It's a new world, an exciting therapy," said Dr. Gwen Nichols, the chief medical officer of the Leukemia and Lymphoma Society, which paid for some of the research that led to the treatment.

The next step, she said, will be to determine "what we can combine it with and is there a way to use it in the future to treat patients with less disease, so that the immune system is in better shape and really able to fight." She added, "This is the beginning of something big."

At the meeting, the panel of experts did not question the lifesaving potential of the treatment in hopeless cases. But they raised concerns about potentially life-threatening side-effects — short-term worries about acute reactions like those Emily experienced, and longer-term worries about whether the infused cells could, years later, cause secondary cancers or other problems.

Oncologists have learned how to treat the acute reactions, and so far, no long-term problems have been detected, but not enough time has passed to rule them out.

Patients who receive the treatment will be entered in a registry and tracked for 15 years.

Treatments involving live cells, known as "biologics" are generally far more difficult to manufacture than standard drugs, and the panelists also expressed concerns about whether Novartis would be able to produce consistent treatments and maintain quality control as it scaled up its operation.

Another parent at the meeting, Don McMahon, described his son Connor's grueling 12 years with severe and relapsing leukemia, which started when he was 3. McMahon displayed photographs of Connor, bald and intubated during treatment.

A year ago, the family was preparing for a bone-marrow transplant when they learned about the cell treatment, which Connor then underwent at Duke University. He has since returned to playing hockey. Compared with standard treatment, which required dozens of spinal taps and painful bone-marrow tests, the T-cell treatment was far easier to tolerate, McMahon said, and he urged the panel to vote for approval.

A third parent, Amy Kappen, also recommended approval, even though her daughter, Sophia, 5, had died despite receiving the cell treatment. But it did relieve her symptoms and give her a few extra months. Sophia's disease was far advanced, and Kappen thought that if the treatment could have been given sooner, Sophia might have survived.

"We hope that more families have a longer time with their children fighting this evil disease, and our children deserve this chance," she said.

The treatment was developed by researchers at the University of Pennsylvania and licensed to Novartis.

Use will not be widespread at first, because the disease is not common. It affects only 5,000 people a year, about 60 percent of them children and young adults. Most children are cured with standard treatments, but in 15 percent of the cases — like Emily's and Connor's — the disease does not respond, or it relapses.

Analysts predict that these individualized treatments could cost more than $300,000, but a spokeswoman for Novartis, Julie Masow, declined to specify a price.

Although the figure may seem high, people with cancer often undergo years of expensive treatment and repeat hospital stays that can ultimately cost even more.

Because the treatment is complex and patients need expert care to manage the side effects, Novartis will initially limit its use to 30 or 35 medical centers where staff will be trained and approved to administer it, the company said.

As to whether the treatment, known as CTL019 or tisagenlecleucel, will be available in other countries, Masow said by email: "Should CTL019 receive approval in the U.S., it will be the decision of the centers whether to receive international patients. We are working on bringing CTL019 to other countries around the world." She added that the company would file for approvals in the European Union later this year.

The treatment requires removing millions of a patient's T-cells — a type of white blood cell often called soldiers of the immune system — and genetically engineering them to kill cancer cells. The technique employs a disabled form of HIV, the virus that causes AIDS, to carry new genetic material into the T-cells to reprogram them. The process turbocharges the T-cells to attack B-cells, a normal part of the immune system that turn malignant in leukemia. The T-cells home in on a protein called CD-19 that is found on the surface of most B-cells.
The altered T-cells are then dripped back into the patient's veins, where they multiply and start fighting the cancer.

Dr. Carl H. June, a leader of the University of Pennsylvania team that developed the treatment, calls the turbocharged cells "serial killers." A single one can destroy up to 100,000 cancer cells.

Because the treatment destroys not only leukemic B-cells but also healthy ones, which help fight germs, patients need treatment to protect them from infection. So every few months they receive infusions of immune globulins.

In studies, re-engineering cells for treatment sometimes took four months, and some patients were so sick that they died before their T-cells came back. At the meeting, Novartis said the turnaround time was now down to 22 days. The company also described bar-coding and other procedures used to keep from mixing up samples once the treatment is conducted on a bigger scale.

Family Shorts

Feast your eyes on Quinn Catherine Ray Riel, all 8 pounds 13 ounces of her.

There will be much more information in next month's edition of the newsletter