

Genome readers honor genetic counselors who interpret complexity with compassion.

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Kathryn Mraz The Luckiest Man I Know

Kathryn Mraz

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Nominated by Travis Bray

Photograph by Todd Spoth

The University of Texas Health Science Center Houston, Texas **My story is** one familiar to many in our community, but with a twist. Familial adenomatous polyposis (FAP) started in my family when my grandfather was diagnosed with terminal colon cancer at the age of 36. Three of his six children, including my father, were later found to have FAP.

My mom suspected I had FAP as a toddler, although I wasn't officially diagnosed until I was 15. The summer before my junior year of high school, I underwent a colectomy (removal of the colon) with the creation of a J-pouch (a surgically created reservoir that takes the place of the colon). For the next 20 years, life was pretty awesome. I received a Ph.D. in chemistry at Auburn University, studied the chemistry of plutonium at the Berkeley Lab, backpacked in northern California, and globe-trotted with my (now) wife, Shawnie.

I was thrown a curveball in 2011, though. A year after my dad died, and at nearly the same age his dad had passed from cancer, I became severely deficient in vitamin B12 and iron and had a critically low blood count. After months of increasingly invasive tests that offered no answers, my mortality became a common topic of discussion. I began to fear that I would widow Shawnie within a year of our marriage.

During this time, my research efforts focused on finding the

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cause and cure of my illness. But all I unearthed was the unfortunate truth that no organization existed to support this community, and very little patient-friendly information was available to families, like mine, with FAP.

My journey took a sharp positive turn in March 2012, when I finally came under the care of an expert team at the University of Illinois. Kathryn (Kate) Mraz was then working at the University of Illinois and was my genetic counselor. Working with her was not only more than I could have asked for but more than I knew existed. For the first time, I could relax and trust that my medical team could care for me.

She researched my family history, determined my specific family mutation, and spearheaded the development of a personalized healthcare plan. When I needed a test, Kate worked with the insurance company to make sure it was covered. She also pushed the gastroenterologist she worked with, Dr. Xavier Llor, to take thyroid risks seriously. This was at the time when FAP-related thyroid cancer risks were just being published, and they were not completely embraced by the medical community. She was literally on the front edge of the wave advocating for my care.

Ulcers were eventually identified as the source of my bleeding, which Shawnie and I were able to remedy through dietary changes.

Kate was an integral part of that diagnosis.

While my experience lasted only about six months, it gave me an insider's look at many of the difficulties faced by people with hereditary colon cancer syndromes. As I recovered, a vision grew of how I could make real change in this community. In June, I left my career as a research chemist to start the Hereditary Colon Cancer Foundation. We develop patient-friendly educational resources and healthy social networking opportunities for families. Additionally, I work alongside brilliant medical professionals, like Kate, to improve the quality of care for families around the world.

Kate has taken a keen interest in the success of the organization and has been an advisor throughout. I'm not sure we would have even started the foundation had we not had her support from the beginning. She made sure we knew the importance of what we were doing and helped us distill our outreach to be the most effective.

Living with a hereditary syndrome can be incredibly difficult at times. One of the most important things a family can have is a qualified, passionate care practitioner to work with. Today, I consider myself the luckiest man I know, because I have had the good fortune to be cared for by individuals like Kate Mraz. She most definitely deserves to be recognized for her contributions to the field and the health of the families she cares for.

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