

The Button Behind Her

My fear is that my daughter won't get her stem cells before Putin starts a nuclear war; she will be left here with nothing in her bone marrow. If she gets the transplant cells, we have two days at least after that. We could hope that she might make it with those cells from the nineteen year old, if she doesn't get an infection. Even if we have to run out on to the street if a bomb blasts Boston, we would run with some chance. There are always those stories of how, against all odds, on and on... The odds of making it through the first month after transplant without the drip and drugs in the hospital are slim. Of course, the hospital would be one of the first on Putin's list, here in a major city on the East Coast- a strategic hit. Last night, Putin said that he was removing holds on his "nuclear deterrent," whatever that means. I get the gist-he is throwing around the one word that terrifies the world and me.

So, I imagine, as I walk from the Boston House for Families in the crunchy snow, what I would say if I had a coffee with Putin. First, I would let him know that I am open to understanding his way of thinking, and I have respect for other cultures. The West is disrespectful and arrogant for bombing Baghdad and invading Afghanistan. Why should the West see this take-over in the Ukraine as any different from our own invasions? These people in the Ukraine are Slavic, and they sit at the Russian border-not half way across the world. Yes, Mr. Putin, I see why you feel slighted. I mean, the least we could do is to

invite you to coffee, like normal, umm, human beings. So, isn't that really all that you are asking for here- some casual banter or maybe a bit of warmth from the NATO allies?

I learned to negotiate this same way with the medical "Overall Survival" vs. my "Quality of Life" argument. Most of the doctors, including the one who gave us a second opinion, the former Head of Pediatric Leukemia, do not mention life happiness for Celeste. We both know that the "Q of L" is not represented fairly in the studies. It is "down the line" and subjective, and not a notch of success for researchers doing the studies. The focus is on OS, where seven months alive past a chemo treatment or transplant is a four star rating. If a patient has itchy skin over her entire body for the rest of life or has no babies, it is not as important as being alive for a certain amount of time, possibly just months more than with another drug in the previous study.

The syringe is empty, so the beeping starts. It won't stop until I find the remote control. I avoid contact with objects that might contaminate Celeste, so I say, "Behind you." She fumbles and grabs it behind her head on the mattress. She pushes the big "Nurse" button by feel.

Her stem cells arrive in a bag hanging off an I.V. pole. The nurses make a big hoopla and bring in a hand-made sign, "Happy Transplant," and they tape it the bulletin board. I am thrilled too to see that 1,100 ml bag of blood cells, with its full array of red and white ones along with platelets for clotting. The teen donor produced at least three times the average volume of cells, so we are encouraged.

Celeste's face puffs up right away, and she gets red ears and lips. Her eyes become glassy as she absorbs the cells into her blood stream. I am relieved that she has the cells in her before Putin attacks the U.S..

MSN News Reports Russian Forces Invade Mariupol

The next morning the dreaded pain and burning in her back, abdomen, throat, and head begin as the chemo. drugs, given during the last week, kill and suppress her immune cells, so that her body accepts the donor cells. She touches her head often, hoping she will keep a few downy hairs that had grown over the last three months during the immunotherapy from pre-transplant treatment. We are doing this transplant to prevent her leukemia from coming back. The doctors agree that a transplant is the only chance for survival from a relapse of acute lymphoblastic leukemia.

MSN News reports today that the Russians shelled the Chernobyl Nuclear Power Plant, and no one fights back.

All but one reactor has been turned off in preparation for the Russians to take over the plant, but that one reactor could have a meltdown if it doesn't have electricity to cool it.

"So I get it now Vlad. The cities don't really mean much. The nuclear capabilities in the Ukraine are what you worry about-they're right next-door.

That must be quite a source of anxiety for your people. I see how urgent it is for you to level things out, like balancing a teeter-totter. You know... this board on a... " I make a triangle with my thumbs and pointer fingers. "The board goes up and down." My flat hand moves in the air to show him. "The kids play on it," I say. He nods.

Celeste has a fever. "We are starting some antibiotics, and we're doing blood tests," the nurse says. I look at her head and the blond hair pulled up into a knot at the top. She has the nurturing quality that is familiar now, even though her facial expression is covered by the mask and goggles. I have learned to accept the best intentions of others. She says she is giving Celeste a bolus of magnesium, so she will be on a heart monitor for a while. This is the same treatment I received for preeclampsia after Celeste and her twin brother were born. Magnesium is quite safe. It is usually retrieved from ancient sea beds, like those in the Mediterranean. We use this up when our bodies are under physical or emotional stress. Is it possible that all of this illness is just because we don't visit the seashore enough? Isn't it old wisdom to send the sick to recuperate and revitalize on the beach with the sun warming their skin and their lungs breathing the fresh air? I have thought of thousands of possible causes and remedies for leukemia during the last four years that this disease has occupied our lives. I store the information from personal observation and research articles in my head. I will one day spit out a ticker tape with all of the dots and connections in a final readout. We will all sigh, "It is so simple, and it has been right in front of our noses all along."

Putin and Zelensky agree to a cease-fire, so that civilians can flee Mariupol and Volnovakha. However, Zelensky says this morning that all the civilians have run back to their covers because the shelling is still going on.

“But Vlad, you do see that it is common that kids don’t want to be friends. I know that you offered to be friends with the US. You smiled at the summit because you meant, “Let’s be friends” and “Do you want to play?”

I notice more raw, rash-like skin underneath Celeste’s arms again this evening. I don’t say anything because she is about to fall asleep.

The big decision for today is the blockage in my daughter’s bowels. The doctors confirm constipation by doing an x-ray. It shows a mass centered in her colon that they say has to come out soon or it could contaminate her with e-coli. My remedy for this has always been to give her a few dried organic apricots, but this fruit is thin skinned, so it might be full of germs that she can’t fight off. The chemo treatments and the total body irradiation wiped out her immune system intentionally so that she would accept the stem cells and avoid graft versus host disease. There are so many fronts that we were fighting that it just seems like a game of catching the side effect before two more sprout up. When this transplant was first described to me I saw an endless list of assaults and damage on Celeste’s frail body; the non-functioning ovaries, the lung and heart weakening from the radiation, and the cataracts. I had no idea of the expanding list that we fight each day here. We have

the constant fight to keep her ANCs, the infection fighting cells, high enough for her to live, but low enough to accept the donor cells. We are on a treadmill of fending off infections and fevers; Tylenol lowers the fever, but harms the liver. Keeping enough nutrition in her body is an ongoing struggle. The intravenous feeding contributes to constipation, and the morphine stops the colon muscles from contracting properly. The antibiotics wipe out most of her intestinal flora, and the low bacteria diet prohibits her from eating most fresh vegetables like carrots, and cucumbers.

Two of her fluids bags are empty, so we have a persistent beeping in our ears. She pushes the button for the nurse. She pushes the button again.

The Russian forces are three miles from Kyiv. Zelensky claims that his Ukrainian fighters are ready.

“My son wants to be friends with everybody- the guy who drinks beer in the lawn chair at the beach and the checkout person at the Food Coop. Everybody. But, they do not always want to be his friend. Some say that he is annoying and loud, but others predict that he will be mayor of our town one day. I remember, Vlad, when my son was not invited to a birthday party at a classmate’s house. The rest of the kids went. He cried and cried. That is how it is here in America. People are individuals. Kids choose who they want to come to their parties. It is different for you in your country.”

I always choose rest or a good time on a bicycle ride first before relaying any upsetting news to Celeste. I pretend that I don't notice some things so that she can have some extra time in peace. But, by the next morning it is obvious that this horrid rash is all over her body-raised pin pricks of red on top of a background of pink, like a sunburn. There is no red on her face, luckily. Two doctors come in to take a look. They didn't know what it is, but they say that it doesn't look like the rash from Graft v.s. Host disease. "We see rashes on many of the patients in the Stem Cell Unit," they lament. Celeste responds, "The wipes," in her weak voice from under the cave of blankets. I know immediately that she is right. I ask her to let me pull open her gown in back. Her shoulders and lower back were swollen and shouting, but there is clear skin inside a ragged outline in the center of her back. I always offer to help her wipe her body with the disinfectant wipes in the gold package that she uses instead of a shower. She says "no" every time because she wants to feel self-sufficient. I ask her if she used the wipes on her face. She nods, "no".

"So Vlad, you won't believe this, but I had a Russian boss one time back in New York. He started a college in Brooklyn, and I was one of the teachers there. I had students from Haiti, Thailand and lots of place I never heard of like Uzbekistan, Khazistan. The best thing about that college was the holiday party. I have never seen anything like that for the employees here in the U.S.. Everybody was invited-girlfriends, secretaries, administrators, parents. I mean it was a real party. I took the train out to Sheepshead Bay and walked to the big Russian Restaurant. It had a stage in front of long tables connected

together, each with an open bottle of Vodka for every two people.” We both smile as we imagine the scene.

“Look,” Celeste says. I turn toward the window. I see two men, then three. They touch the grey barren limbs of the tree in the pot in the hospital roof garden. The garden is off limits to the patients now. A sheet of snow might fall off the roof and hit a person below. “I want to go out there” Celeste pleads.

“ We all heard that you ride a bear, Vlad. They seem broader than a horse. How do you stay on?”

“Not hard-just hold on. That’s all,” he says.

“Bears can be pretty stinky. Sometimes I smell them when I’m hiking, “ I say. He laughs.

Celeste has diarrhea. I tell her to eat bananas. I learned while traveling in Mexico that they cure any problem –too much liquid in the bowels or not enough. It is hard for her to enjoy food because her mouth lining is so destroyed that the taste buds don’t work. She must be hungry though. It has been almost two weeks since she wholeheartedly consumed a meal. They have robbed her of everything.

I feel my resentment rise, but this is what I signed on to. This is the treatment that the doctors say will make the best OS. I signed on, consented, and so did she. She wanted to live, and I wanted her to live and be happy and have full health and enjoy high school and maybe have a child. Her ovary is now in Florida-frozen at the

storage facility, waiting. I don't know what will be the tipping point of that next decision; when to put her ovary back in her body. When is the precise time that we want to attach the frozen slices of ovary onto the non-working ovary left in her body? Can she just say, "I feel like having my ovary back? I want it back. It belongs to me."

MSN reports Russians hit a couple of hospitals and a theater where civilians were taking refuge.

Although Celeste is weak and struggling, the docs say we can leave today, so we shift gears and begin the move. It takes all morning to prepare, and we have to wait for Celeste's temperature to go under 38 degrees Centigrade for a full 24 hours. We pack the clothes and all of the boxes of colored pencils and drawing pads she collected over the last month. We throw out half-full cartons of Ensure, water bottles, and lotions that have been sitting around.

We are out of the hospital, and she continues taking medications and checking her temperature in our small house nestled in the woods. We watch for side effects of the medications. Celeste's shaking hands are hard to miss, even from across the room. Holding a pen or picking up a piece of toast reveals her brain cells sitting at the bottom of trench, trying to relax, but still sensing danger.

Ukrainian officials say that they hit a Russian naval ship yesterday with a Neptune Missile, but Putin claims that the warship had a fire onboard that

caused munitions to explode.

We have been home for a couple of days and Celeste's forehead feels warm, so I call the "pediatric oncologist on-call" at Dartmouth, who sounds half asleep, to report her status. Our second call with the report of a 101.2 temperature requires furious dressing and packing. We hope the car will start and not break down on the ride to the hospital. We have a window of one hour to get antibiotics into her body so that an infection doesn't get a foothold. These fevers seem alive, each with their own personality and traits. We take them seriously and attend to them at once. My own body has learned to perk up into a state of high alert and focus to prepare all details of the ride. Most all of the visits to the E.R. are at night because the fevers are the highest at that time. If we leave without the thermometer, we back the car up and Celeste hobbles back inside so that we can monitor the speed of the approaching heat in her body during the ride.

The moon is brilliant in the center of our windshield. It glows above foggy hills in silhouette with mysterious stretching clouds behind. We are the only ones on the road. Our night forays give us a rare glimpse at the beauty of the austere landscape and unmarred highway that connects our small town with the nearest city with shopping, schools and a hospital. The day drive and the night drive are astoundingly different in atmosphere and lighting. It is as if we are chosen to see this part of existence that is reserved for special guests, like astronauts exploring the dark side of the moon.

We arrive at the Emergency Room in Keene at 4:55 am. It is sleeting slightly outside and the room is empty except for a longhaired young man under a hooded sweatshirt in front of us at the intake window. He goes on and on with registration details that he appears to think are very important. A girl from behind walks up to usher him on. It seems as if she is the girlfriend, but the space between them throws me off. I signal for Celeste to come up to the window. I answer the nurse's questions quickly; she says that someone will be out to get Celeste shortly.

I see one of the double glass entry doors open slowly and Vlad walks slowly in. He is favoring his left leg, as he does most of the time now. He makes a slight semicircle as he pulls one leg around to meet the other. His face is solid as always, with no sign of discomfort. He allows an elderly couple to pass as he stops to sit at our table. I smile and comment, "so glad that we could get together today, Vlad.