

The Most Ruthless Cancer

Category: Cancer

written by Sara Ann Conkling | June 7, 2021

Most people aren't aware of a cancer that is ruthless above the rest. This cancer lasts a lifetime and never fully remits.

I first became aware that I was susceptible as a child. I was on an examining table and our pediatrician asked my mother to step outside the room. I then heard him berating her: "This child is sunburned! How could you! You know you have genetic skin cancer!"

This wasn't just any skin cancer. It was Basal Cell Carcinoma Syndrome, or Basal Cell Nevus Syndrome, or Gorlin-Goltz Syndrome. Or, more recently, just Gorlin's Syndrome. (I felt sorry for Goltz when that happened.)

Just as the medical community can't decide what to call it, they also can't decide where we fit in the "Cancer Community." We never leave a doctor's office with the hope of remission. Except in very rare circumstances, we also don't leave with the ultimate despair of impending death. Instead, every few months we walk into a doctor's office knowing we will lose pieces of ourselves. Every few months, I look into a mirror and say goodbye to my face. Over time, for instance, my nose has been robbed of its symmetry. I acquired a "Van Gogh" ear. One eye opens a bit wider than the other. It's not all completely terrible: I have also lost a lot of wrinkles as the skin on my face has been carved and stitched back together, again and again.

In this rarefied journey, I've had some good fortune. My dermatologist is a decent surgeon, and an exceptional human being. He kept carving my face (and everywhere else) and paying the pathologist from his own pocket during a pre-ACA period when no company would sell me insurance. Over decades of sad ritual, we have been bound together in a way that most patients and doctors are never bound. Our relationship breaks both of our hearts, and we still both fight to maintain it.

One might hope that the medical gods would exempt someone with this illness from additional suffering. But fate has a cruel disposition: mine would include spine injuries, sarcoidosis, and the devastation of Cushing's Syndrome. Lately, my dermatologist introduces me to people he is training by saying, "This is ... She has Gorlin's Syndrome, and it's not her biggest health problem." Invariably, the students fail to imperceptibly recoil. They know they can't catch my cancer, but they also don't want to catch my fate.

Sara Ann Conkling
Cocoa, Florida