Once there was a Snyder-Robinson bike ride. A little girl named Jadyn was in the bike ride with her Dad. They had a Snyder-Robinson tag on their bikes. Then they met a Snyder-Robinson Tooth Fairy while they were there. She gave us a special Snyder-Robinson surprise for their little brother Levi. When they were done they went inside to meet the Tooth Fairy more. The Tooth Fairy showed them some of Levi’s Snyder-Robinson things. Then they went home and did show and tell with the Snyder-Robinson things from the Tooth Fairy. The End.
I was inspired by my sister’s ketogenic diet and that my parents weigh out every single ingredient of her food to the tenth of a gram. It can be time consuming but it has been a miracle to her and our family. We need to focus on finding better treatments and cures for rare diseases. It may not happen right away but we need to take it one step at a time. Solid research is a key ingredient to finding a cure.
This is Super Millie and she has superpowers and an orange cape. Her superpowers come from her magic (ketogenic) diet. She can run super fast, swim, read, write, and talk nonstop. Her magic diet is the reason she can do all these things. She is really rare and special. She has Glut1.
“Fan Club Hashioki - Chopstick Rests” are fabricated in sterling silver. I made them in memory of my husband, who passed away on Thanksgiving day 2016, a decade after being diagnosed with APBD-Adult Polyglucosan Body Disease—a progressive neurological disease. During those 10 years, we were each other’s biggest fans—encouraging, supporting and grateful to have each other.
Our family went to Maine last summer to visit Jackson Labs, where researchers are working on Snyder-Robinson Syndrome (SRS) research. We also wanted to hike as a family to the extent we could, so we looked for accessible paths. Our youngest son has SRS, which causes developmental impairment and walking for him is difficult. If he falls, he is at risk for breaking his bones because SRS also causes osteoporosis. We are always so careful.

We first went to the Jordan Pond Nature Trail and, although it wasn’t posted, we thought we all could make it around the pond with our son who requires a push wheelchair for long distances. We were alternating pushing our son in his chair until the path got rocky and it became impossible to do so. About halfway around the pond we had to turn around because he was getting tired walking so much and the path was getting increasingly difficult.

We got to this crossway, and I stopped pushing his chair and took this picture. The afternoon light was starting to fade. This picture captures perfectly the love, the light and the hope that raising our son with SRS has brought us.
A bridge in white water. Even in dark times light show though

A guy falls out of canoe from white water. He crawl to beach to find beautiful sunset and calm water

Show a little bit of light can go a long way
The million dollar bike ride motivates people to cycle towards one goal—a cure for one or more rare diseases. As I was drawing I couldn't help but think of each person as a wheel in this movement—some perfect...some not...but who defines perfect??
In 2011 we took some time off our search for a diagnosis to cycle down the Oregon Coast as a family. The next year we discovered Josie has Infantile Neuro Axonal Dystrophy. Riding still brings us joy.

Canon PowerShot SD1300 IS
f/4 1/400 10.906mm ISO80

Bilenky Viewpoint Semi-Recumbent Tandem