

3/2001

“A mother’s body remembers her babies-the folds of soft flesh, the softly furred scalp against her nose. Each child has its own entreaties to body and soul. It’s the last one, though, that overtakes you

A first child is your own best foot forward, and how you do cheer those little feet as they strike out. You examine every turn of the flesh for precocity, and crow it to the world. But the last one: the baby who trails her scent like a flag of surrender through your life when there will be no more coming after--oh, that’s love by a different name. She is the babe you hold in your arms for an hour after she’s gone to sleep. If you put her down in the crib, she might wake up changed and fly away. So instead you rock by the window, drinking the light from her skin, *breathing her exhaled dreams.....*”(Barbara Kingsolver: The Poisonwood Bible, 381-82)

Please come with me on a journey back in time so that hopefully you can maybe understand what lies in the heart and soul of this mother. Let’s travel back to a cold December day in 1981, just outside of a hospital room in Utah and listen in to a conversation... “We need to tell her just how extensive the surgery was.” “I really don’t want to be the one, we have been hoping and dreaming for 3 years now, she will be devastated.” The two men walk into my room with the news I don’t want to hear, to tell me that the dream we had been pursuing the last two years might never come to be. Words spring from their lips....heavy involvement of the ovaries, we saved what we could, and then like heavy rain falling upon my ears, “it is questionable whether or not you will ever be able to have a baby”...silently a scream emerges from the very center of my soul, my thoughts speed in a whirling dervish, and I hear no more the words that were uttered to me that day.

Our journey now takes us briefly forward, 4 months to be exact, to an exam room “ Dr. Carl, I think that I am pregnant!!! “ “Now you know better than to get your hopes up, you know the results of your surgery, as well as the other fertility problems that were already diagnosed.” I plead, “Please check. I know that I am.”

Moments later, Dr. Carl’s twinkling eyes look up, the good news confirmed by the gentle smile, that by now is spreading into a wide grin, “...by damn, you’re right.” My soul soars during the next seven months, the memories of the tests, procedures and monthly disappointments fade from my mind.

Three years later, the joyous news is shared again, and son number 2 joins our family. I feel blessed to have our little family, especially because I

never dreamed that it would ever be greater than two. And then, oh blessed day, seventeen months later, “I can’t believe that we are going to have another one, how can this be, we never used the fertility medication, it must be a miracle.”

A few short months later, that miracle lay sleeping quietly in my arms. I can hardly believe I have a daughter, to complete our family. I softly hum to her and she opens her beautiful blue eyes, with the most incredible eyelashes and she begins to gently coo to the music. Time passes quickly when there are babies everywhere, but love and music abounds in our home. From the very beginning, this precious child’s eyes would light up and her little body would begin to move with the music. She never took first steps, she took dance steps. This dream child has such a strong, yes, even headstrong personality; she became the ruling princess of our castle. And she ruled her brothers with an iron hand. I remember the day when she was maybe 18 months old and her older brother would not do things her way, so she reached up, grabbed him by the hair on his head, and dropped him to the floor. But even back then, music could always tame this wild princess into a dancing fairy princess, her eyes would light up and the music would take her soul on its own musical journey.

The years quickly pass with pre-school, baseball, soccer, swimming and of course, dance classes filling our days. This beautiful princess is active with everything, and is only truly content when her schedule is brimming over the top of the calendar. She continues to be headstrong, good leadership potential, some might say. But I slowly begin to notice a change in her usually overabundant energy level, and something didn’t feel right in the heart and soul of this mother. And that fateful day, as she was putting on the finishing touches to her makeup before going on stage...”Mom, why do you think my eyes are turning yellow?” And so the next phase of our journey begins.

To slowly watch this once over-energized child turn into a tired, listless soul, unable to rise up to the music that had always been able to make her soar to my very being. But deep within those incredible blue eyes, the spark remained that only the music could once again fan into the bright fires of her dreams. The next several months were very trying as I watched this child struggle back to reclaim her life. The havoc that the steroids played on her once lithe body was especially difficult to watch. When once again enough energy returned, the fateful words came, Mom, “I want to dance.” To

watch her struggle to try to reclaim this body, to move even on the days that her joints ached, and her body was weary, was a testimony to the valiant spirit that lived within her. The spark in her eyes grew brighter as she began to hear the music again and it was able to once again feed her hungry soul.

And the journey continues... to know this child is to see her through the eyes of her mother and to truly begin to understand this princess child of mine is to know that *the music* is her heart and soul. Her very essence depends on being allowed to unleash her soul to rise with the strains of the music, because in the strains of the music she is able to find the courage to face another day, to have the will to continue the fight. How this journey will end, I'm not really sure. I just know that once again I am slowly seeing the energy drain from this child. And I know that the one thing that is able to fill her spirit is being able to drink from the well of music that has always been able to revive her spirit and that it gives her dreams the wings they need to survive. This is a child that needs not only to have her mind stimulated, but she needs to feed her soul and her dreams.

9/2003

The journey has at least been level at times, this beautiful princess has been able to move to the music, but daily it is becoming more and more of a struggle. Her body is not able to do the things her heart and soul wants to do. Her determined spirit will not give up...she so wants to live. We often will talk about her dreams for the future...she wants to be able to be a dancing mommy doctor... (We have laughed about this for years!)...the dancing of course is a given, that is just the essence of her soul...the mommy part makes me smile, she has always loved children, even thought she herself is one...she is always the one in charge and she very ably was able to run our home based day care when she was young. Every day she would plan the "events" for the day, whether it was a play school or a full on dance recital that included costumes, makeup and of course her own original choreography! She often says that she wants to become a doctor because she wants to be able to tell her patients that she really does understand where they are coming from, that she can relate to their experience. She says that she wants to be a doctor like her first hematologist ...Dr. _____ was a miracle worker...she was able to keep Jessica as active and as healthy as possible for a number of years. Eventually though even her magic was not strong enough to defeat the dragon that was trying to capture the heart and soul of this princess. I remember well her hospitalization in September of 2003. We decorated her room like a palace for a princess...we even had the

dragon, a septor and crown! Her father decided that she needed a knight to come a rescue her so the next day a huge poster of Vin Diesel adorned the walls, ready to battle this terrible dragon of disease.

As the years pass, the journey begins to climb up a steep mountain that never seemed to end...some days the road is steeper than others...at other times the road will level off very briefly, or even allow us to gently glide down hill for a very brief period of time. We just know that at the end of this journey there will be the castle and fairy tale ending that we have been hoping for ...that there will someday be an end for this difficult journey that our princess has embarked upon. Every day we continue to hope and pray that there will come a valiant soul, strong enough to slay this horrible dragon of disease and our beautiful princess will be released from its terrible grip.

July 25, 2007

I am sitting in my Wednesday meeting with my manager and we are discussing the unit concerns and the plans for the new graduate nurses that will be starting with us in 4 weeks...my phone rings and a voice says, this is _____, one of the transplant coordinators at the Medical Center. We think we have a liver for Jessica, but the surgeon needs to speak with you first...my heart stops beating for just a moment and I look at my manager and say in a whisper "it is the hospital"...those are the only words that I can get out of my mouth, I seem to have lost my ability to speak. A voice comes on the line, "this is Dr. _____, one of the transplant surgeons at the Medical Center...I see that Jessica is just 19 years old, is that correct." I answer in a very shaky voice, "Yes"...the voice continues, "I wish I had realized that before I called you, but she is #1 on the list (which we had no idea!) but I have some concerns about this liver...we have a 49 year old donor, but the liver has multiple liver cysts...she seems to be a match for your daughter"... this is the phone call we have been waiting for and I can't believe the next words out of my mouth..."Dr., we need to trade up, not down...I think we will decline this liver and wait for the next one"... I can't believe I just uttered those words...my manager is looking at me very quizzically waiting for me to tell her what is happening. I calmly thanked the doctor for the call and hang up. What have I done?!? Did I make the right decision...did I totally throw away any chance that Jessica had to ever receive a second chance at life...my thoughts are racing. My manager gently asks me if I am okay and I answer that I think so, but I can't believe what just happened. Have I caused irreparable damage to Jessica's chances? She gives me one of her big hugs and tells me that I should probably call it a day...yeah it has been A DAY! I am to meet Jessica and her brother at the movie theater to

see the new Harry Potter movie...how do I tell her what I have done? I call Alex and he is speechless...then he asks "what does this mean?" I answer that I don't know...probably that I have pissed off the hospital and that we will have to wait another 9 years for a phone call. As we sit in the darkened theatre I put my arm around Jess and try to explain to her about the events of this afternoon. She looks at me with wide eyes trying to comprehend the significance of the event...and then the movie begins. I watch her throughout the movie and as tears roll down her face. I can see that she is scared that we might have lost the chance but at the same time I can see the realization in her eyes that yes, she is so sick that she is #1 on the list at the hospital...

July 28, 2007

A typical Saturday, I am at work at the hospital and my husband has gone to the mine to help with the usual "crisis" that always seems to arise on the weekends in the processing plant. My middle son is at National Guard, and my oldest son is of course at work as well.

12:20 pm...my phone rings...Susan...this is the Medical Center, the name of the transplant coordinator escapes me...we have a potential donor for Jessica...the world has just stopped spinning on its axis...can this be happening again in the same week? The coordinator continues we need to have you here in 4 hours...I will give you until 5 pm...I tell her I have to talk with Jessica...she is over 18 now and needs to decide. I get her number and hang up the phone...I feel as I am in a time warp...I try to call my husband...he is in an area that does not have cell service...I quickly try and call the boys as well as my daughter-in-law...no one picks up the phone, I had wanted someone to be with Jess when I gave her the news and to have someone be there as she makes this life changing decision...I am left with no choice but to call Jessica...I slowly dial our number and Jess's very sleepy voice says hello...I quickly tell her the situation and that she needs to decide in the next ten minutes what she wants to do...yes, I am leaving work now and will be home as soon as I can. I tell her that I will call back in 10 minutes because we have to give the hospital an answer. I run to my office and literally throw everything in a drawer and grab the flowers, the three yellow roses that my husband had sent me just the day before. I calmly call my boss and tell her that I am leaving for the Medical Center and that I don't know when I will be back...she calmly replies..."what are you doing wasting your time talking to me? GO!!!" I run-walk down the hall and tell everyone at the desk what is going on, then the tears start to flow, mine and along with everyone else...and the time for prayers has begun. As I drive

home, I call Jessica and ask her if she has made a decision...and right there...in front of a local hotel she makes the decision..."yes Mom, I know that I need to...I can't continue like this..." such a brave decision made by my beautiful 19 year old, all alone to make this monumental choice..."Baby, I am so proud of you, I will call the hospital and will be home in 10 minutes..." The whirlwind has begun. I finally am able to get in touch with everyone by phone...how odd...was it suppose to happen that way? Was Jessica destined to make this decision on her own? I believe that is the case...it is the first step that she alone had to take to be able to crest the mountain that she had been climbing all of these years. Within 15 minutes of arriving home, my two sons and daughter-in-law (and baby grandson in the belly) arrive followed by my husband 10 minutes later. I quickly call Southwest airlines and yes, they can get us on the 2:45 flight. We literally throw things into a suitcase, but my husband will stay at home a do some laundry and catch the 8pm flight. The others are quickly re-working their lives so that they can be at their sister's side...I can not believe this is happening...and the race begins. We quickly get to the airport just in time to be pre-boarded only to find out that this was a full flight but miraculously there were two tickets for Jess and I...His hand is evident in this day...We board the plane to begin the next phase of our adventure

California 7/28/2007 4:45 pm

We made the 5 pm deadline with 15 minutes to spare! Glad that part is over. The kids are driving two cars down and will be here as soon as they find dog sitters and get gas in the cars. My husband is catching the 7:50 flight and he will bring the clean clothes...Saturday night is laundry night...the end of long work weeks and by Saturday it is pitiful what is left clean! We are met at the admitting desk by a delightful young lady...she says that she has never admitted a transplant patient before...I think that she is more scared and nervous than we are...we get through the paperwork and are then instructed how to get to Jessica's "holding" room and the process begins. I call Mom and Dad in Utah to tell them what is going on and get the phone number for some friends in the area so that Jess can get a priesthood blessing before surgery. I call them and they say that they will be to the hospital as soon as possible so that we can have the reassurance of the Spirit. Later in the evening we begin to see the parade of doctors...we meet the PA that will be assisting in the surgery, we meet the Fellow (who happens to be Greek, a good sign!?!)) and then we meet three of the transplant surgeons...Dr. B., Dr. B., and Dr. C...each one has gentle eyes and are very aware how frightened

and nervous that we are...it turns out that Dr. C will be Jess's surgeon...I feel, I know that she is in good hands. Soon after the family starts to arrive and the long wait begins...we sit up all night in the atrium just "hanging out" as a family, all of us recognizing that something monumental will be happening soon...it is so overwhelming to me to sit and watch this precious family of mine, they truly do love each other...the compassion and caring and especially the tenderness that they are showing to one another...I am so grateful that my daughter in law is here with us...I hope she now realizes that she is a true part of this family...the night slowly passes. Around 3:30 the nurse comes out and finds us...it is time for Jess to take her shower to scrub before they take us to surgery...it has been a long wait...and around 4:30 am on July 29th they come to take her upstairs ...she says her "see you later" not good byes to her family and with tears streaming down all of our faces they wheel her into the surgical holding area. I am thankful that I am allowed to go back and wait with her...soon the recovery team arrives carrying two cardboard boxes!?! , the large one for Jess and the smaller one for a young boy that will soon receive a new kidney...miracles do come in all shapes and sizes...even cardboard square ones! Dr. C approaches us and takes Jessica's hand in his...he tells her that with his hands and God's help...she will come out of this just fine...and then he gives her that radiant smile of his and we both know that his hands will be Guided and that everything will be as it should...

The surgery could be as long as 16 hours, but through the power of many, many prayers, Jess is finished in under 10 hours, and she did not even require any blood products...a miracle in and of itself! We are all anxiously awaiting her in the hallway so that we can catch a brief glimpse of her as they take her to the ICU...when she comes out...it takes our breath away...so many wires, machines and people tending to her...and in a fleeting moment they whisk her away...and we wait some more...soon we are allowed 2 at a time into her room...we only have a total of 30 minutes every two hours that we can be with her...so not like our local hospital where we can sit and watch her around the clock...we decide to keep her intubated over night so that she can rest...silly us...she sat up in bed, tubes and all and extubated herself by 6:30 the next morning! She wants to get out of bed as soon as they let me into the ICU...so this princess of ours is sitting up in a chair less than 24 hours after major, major, surgery! The transplant did not make her any less head strong...but that is a good thing for there will be days of recovery ahead... ..we had a few glitches in the hospital, the snapped JP drain, the dilaudid overdose and who can forget, the PROGRAF

reactions!!! We met many wonderful people in the hospital and Jess had great care but it is now time for our next segment of our journey... we now move into the apartment that will be our home for as many as 6 weeks...there we meet some fellow transplant recipients who will end up becoming like family to us...C and A, L and A...they have all been on similar journeys and are also perched at the edge of a new life...So many blessings have come out of this experience...the friendships we have made, the re-kindled relationship that has been established with my husbands' step-sister, our family and friends surrounding us with love, prayers and good wishes...we are so grateful...

Saturday August 25, 2007

We are finally getting to come home, three weeks sooner than expected but that is good! We are barely able to fit everything into the Jetta, but we do! It is with very mixed emotions that we take Jessica and her new liver back to Nevada, I hope "she" likes a dry warm climate! We get home to discover two WELCOME HOME signs plastered across the garage door, and to this day we do not know who put them there...and a house filled with hundreds of balloons...(I think my husband thought the balloons would distract me from seeing all of the dust bunnies hiding everywhere!) even Cassius had balloons tied to him as well as Montana and Jasmine (our dogs)...we are so thankful to be home...Sunday we go to the Make-a Wish annual duck races and Jess is able to proudly show her scar to S and to thank her once again for making her a wish kid...Monday brings a doctor appointment with Dr. M...who is crying as we enter the office...(we love this woman!) and then off in a plane to join other family at the beach house that a friend has so graciously allowed us to stay in for a week...a week to relax and recuperate from the last 4 weeks!

September, 2007

Back home to work, to school and to life...the journey continues... Jess has already started to the local community college...she intends on pursuing a career in medicine...I know that she will be an incredible physician. In my job I have the opportunity to see competent physicians and amazing physicians. I think Jess will be an amazing doctor ...caring, compassionate and most of all understanding. The school semester passes quickly. Jess has her ups and downs...energy levels and pain continues to plague her, but she continues to be valiant. Soon it is the end of the semester and she passed both of her classes! What an accomplishment...first time in

a classroom setting since 6th grade! Just days later another miracle occurs, our grandson is born...he is beautiful and everyone is so excited...but it is to be short-lived...just two days later we get a frantic phone call from the kids at the hospital...the baby has started having seizures and they will need to put him on a ventilator...our seasoned reactions kick in (what a rotten skill set that we have developed!) and we all race to the hospital...after a very long three weeks the baby is doing better and he is able to come home. Jess loves being an Auntie...I think she really relates to this precious little one...she understands the pokes and prodding that he has had to endure better than anyone else...Nothing makes Jess smile than having the opportunity to spend precious time with this sweet baby.

Soon it is time to return to school and another semester whirlwind begins. This time she takes three classes and once again passes all of them. Every day is still a struggle to overcome her lack of energy...but she keeps plodding along. The transplant doctors say it takes a least a year to recover from such a huge surgery as well as all of the many years that she was so sick.

July 2008

Has it been a year?!? Where did the time go? ... I know, two semesters of school for Jess and for me (graduate school), the baby arriving, family vacation and a quick trip to see the Utah relatives...it is now time to return to the Medical Center to meet with all of the doctors...Jess has been making a super hero basket for Dr. C. (He is a super hero, a very humble one, but none the less, a super hero to us!) and we have filled a basket of goodies for all of the hepatology and transplant staff to share. We also take some special gifts to some very special people...those who have touched our lives, transformed us...to never be the same. Jess spends much time deciding what the perfect gift would be for each...how do you ever say thank you for a second chance to live?...and then one day we stumble upon the angel bracelets...all bound together yet each one individual and unique...the perfect gift...Jess will keep two, one for her and one representing the angel who gave her the gift of life...the rest she will share with the many angels that have influenced her journey...if she ever gets the opportunity to meet the family of the angel who shared of herself...she will give the angel to them...we soon find out that there are far too many angels for one set of bracelets...we will need to get more...we are so blessed. The visit to the hospital was so amazing...we got to spend time with so many very special people. After the hospital visits, time to reconnect with our friends that have

experienced the same transplant journey...and where did we meet...Great America of course...Jess only wanted two things for her anniversary...a cake and the chance to ride on roller coasters! (forbidden since she was in 5th grade!) Both wishes granted.

Every day continues to be a celebration of life and of miracles...this princess, my wide eyed baby girl is now entering her third semester of college and is more determined to fulfill her dreams...And then another miracle...at her anniversary celebration her dance teacher invited her to attend a class...on August 4th, 2008, the dancing princess was able to put on her tap shoes and once again the music was able to touch her soul and that spark that had been missing for many years was now back in her eyes...quickly she adjusted her college schedule so that she could fit dance back into her life...So let the dancing begin as this amazing journey continues once again!

Susan Drossulis