



Katie Hruby, with her husband and daughters



A Q&A WITH KATIE HRUBY AND HER SISTER, LORIE GILL

Katie Hruby was diagnosed with cystic fibrosis (CF) when she was 5 months old. She is now 38. One of 7 children, she is the only one of her siblings with CF. Katie lives in Long Island with her husband and two daughters. Her older sister, Lorie Gill, lives in Rhode Island.

WHAT WAS YOUR EXPERIENCE GROWING UP WITH CF?

Katie: I was the fifth of 7 children, and the only one with CF in the family. It was sometimes difficult to have CF – there were certain milestones that I was looking forward to but wasn't able to participate in because of my illness. For example, I collapsed while getting ready for my high school prom, and I was rushed to the ER and then admitted to the ICU. And one year I was in the hospital on Christmas. But for the most part, I was always encouraged to do what I wanted to do. Having CF helped me learn not to get upset when something doesn't go my way.

Lorie: As a child I didn't realize that there was anything different about Katie. I do remember that when she got diagnosed we all had to go to the hospital for a sweat test, but none of my other siblings were diagnosed with CF. My mom tells a funny story about the birth of our younger sister, Mollie. She came along right after Katie. One day, Katie brought her pills to my mom, and said, "These are for the baby now! I'm not the baby anymore, so she can have my pills."

WHAT WAS IT LIKE TO TRANSITION INTO ADULTHOOD HAVING CF?

Katie: It was really tough because I had always been treated by pediatric doctors. At the time when I was transitioning into adult care, there were very few adult CF centers.

Now as an adult, I try not to take any time off from work – I need to save it in case I get sick, so I still have a paycheck if I end up in the hospital.

I've had to alter my career plans. I was a nurse and worked in the ICU, with very sick patients. I loved my job, especially because I am a "professional patient." However, I had to make the decision to pull away from the bedside because of the risk of infection. Now my focus is education, where I'm not one on one with patients. I am currently pursuing my master's degree in nursing education.

WHAT ARE THE BIGGEST CHALLENGES OF LIVING WITH CF?

Katie: I have two daughters. My oldest is 12, and my youngest just turned 3. It's tough to balance it all – work, parenting, taking care of myself. Even on the days when I'm so exhausted that it's hard to breathe, I still have to be a mom.

The trouble with CF is that on the outside, we don't typically "look sick." It can be hard for people to understand why we're sick a lot, and coughing a lot, when we don't look ill.

HOW ARE YOU INVOLVED IN THE CF COMMUNITY?

Katie: CF patients can't be in a room together because of the risk of infection, but there are a lot of active social media groups. I am part of a Facebook group for moms with CF. I often go there and read people's stories, and sometimes I chime in to give others hope. I also get support from moms in the group when I am struggling.

KATIE, WHO IS "ALL IN" FOR YOU?

Katie: My main support comes from my mom and my sisters, and from my oldest daughter. Now that she is 12 she is starting to understand. She'll say, "Do you feel ok?" And she watches her younger sister so that I can rest. My husband is also all in for me.

LORIE, WHY ARE YOU "ALL IN" FOR YOUR SISTER?

Lorie: Of the seven children in our family, Katie should have the most reason to feel sorry for herself – but she just doesn't. She's run a marathon, she went away for school, she traveled to Spain in college. The rest of us stayed close to home.

Katie challenges herself all the time. She's finishing school, she teaches religion classes, and she is at every one of her daughters' soccer games and swimming lessons. It amazes me how she juggles it all. She never complains – she just quietly lives her life and does amazing things.