

Living Life

A Parent's Perspective by Suzanne Perryman

We have found a sacred space, my husband and I. A place to escape for the weekend with our daughters, Olivia, 6, and Zoe, age 4. Somewhere we go to just be together and experience life to the fullest. We pack the medicines, our food, a bottle of wine, books and puzzles, bubbles and balls, Zoe's walker and wheelchair stroller, the fly fishing rods and the pink Barbie fishing poles too. We leave behind the stress of work, the complex schedule of therapy and doctors appointments, the quarterly progress reports stacked on the counter, email, voice mail and the insurance statements waiting to be opened. We head to a ranch in Greer, Arizona, where we settle into a comfortable rented cabin that we call home for the weekend.

We schedule these weekends four times a year, in lieu of a family vacation. Our family's "vacations" are spent with twice yearly trips to The Cleveland Clinic where the expert neurologist on mitochondrial disease manages the care of both our daughters.

Recently, we decided late one Wednesday evening to head for the ranch that Friday. This time we really needed an escape, we wanted to leave behind the fallout from the recent news that Zoe's disease was progressing, the distracting emotions of sadness and fear.

We settled in easily, and the girls and I painted bright watercolor pictures that we hung around the cabin. We decided to head outdoors and began to travel down the dirt path, the girls collecting wildflowers along the way. The dirt path came to an end at the bottom of the hill and we entered the field where the horses were fed each afternoon. Within minutes the horses were coming from every direction, running into the field, where soon they

stood surrounding us awaiting their dinner. The girls were delighted, as if we had summoned the horses for their pure enjoyment. The next day we had a picnic lunch in the grass near the barns, where we took our time, studying and petting the horses, and calves. Zoe followed the puppies, navigating her walker over the cracks in the well worn side-



(Top) Zoe and Bruce share her first time atop a horse.
(Right) Olivia enjoys heading for the hills.

walk while Olivia tried to coax the kittens out from hiding behind the bushels of hay. We spent time at the fishing pond, my husband Bruce taught Olivia how to manage the fly rod. She caught her first fish and happily held it in her hands for a photo. I walked Zoe to the ponds edge, holding her hands out in front of me, the way you hold the hands of a toddler learning to walk. We do this sometimes, my body adding strength and support to hers; taking her somewhere her walker cannot go. I sat down on the damp ground, my hands supporting her waist, while she stood tossing rocks into

the pond, impatient to hold her pink Barbie fishing rod while she eagerly asked My turn now? "ish", "ish," please...?

This weekend was the first time Zoe sat on a horse, with some encouragement and the strong grasp of her fathers hands, she smiled and held on for a picture. Olivia and I went horseback riding across the creek and over the hills that surround the ranch, and for more than an hour I focused on the glorious scenes of nature and the easy smile on my six-year-old's face.

We made great dinners with chocolate desserts. We ate sitting at the rustic farm table, looking out the windows onto the open fields and the setting sun. We cuddled in front of the fire until the girls were sleepy, and we tucked them into bed. And then just the two of us sat in the dark, in the quiet of our last night, studying the glow from the fire.

Sometimes we held hands, as we sipped wine and talked about our weekend at the ranch. With the sadness still miles behind, we talked about the day and the girls' continued excitement. We were happy, and we celebrated the smiles on our daughters' faces and the achievement of living our life fully.

Suzanne Perryman is the mother of two girls, both living with mitochondrial disease, and a Family Faculty volunteer with Raising Special Kids. She lives in Scottsdale with her husband Bruce, and is also the AZ Chapter President for the United Mitochondrial Disease Foundation.