

Disappointments

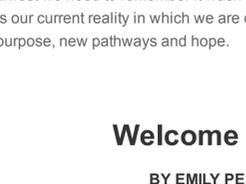
The Downside of Hope and Expectations
Finding your way from Italy to Holland



In May, I worked a whole week in the hospital in Hendersonville without any kind of coronavirus exposure. It was a joy to be able to come home and welcome families again to The Still Place. Instead of 5 days at home before my next shift I had 3 glorious weeks in our Tusquittee heaven. I started to hope those saying Covid 19 might be seasonal were right. I started to hope the summer would be filled with joy and TSP fun after all and I started forming expectations of a summer of hikes, lake splashes, visits to High Mountain Creamery and Still Water Landing, bringing happy smiles and laughter and firefly memories to The Still Place families.

I got through 4 of my shifts at the hospital in June with no problems then the new Coronavirus reality descended. We were seeing regular people getting exposed, not the nursing home population but every day people back from a vacation here or there and then nearby Macon County exploded with cases and I realized this is not going to be like influenza, not going to be seasonal, not going to be predictable. I left the hospital feeling disappointed in the future. And today, as I update this newsletter, I am overwhelmed with dissatisfaction as we all are watching Covid 19 cases skyrocketing pretty much everywhere in the Southeast.

But then, a phone conversation I had the week ago with a new TSP family echoed in my mind. It was a young mom, newly married, their first baby was born unexpectedly with multiple congenital defects. There was still no diagnosis after 18 months. Their baby had to have 24 hours of care, suctioning, tube feeding and more. The parents were still holding down their jobs. The mom said, two weeks ago we realized we needed to shift from "survival mode" to "the long haul." As I wallow in my self-pity I realize, such is our country's season of disappointment and unknowing about our futures. I turned again to the wisdom and lessons learned from the daily lives of families with seriously ill children and a memory of a story.



When I was a junior faculty member at the University of Florida, I cared for a special child named Heather.

She was tenderly loved by her family into her teens, never able to speak, eat on her own, walk or crawl. I cared for her as her primary care physician until her death and for her family for many decades thereafter. Her family was one of the first families to visit The Still Place before we were officially The Still Place. Billy, one of their children had such bad sensory integration issues he could barely stand and walk into my office but here on Compass Creek he was able to cross the creek on a two by four.

Luke and Ashley were our first Iron Chef's making a pancake breakfast for their mom and dad on the deck. I will never forget Ashley carefully spooning the pancake mix one spoon at a time into the bowl and Luke carrying the butter to the deck dropping the butter from the plate slowly stooping to pick it up and then turning to look at me. With a nod of approval from me he beamed his little smile and carried on out to the porch with firm determination as if he were carrying the crown jewels. When Heather died her mother read this story at her funeral. I found it again and feel in these days and times of this Covid 19 pandemic, racial injustice, riots and civil unrest we need to remember it wasn't what we hoped for or expected but it is our current reality in which we are challenged to create meaning, purpose, new pathways and hope.

Welcome to Holland

BY EMILY PERL KINGSLEY

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland." "Holland?!" you say. "What do you mean Holland??" I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay. The important thing is they haven't taken you to a horrible, disgusting, filthy place full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you never would have met. It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around...and you begin to notice Holland has windmills... and Holland has tulips. Holland even has Rembrandts.

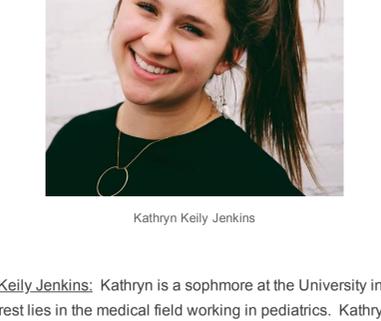
But everyone you know is busy coming and going from Italy...and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away...because the loss of that dream is a very, very significant loss.

But...if you spend your life mourning the fact that you didn't get to go to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland.

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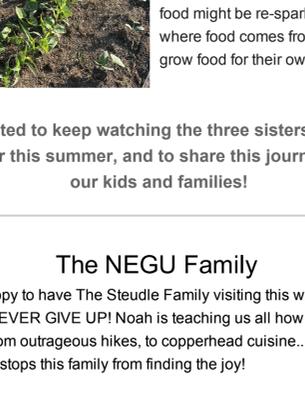
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Wrapping it up I think it is important for us to articulate and name our own personal disappointments. From missed graduations, and missed birthday parties and weddings, missed births and deaths, missed paychecks and meals. Our disappointments may even be petty or small when we look at the challenges others face but it is good to say we are disappointed and to look at the expectations from which they were birthed. My expectations and hope that Covid 19 might be leaving were not the reality. My choice I realized was to wallow in my disappointment or to listen to the echo of that phone conversation and move from "survival mode" to "long haul mode." I remembered my early corona mantras...get strong, be strong and now, stay strong. My choice is to stay strong and work at moving on from my disappointments and expectations, and instead, to be curious, look around and see what I can learn, experience and maybe even enjoy in this unusual season in which we find ourselves. I am thankful always we found our way to this beautiful and blessed mountain southern Appalachian community that always gifts The Still Place guests so richly.

Our Summer Interns

Welcome to our new summer interns who will be helping us while we look for someone to replace Kayla.



Olivia Baker

[Olivia Baker](#): Olivia is a rising senior at the University of Virginia. She has a double major, Evolutionary Biology and Art. She hopes to dedicate her time after college to seeking creative ways to address the climate crisis.



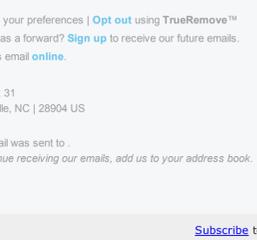
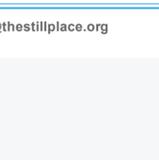
Kathryn Keily Jenkins

[Kathryn Keily Jenkins](#): Kathryn is a sophomore at the University in Georgia. Her interest lies in the medical field working in pediatrics. Kathryn's goal is to achieve a Bachelor of Science and Master of Science degree in nursing. She will then work as a Pediatric nurse Practitioner.

Garden of Hope

Thank you Dub and Murray Martin Foundation!

Green leaves shot up out of the ground like a fresh surprise! This month we began planting the Garden of Hope-- tomatoes , eggplant, kale, and best of all- the three sisters! Before a huge storm, we planted the three sisters-- corn, beans, and squash side by side in long rows down the edge of the garden. Big thanks to TSP Volunteers Karen Troster and Don Jones for supplying those masters! Just about a week later, after massive amounts of rain, we returned to find awesome huge sprouts ready to provide shade and support for each other.



Along with the good news of sprouting vegetables came news to celebrate-- we have received a grant to build a greenhouse! Children visiting The Still Place will be helping to plant, tend, and harvest plants growing in the greenhouse! Some Still Place kids lose interest in food after their cancer treatment. Our hope is their interest in food might be re-sparked by learning where food comes from, and helping to grow food for their own family!

We are so excited to keep watching the three sisters grow with each other this summer, and to share this journey with our kids and families!

The NEGU Family

We are so happy to have The Steudle Family visiting this week to remind us to NEVER EVER GIVE UP! Noah is teaching us all how to celebrate the moment from outrageous hikes, to copperhead cuisine...nothing and I mean nothing stops this family from finding the joy!

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