The Girl with the Mechanical Leg

Loreen Niewenhuis

You wait for the shuttle to take you to the fields to U-Pick blueberries. The day is warm. You scan the high clouds for signs of rain, but it seems to be holding off for the moment. As you turn, you notice a family approaching. They look as if they just stepped out of an ad for The Gap, the model parents and three model kids: two young girls and their toddler brother.

The younger of the girls, the middle child, catches your eye. You notice the curly, sun-blond hair, the pudgy cheeks, the bright blue eyes, so it is not the first thing you see. Only when she walks with a hitch in her step do you look at her legs and are astounded to see a mechanical leg mismatched with her perfect one.

The leg is titanium, you are sure of it, bright orange and brilliant blue. The different colored parts hinge together at the knee. You see her little tennis shoe with the dark purple sock on the end of the mechanical leg and you imagine a perfect little girl's foot laced up inside of it. Then it strikes you how impossible that is.

They are there to pick blueberries, too. You can tell that they are new to this because they wear their model clothes and it has been raining all week, which means the fields will be muddy, the berries swollen and bursting with juice. A worker gives a picking bucket to everyone, even the girl with the mechanical leg. You notice the dad move to hold her bucket for her, but then he stops and, you are sure, reminds himself not to coddle her. Don't coddle.

The tractor arrives pulling a flatbed wagon to take everyone to the field. On the slow, bumpy ride, you smell the tractor exhaust and the muddy earth. You pick out the deer tracks between the rows of blueberry bushes and wonder how the little girl lost her leg. You wonder if the loss of the leg shattered the family into pieces, or if they were the type that grew stronger because of it. You wonder if the girl with the mechanical leg was diagnosed with a Ewing's sarcoma, if that is why they took the leg. And then you remember the other girl you knew with Ewing's, a patient you helped treat years ago.

She had just turned sixteen, just learned to drive, when she came to the oncology group where you worked. You were astounded that you would be treating a kid. The treatment that your group performed was radical and toxic so you knew it was probably a last hope measure offered to the girl, the sixteen-year-old girl. You were told that she wanted to see the lab. A few of the patients treated by your group insisted on seeing the lab, learning about the procedure, and—you were certain—checking you out to make sure you were competent to hold their lives, quite literally, in your hands. You answered their questions fully, honestly, scientifically:

You had gone to the hospital library to read up on Ewing's sarcoma and how many patients had undergone this treatment. There were only a handful of cases; the results were not encouraging. You wondered why they were offering such a radical treatment when it didn't seem to be working. Then you remembered that this disease could erode a limb in a matter of months, and the rest of the child soon after if it wasn't stopped. You prepared the lab, wiping everything down with disinfectant, straightening the data binders, then setting out the supplies that would be used to gather, process, and freeze the girl's bone marrow so her precious cells would be spared the cancer-killing treatment that the rest of her would have to endure.

You would explain to the girl and her parents how you would protect one little part of the healthy her: some of her bone marrow. You would care for it, separate out the part without which she could not survive. You would freeze it so that the cells would be preserved, then you would bring the frozen cells back to her bedside. You would be there that day after she had endured four days of intensive chemotherapy and thrice-daily radiation treatments. You would be there on the other side of hell and would, at her bedside, thaw her cells, insert them back into her, and they would find their way around her ravaged body and back inside her bones. The cells would begin to divide again and the offspring of these cells would re-populate her blood with fresh red and white cells so that she could live. You would explain that most of the bone marrow in her body would be killed by the treatment she endured, and that is why we take out some bone marrow and freeze it before the treatment. To protect it, then give it back. You would tell her: “This is my lab, this is my job: to hold your life in my hands, freeze it, then to resurrect it and give it back.”

You held the door to your laboratory open for the family, the girl on crutches and her parents with their hollow eyes. She looked younger than sixteen, probably because she was so scared. You remembered that you were there to give her confidence in you, in your expertise, in the treatment itself. You could tell when people were familiar with science, and when they were not. The frightened parents looked around the laboratory and you knew this
was a foreign place to them. They had never traveled here, didn't know the language, the customs, even the exchange rate. You noticed that the girl was not very stable on her crutches, and you looked at the leg.

It was swollen from the knee down, and the calf—what you could see of it—was purple. You had seen pictures of this sarcoma in the journals, but they didn't do it justice. You really need to see one, to see a young person—a kid—tottering on crutches, trying to balance this leg that has turned on her, swollen to the point of bursting, turning the color of death—not the purple of a bruise, but a deep black-purple—to really appreciate the power of this cancer.

You know that doctors usually, routinely, cut off the limbs of kids with advanced Ewing's sarcoma. Sometimes they try chemotherapy, maybe some radiation, but then they bring out the saw. They put the kid under, tell the parents to suck it up, that it is the leg or the kid's life. The parents always choose the kid's life, the rest of the kid's life, their child's life. They vote to sever a part of the child in order to preserve the majority. The vote is always unanimous.

A nurse will carry the severed limb down to pathology and plunk it onto a stainless steel table. While the rest of the child is still asleep on the operating table, the pathologist will 'test the margins,' examining the tissue under the microscope and hope that he sees only normal, healthy tissue. If he sees Ewing's sarcoma—even a single cell in a field of tens of thousands of cells—he must call down to the operating room and tell the surgeon to cut off more of the limb because he didn't get all of the cancer. Then the surgeon must cut higher on the limb that has clamps on the major vessels so the child will not bleed out, the child lying asleep and unbalanced on the operating table now. The surgeons are experts at dark humor—if the surgeon has done an ungodly thing by removing part of a limb—but not enough of it—to save the child.

And the surgeon, the surgeon must cut higher on the stump of the limb. He concentrates on the task, not on what he will tell the parents, not that removing the leg above the knee will limit the child's abilities in the future. The surgeon tries to preserve the knee. The surgeon always tries to preserve the knee. Many kids hardly miss a step—surgeons are experts at dark humor—if only they can keep the knee. The surgeon will curse, but when the pathologist tells him that there is a microscopic field completely infiltrated with the sarcoma, the surgeon will make an incision above the knee and he will regret having to do so.

The lab will keep microscope slides on file of the margins, the tumor, miniscule portions of the leg, and the rest will be ground up in a massive grinder and processed as hospital waste. The child will be light one leg and the hospital will have waste.

You swivel a chair for the kid to sit. She stretches the leg out in front of her. It is cocooned in soft, grey foam held loosely in place with padded straps. The mother chatters away about how the daughter is an athlete and that is why they are doing this procedure, that they want to heal the leg, that she is an athlete.

You notice that the dad is not able to look at the leg, that he is stricken, completely stricken and the mom chatters. The kid is looking at all the equipment in the lab. You can see that she wants to know how this works, and the mom chatters, basketball, softball, medals, forward, pitcher, chatters, practices, scholarships, university, teams, athlete, chatters. And the dad is stricken, unable to feel the strength in his muscular arms.

You want to answer the kid's questions. It is her leg, it is her cancer. You lift your chin to the kid giving her permission, but the mom chatters on, so the kid just points to the five-foot tall, stainless steel tank. You walk over and rap on it with your knuckle which stops the mom's chattering. You explain that the tank is filled with liquid nitrogen, which is at negative one hundred and ninety-six degrees Celsius—that's negative three hundred and twenty-one degrees Fahrenheit—the parents love the numbers, they cling to the precision of the numbers. You tell them that liquid nitrogen is used to freeze the bone marrow cells in a special computer-controlled chamber. Then the frozen cells are submerged in the liquid until the patient is ready to get them back.

The kid asks how they are removed. You know that your boss, a wonderful oncologist, has explained this to the child and her parents, but you also know that they can't process everything while they are questioning the concept of justice and truth and god-why-my-child?, so you pull out a bone marrow harvest needle and begin your speech with, “while you are asleep in the operating room…” But you can tell at once that this is too much. (They don't understand the language—This custom is too foreign—The exchange rate too high!) This gigantic needle with the handle for piercing the bone before attaching a huge syringe and sucking—literally sucking—the marrow out of her bones, the edge of her hipbone, the iliac crest.

This is too much, this large needle with the handle, so you move on to the laboratory portion of the process. You point to the large centrifuge. You explain that you will spin the girl's bone marrow harvested in the operating
room under general anesthetic. You add: “You won’t feel a thing,” because you know that after surgery she will be given pain meds and a wonderful anti-anxiety drug that has the magical side effect of disrupting short-term memory so that most of her time in the hospital will be fuzzy, dreamlike, or, mercifully, erased completely. Oncologists love this drug and dispense it wildly.

You tell her that you will be the one to carry the bags of her marrow from the operating room to this lab. You give her your confidence. You are wearing your newest lab coat, the one with your name embroidered above the pocket, the one that has the initials of your newest advanced degree. You gesture to your lab, to the expensive and shiny equipment, and end with the embroidered name facing the shattered family.

This is where you give them confidence in the cumulative power of all of this—the science, technology, the sharp angles of stainless steel and the crackle of ozone from all the electrical outlets—to beat back the death in her leg. You glance at their eyes and you see that the mom believes, that the dad wishes he could, and, surprisingly, that the kid wants to be you when she grows up. You will yourself to forget the statistics that tell you that she doesn’t have a very good chance of growing up at all and you will yourself to ignore the swaddled leg that points at you like an accusation.

You streamline the presentation; you talk about the freezing and the cryoprotectant solution. Cryoprotectant. This puts color back into the parents’ faces: something that sounds like it will protect their child, something they obviously have failed to do because she has death living in her leg.

You hand the glass bottle with the clear liquid to the girl. You explain that this compound will protect her bone marrow cells during freezing so that they can live again within her bones and help to restore her. You tell her that this solution, when put back into her with her cells, will make her breath seem like she has been eating cloves of garlic! The compound does its job, then it leaves the patient’s body mainly through the lungs. It is an odd fact, the garlic smell, that you see amuses the kid and parents alike.

You wonder where their coats are, then realize that they left them in Oncology and will have to go back up there before heading out into the cold December afternoon. You wish it was brighter outside or warmer or that the kid wasn’t going to have to go through this right before the holidays. You want to wish that she didn’t have cancer, but you know it is too late for that.

The girl appreciates the fact that you shake her hand first. You tell her to stop by if she has more questions only because you know that she won’t. You dread treating this kid. Dread carrying the bags of her bone marrow harvested by puncturing the crest of her hip bone, her iliac crest, you dread spinning it down, pulling out the white cells, counting them under the microscope, mixing them with the cryoprotectant and freezing them with the computer-controlled freezer, then slipping them, submerging them into the liquid nitrogen, watching the bubbling of the sub-sub-sub-freezing liquid until they are at the temperature of the sub-sub-sub-freezing liquid.

But most of all, you dread having to take the frozen bone marrow to her bedside, thawing it there over the minutes, hanging the bags and watching the red liquid stream back into her. Because, when you do this, there will be hope in the kid’s eyes and in the eyes of the parents and you will have to look at this hope and wonder if they know that this is not supposed to work, that the only reason their daughter, the athlete who just learned to drive, is a candidate for this treatment is because the surgeons were not able to cut off her leg in time to save her.

Of this, you are relatively sure. You could read her chart or ask your wonderful oncologist boss if this was the case, her case. But then you would have to ask your boss if they knew this truth, if the shattered family, the parents and the kid, knew they weren’t saving the athlete, their child, that she probably, statistically (My god, it’s advanced Ewing’s, people—You fucking cut off the leg to save the child—The vote is always unanimous!) was going to die and therefore, by some sort of medical ethics committee default, was a candidate for this high-risk, high-dose, high-mortality treatment.

You do your job. You process and freeze the bone marrow. She has a good cell count and you are glad for her. You hope that she can get out of the hospital quickly. You freeze her bone marrow and count off the days until you give it back to her. You circle the date on the calendar and you put her name there. You usually write the numerical designation for the patient, but you know this kid, you know her name, you write it: Bobbie.

This, alone, was probably too much information for you to take in about this kid once you learned about the strength of the death in her leg, but you learned so much more when she came to your lab. Like she is an athlete, like the way death looks in the leg of a kid. You learned she has brown eyes and curly hair that she shakes back when it crowds her eyes or when she’s nervous. You learned that she has a head for science and that she wants to be you when she grows up.

On the circled day, you remove her three bags of marrow from the liquid nitrogen, pull out the metal canisters using the thick, padded gloves to protect your hands from the burns you would get if you touched them. You put the bags into a foam cooler and place the cooler on a cart with a heated water bath. Then, you go to her room.
This is usually the only time you see the patients, the “after treatment” day. But you saw Bobbie before, so you can see what the treatment has done to her, her face, her eyes, the curl in her hair. The meds have her partially submerged, but she still tries to smile at you and she tries to watch you do your job.

In a soft voice, you explain to her what you are doing. The dad has to leave the room. It is too much. You watch him remove the surgical mask he wore to prevent the spread of germs to his little girl with death creeping up her leg. In the hall, he grabs his knees and gasps for air. You look at the mom still sitting dutifully at the foot of the bed. Tears run out of her eyes and down under her surgical mask. You nod to her that you will be here for this part, that it is okay to leave and she, mercifully, rises.

The mom peels off her mask and embraces the dad in the hall and they cry on each other. All of their hope is invested in this moment. They have conferred healing powers to the frozen and resurrected cells. It is not uncommon; many patients do it. It is understandable to think this way after four days of high-dose chemo and thrice-daily radiation. The thawing cells in a warm water bath on a cart at their bedside is the physical proof that the treatment is over and recovery can begin. The faces of the parents are framed by the square window in the center of the door.

You hang the first bag of thawed bone marrow cells and hook up the line so that the red liquid flows into her vein. You smell the garlic scent almost immediately. It surprises you every time. The kid runs her tongue over her blistered lips, she tastes it and smells it and looks up at you with a smile. “Told you,” you say.

“Cool,” she whispers.

You tell her that she had a good cell count, that you froze many cells, that hopefully they will get back to work and she can get the hell out of here. She smiles at you cursing, like a secret pact between you, and then she rolls her eyes at the room, at her predicament, at the death in her leg. She actually looks at her leg, free from the foam cocoon, cradled on a pile of pillows on top of the bed. You look at it, too. It is darker, more menacing, the black-purple of overripe blueberries. She says something like “I’m going to beat this” and then she looks at the red liquid rushing into her veins then, finally, at your eyes. You had enough time—those few seconds while she was looking at the bone marrow—to arrange your face so that she sees only confidence there.

You hang the second bag. Your boss visits while it drains and the parents retell the story about your boss who is saving the life of their child, how she said that their daughter had “lots of cells,” “a very high cell count,” strong cells that will cure her. They cannot bring themselves to name the disease or even call it cancer even though its presence is strong in the room, you can smell it now, the smell of death emerges over the garlic that the kid is exhaling with every breath. There is death in the room, and it is not coming after the old or the infirm, but after the young, the athlete who just learned to drive. The cards from her teammates, her classmates, her teachers crowd the windowsill. They are all pulling for her; they speak of her miracle treatment. They, too, are afraid of naming the disease. Sometimes, you’ve found, patients and their families will be able to use the word carcinoma, but they will not, under any circumstances, use the word cancer.

They latch onto more friendly words, beatable, more understandable, and they hold tight to them even though these words that they cling to like flotation cushions are really anvils that will speed them to the depths of the sea, devoid of all light, their lungs imploding on the way down, their ribs cracking under the pressure, the sharp shards of bone puncturing their hearts.

They do not know. They dare not know. You understand this. Everyone in this field understands this. There is no way to tell them that they will drown with these words the same way as if they embraced cancer or tumor or malignant. Or even if they embraced the word death.

The last bag drips its last drops into the line. You make a show of tilting the bag and intoning “good to the last drop” to lighten the mood. You didn’t think they would laugh, but the family, the shattered little family giggles, then howls with release. There are pieces missing from this family. Even with time and patience and glue, they will never be whole again.

‘My little athlete will be cured,’ the mom thinks while laughing.

‘I will feel the strength again in my arms,’ the dad thinks while laughing.

‘I will beat death,’ the kid thinks while laughing.

‘Look at us, we’re laughing,’ thinks the little family.

The smell of the parents’ hunger is pungent over the garlic. You will your wonderful oncologist boss to give them something, something to feed that awful hunger. She speaks about Bobbie getting home in time for Christmas. She nods at you when she tells the parents that the cell counts were high, some of the highest ever harvested, that there are three bags to reinfuse. And the hunger is sated. The parents look to the ceiling of the hospital room and murmur gratitude to their god and your wonderful oncologist boss races from the room. Her job is done.

You are left there while the last bag drains into the kid. You listen to the parents retell the story about your boss who is saving the life of their child, how she said that their daughter had “lots of cells,” “a very high cell count,” strong cells that will cure her. They cannot bring themselves to name the disease or even call it cancer even though its presence is strong in the room, you can smell it now, the smell of death emerges over the garlic that the kid is exhaling with every breath. There is death in the room, and it is not coming after the old or the infirm, but after the young, the athlete who just learned to drive. The cards from her teammates, her classmates, her teachers crowd the windowsill. They are all pulling for her; they speak of her miracle treatment. They, too, are afraid of naming the disease. Sometimes, you’ve found, patients and their families will be able to use the word carcinoma, but they will not, under any circumstances, use the word cancer.

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And you unhook the empty bag, hook up the saline solution and open the line so that the last bit of red bone marrow mixes with saline, swirling, turning pink where the solutions meet. You watch the last of the pink, then the light pink travel into the kid’s arm, then watch the clear saline push the last remnants of the bone marrow cells under her skin. Then you gather everything onto your cart, nod good-bye to the family, their eyes filled with tears of relief, and you get the hell out of that room.

You let them enjoy this moment of love, of relief, of pure delusion and you hurry back to your lab where you have the illusion of control.

Over the next week, you punch up Bobbie’s cell counts daily on the computer. They will not recover this early, but you do this to show that you are on her side. You do not discuss the case with your wonderful oncologist boss. You only speak of new cases, or old successes. On day ten, her white blood cell count begins to rebound and you show the counts to your boss who is surprised and says: “Well. Look at that. She might actually get to go home for Christmas.”

You prepare the lab for your absence over the holidays. You order a fresh tank of liquid nitrogen and top off the freezer. You check all of the sensors and alarms, wipe everything down with disinfectant, and order fresh supplies for the new year. Bobbie will go home tomorrow, the first day you have off for the holidays and you are glad for her.

Over your holiday, you dare to hope good things for her. You imagine her surrounded by her family and teammates and classmates and teachers. You imagine the extra presents that she will get because she has defeated death. You imagine her at her prom and her graduation. You are able to enjoy your holidays because you can conjure all of these things for Bobbie. You get really good at it. You see her at college on a sunny day, lying on the grass in the commons, studying for her biology test while getting a tan on the back of her legs, both of her legs.

When you return to the lab, you check the computer for Bobbie’s final white count and you see that she never left the hospital. You pick up the phone to call your wonderful oncologist boss, but, just then, she enters the lab asking about your holiday. You cannot do this, cannot make small talk until you know. You answer her questions with only one word: Bobbie? Your boss scoots a chair across the shiny floor until she is knee-to-knee with you. She tells you what you already know: Bobbie never left. She tells you what you feared: The treatment had no effect. Then she tells you what you could not have imagined: They took the leg yesterday, anyway, probably without helping her because, even though they took it off at the knee, then the mid-thigh, then the hip, they did not get it all, the margins were not clean (the margins must be clean!). She assures you that it had already spread throughout her body when she first came for treatment, that it was important to try to kill Ewing’s sarcoma with this treatment. That when enough cases fail, then they will know, for certain, that it does not work. You know this. A certain number of cases must fail—people must die—to make absolutely sure the treatment does not work.

You ask: How long? Your boss touches your hand for a brief moment and answers: Not days, hours. Then she leaves and you are alone with your cell counts and your liquid nitrogen and your sterile lab. And she is still a wonderful oncologist boss—you know this—it is just a fucking awful business, this war with death. And there should be rules—exemptions—for kids.

You did your job.
You gave them confidence in you.
You gave them your confidence.
And then you realize that this is what a con man does.

You watch the little girl with the mechanical leg pick blueberries. Her older sister picks next to her and tells her she is doing a good job, but not in a condescending way because of the mechanical leg, but in a kind, big sister way.

The girl with the mechanical leg hops along with the hitch in her step and gets a little mud on her new sneakers as she reaches for a particularly large blueberry at the center of the bush. When she finally grasps it, she holds it out for her sister to see.

They smile at each other, then the girl with the mechanical leg shakes back her curly hair from her eyes and pops the berry in her mouth and bites into its juicy, blueberry goodness, the black-purple juice running down her perfect little chin.

Loreen Niewenhuis