

Our Escape to the City



Dear Friends,

Last year was a rough one. My cancer treatment and related risk-reducing surgery, and Jenna's surgery on both knees in December had us confined to the house for months. Kevin suggested we get out of town, and through a (very generous) friend, we had access to an apartment in San Francisco. Kevin, Patrick, Jenna and I escaped for three nights of fun in a city only 90 minutes from home, yet worlds away!

By Teresa Partington,
Jenna and Patrick's mom
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Jenna and Patrick on Alcatraz



SAN FRANCISCO, 2017

Even at our most carefree, cystinosis is present in all we do. The four of us are so used to living with or around cystinosis that we have to consciously consider the extra work we take on as a family in order to “take a vacation.”

We departed Thursday eve with suitcases packed for the weekend, a storage-size bin of waterproof and spare bedding to protect our host’s mattresses from the kids’ incontinence, twelve doses of medications: 340 pills total, for our three-day adventure, plus a set of crutches and a wheelchair for Jenna, who chooses which to use based on how far she has to travel. In the back seat with the kids are four quarts of water, which will just get us to our destination 90 minutes away, with a couple potty stops in-between. This family isn’t afraid of a nature pee. Faster. Cleaner. We can make it off and back onto the freeway in 3 minutes! We arrived, re-made the kids’ beds, gave them their meds, and hit the sack. Eleven hours’ sleep is best for Jenna, who is growing and healing, and who we have to work hard to keep healthy. A missed dose of meds, low blood sugar or too little sleep can put her in a tailspin.

FRIDAY: ALCATRAZ

We awoke to sunny skies for our 9:30 departure to Alcatraz. Laundry. No washer and dryer at the apartment. The kids stripped their beds and I looked up Fluff & Fold businesses on Yelp. Kevin made friends with the owner of Five Star Cleaners on Russian Hill. She took our basket of soaked bedding, and said it would be ready after 5 p.m. We would eat breakfast on the way to the Ferry Terminal. Medications must come after a meal, so I put the kids’ morning doses in my purse.

Alcatraz was so intriguing, and we all enjoyed the audio tour. We boarded the ferry to the island via the handicapped line, as Jenna was in her wheelchair, and we toured the island via tram, as the hills and the distance to the tour site were more than either of the kids would endure. We had two water bottles that we refilled at every water

fountain we came across. At noon, Kevin realized that we had forgotten the meds in my purse, so on the ferry ride back we purchased water and gave the kids their morning meds, five hours late. Jenna returned to the apartment with her dad for some down time. Patrick joined up with friends from his sixth grade class for Pokémon hunting and a tour of a WWII cargo ship docked at Fisherman’s Wharf, enjoying a purely fun afternoon with friends. As the boys pretended to shoot the guns at the bow of the warship, the other mothers and I watched and considered that boys only 5 years older than they were once at the helm of this ship. In the back of my mind I considered a “perk” of cystinosis: Because of the disease, Patrick wouldn’t ever be drafted. We picked up our laundry from Five Star Cleaners (\$45!) and enjoyed dinner at Fisherman’s Wharf before heading back, re-making beds, taking meds, and tucking in.

SATURDAY: FARMERS MARKET, CHINATOWN, NIKE STORE & THE TONGA ROOM

Five Star Cleaners was ready for our fly-by on Saturday morning. We dropped off the laundry and drove to the Farmers Market at the Ferry Terminal. Patrick and I agree that given one meal for the rest of our days, it would be the Chilaquiles at this market. We were a little more punctual with morning meds, giving them to the kids in the middle of the Ferry Building at 9 a.m. We once again divided: Kevin took Patrick to Nike for new shoes, and Jenna and I headed for Chinatown to shop for candy and trinkets at the bazaars. I pushed Jenna in her wheelchair the one mile from the Embarcadero to Chinatown, half of it uphill. If you can conjure a visual of this, and add to it my tendency toward speed walking and a fairly vigorous shimmy in one of the wheels of the chair, you would see why Jenna and I were in hysterics for most of this quick journey. We did find trinkets, ginger candies, pretty painted fans and a flower clip for Jenna’s hair. We enjoyed lunch and hailed



a taxi, making sure the car was one that could accommodate a wheelchair, and went back to the apartment for a nap.

The Finale: Saturday dinner at the island-style Tonga Room. We ordered and ate slowly, the kids enjoyed special drinks, dramatically delivered in carved-out pineapples. Live, island-style music was played from a stage, which was floating in a pool in the middle of the room, tiki torches all around. The kids talked about their futures, their hopes and dreams, where they wanted to live, and the friends they would never lose touch with. To watch them was to know that they were two very happy kids. As we departed the restaurant, Jenna claimed it was the best night of her life.

The future feels more and more uncertain as the kids grow and we manage days filled with the responsibility and heartache that come with cystinosis. In a parallel universe, our trip to the city might have included a lightly packed car, and dry bedding each night. Jenna and Patrick might be seen skipping up the hill on Alcatraz to take their tour, experiencing no more thirst than their dad and me. There would be no pills to take to stay alive, no upset stomachs from pills, and no regrets from giving pills too late. I dream one day, we will find a cure for cystinosis, and that our children’s road will merge with the one in that parallel universe. That road might find Jenna and Patrick, at 20, exploring Europe, with only a toothbrush and a change of clothes in their backpacks: having no thoughts of thirst, pills, or pain.

With our deepest gratitude for your commitment to our dreams,

Teresa Partington (Kevin, Patrick & Jenna)