

Endurance and Abundance Lessons from Rapunzel



September is Childhood Cancer Awareness Month. It is also Sickle Cell Awareness month. Both are severely underfunded in medical research and advancement compared to diseases of adults. My fairy tale art assignment recently was of the story of Rapunzel. If you don't remember it is the one where the beautiful princess is trapped in a tower by an evil witch and she spins gold from her hair. A gold ribbon is the symbol for Childhood Cancer Awareness.

I love to dwell in the fairy tale a bit, listen to a few different versions, apply it to my life and times. In the first version I listened to and in the Disney version, *Tangled*, the story is one of endurance followed by abundance. It is impossible for me not to frame my thoughts without considering the days of Coronavirus we are all trying to find our way through. We are in the enduring phase for sure. My last work week in the hospital I titled "Sequelae" as I witnessed repeatedly the ravages of disease untended due to fear of coming to the hospital. We have all been required to muster strength and endurance in the past 6 months.

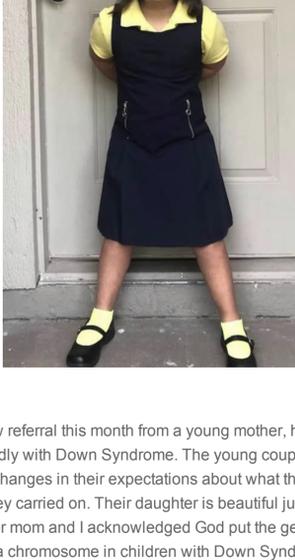
Children with Cancer and Sickle Cell Disease have one thing in common, they endure endless hours of physical pain, yet, just their sweet smile can fill our hearts and souls with abundant love and tenderness. I thought I would share a few of the lessons I have learned about endurance and abundance recently from the fairy tale of Rapunzel and a few of our Still Place princesses.



One of our first Still Place children had a relapse of Acute Myeloid Leukemia last week. It was shocking after we all thought she was in a sustained remission after a bone marrow transplant 4 years ago. Life had returned to normal. I had just sent she and her donor brother a happy Bone Marrow Birthday card never imagining that a few days later she would be facing another battle for her life. This princess has the Rapunzel spirit and a character that is solid, calm, wise, courageous and brave. I remember her first morning at The Still Place weeks after being discharged from The Ronald McDonald house after her first bone marrow transplant. I found her outside sitting barefoot in the middle of the creek...in February. I said, "is it okay for you to be out here alone, do your mommy and daddy know where you are?" She said, "It's fine Dr. Dawn...I came out here last night when they were sleeping."

Somehow even in these last several days, it is remarkable to see how she calmly faces the procedures, the chemo, the pain and the misery of the toxic therapy her fight requires. We all pray that her endurance will result in abundance again with another sustained remission but in the meantime, she teaches me to count each moment as precious and to always remember the children and families that are enduring so much more in these days of Covid 19.

When her brother was told about her relapse, with tears in his eyes he asked his mommy if she had to lose all of her hair again. Yes, our Rapunzel will lose her hair and no it won't grow back with magic power, it will grow back thin and wispy again. Yet, she will remain strong, though she will always have a secret wish for thick shiny hair like every preteen and lungs that can sustain cartwheels and crazy laughter but she won't complain.



I received a new referral this month from a young mother, her daughter was born unexpectedly with Down Syndrome. The young couple grappled with this and made changes in their expectations about what their family would look like and they carried on. Their daughter is beautiful just like Rapunzel. As we spoke her mom and I acknowledged God put the genetic code for love in that extra chromosome in children with Down Syndrome. She is like Rapunzel bringing joy and beauty to everyone they met. Then at 3 she was diagnosed with Acute Lymphoblastic Leukemia. She was hospitalized for most of the next many years. Countless days of endurance and imprisonment hard to imagine for a child who can't even comprehend the needles, the bad feelings from chemo, the endless spinal taps. Then, just as she was finishing her therapy after the standard three years of treatment, she developed an infection that ravaged her little body, nearly taking her life several times. No one across the country could identify the organism and find the right treatment and she remained in her hospital confinement for another year. Finally, a miracle occurred and a special tuberculosis hospital in Washington, DC was able to identify and find a treatment that ultimately worked to cure the infection. Her life was spared. Her skin was ravaged and permanently scarred yet in her abundance of love she smiled and went back into the world bravely, exuding love and joy, stunning beauty and sparkle emerged wherever she went. Unfortunately, human nature is timeless and Rapunzel as she initially emerges from her confinement must face villains, arrows and disaster. This little princess had to face villains who bullied and injured with words and behaviors more painful perhaps than all the needles and spinal taps she had already endured. Yet, she continued to smile and laugh. Just like Rapunzel she continually transforms evil into abundant love through her smile, hugs and joy filled antics.



Another princess I know has Sickle Cell Disease. When I first met her, she jumped out of the car in her jammies, long braids bouncing everywhere in the afternoon summer sunshine heading directly to the swimming pool. I thought she might jump in right then and there. When I first trained as a pediatrician, I remember tiny little babies coming to the Emergency Department crying incessantly. Mothers had been told their babies had colic or were just fussy. One look at their tiny little brown fingers and toes swollen and tender would be the moment they were diagnosed as having a disease of pain that would last a lifetime. Thankfully, today babies are screened for Sickle Cell Disease at birth and hopefully they are not labeled as difficult babies as often as they once were. Craig and I have had the privilege of serving during Sickle Cell Disease week or weekend at Camp Boggy Creek a few times in the past few years at The Patch (the clinic). The children try to avoid coming to the patch, trying to keep up and have fun. Then we get the calls in the middle of the night from their counselors, of the children muffling their brows from pain as they try to sleep. Thankfully we have had morphine and IV fluids to immediately improve their pain. I recall one day getting to zipline the next morning with a teen unable to walk, lifted to the zipline by her fellow campers, each knowing firsthand what it is like to have this pain limit your plan for the day let alone your dreams.

Sickle Cell Disease remains one of the most difficult diseases. Stress, dehydration, getting too cold, getting too hot starts a cascade of pain that can quickly spiral out of control. After years of experiencing this pain, fear of painful crisis emerges which is equally debilitating. Many adults with this disease become dependent on narcotics which in turn steals their enthusiasm and joy for life. Bone marrow transplant is curative but there are challenges which are almost insurmountable from lack of donors, to fear of complications, to lack of financial resources and lack of centers of excellence. We need way more awareness for Sickle Cell Disease in our country. Frankly, I believe it is a health care disparity of paramount importance.

Our princess has that wise soul of children who have endured suffering. She has boundless energy, yet when you look into her eyes, pure yellow from her blood cells sickling and being destroyed we slow down a bit and let her bone marrow catch up with us to deliver oxygen to her brain and muscles. I know she hurts but she is resilient like Rapunzel. She already has her own business, Zee Organics, which I encourage you to support! Christmas is just around the corner! Click the link below!

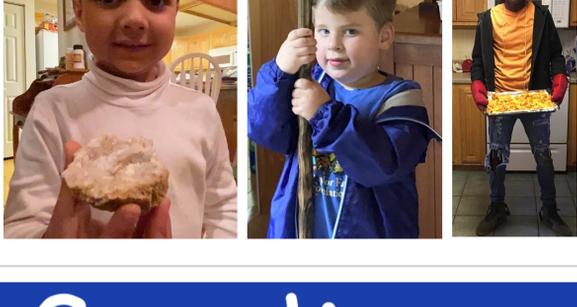
[Zee Organics](#)

Rapunzel lived on the Island of Corona. Seriously, can you believe that? The way I see it we are all kind of trapped on this Island of Corona for the near future. I hope through our times of endurance we can live with abundance like my modern day Rapunzels and the thousands of children out there in this moment living through the very real pain of Childhood Cancer and Sickle Cell Disease.

I encourage you to watch *Tangled* and illuminate your days with hope and joy instead of fear and grumpiness. Spin your yarn of Gold and Red. Educate yourself on how you can make a difference for children with Cancer and Sickle Cell Disease. One powerful way is to be their voice to your US Senators and Representatives supporting funding for desperately needed research. Or join The Still Place team as a volunteer or sustaining donor and experience the love firsthand!

And next year I promise I will spin a yarn about all our princes. Sneak Peek below...

-Dr. Dawn

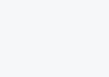


Creations for Cures

THANK YOU FOR THE ART KITS!

Creations for Cures is a non-profit organization that helps children and their families battle cancer using the power of art. We do this through our Art Kit and Art Hour programs. In addition to our programs, we host art events and partner with other organizations who have joined the fight in defeating childhood cancer. They were kind enough to make us several art kits to share with our kiddos when they leave their retreat at The Still Place.

For more information about Creations for Cures visit their website www.creationsforcures.org



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