



The Gut Check

A quarterly newsletter serving the hereditary colorectal cancer community

Issue No.7 - June 2015

In Awe and Fear of the Scalpel

Mom says she saw blood in my diapers as a baby. My father had just had his colectomy eight months before I was born; my grandfather, the de novo FAP carrier in our family, died six years prior. Mom, who only found out about FAP in my dad's family after I was conceived, was fiercely on the lookout for any signs that I, too, might have FAP. Fifteen years later, I became a third generation previvor.

In my family, whining got you nowhere. "You don't get a choice. You might as well suck it up and get it done." That's what I heard for years as I underwent colonoscopies which, at the time, were performed sans conscious sedation. I took this stoicism with me as best I could to the Cleveland Clinic, FL for my colectomy and j-pouch creation.

I remember vividly the day of my first surgery. It was late May, 1993, and I had just finished my sophomore year of high school. At 6'0", 160 pounds, I would eventually rejoin my classmates 2" taller and 50 pounds lighter. Nurses were flying around prepping me for surgery. I laid in the bed internalizing my fear and doing little to hide my fascination. An IV was started, leads for an EKG were placed, the blood pressure cuff started its cadence of inflating and deflating, and machines

were flanking me with beeping and flashing lights. It's crazy to think I was only fifteen years old. Although I knew my entire life this day would come, and fully recognized I was powerless to prevent it, there was no way to be mentally prepared for a surgery that simultaneously alleviates the risk of colon cancer while negatively affecting quality of life.

My family sat around me waiting for the word that it was time. When the nurse came to take me to surgery, my mom kissed me and told me she loved me. I responded with all the false bravado a fifteen year old could muster, "See you on the other side." (Story continued on HCCtakesGuts.org under "From the Desk of Travis")



Travis & Granny, 1993

Attenuated FAP	Juvenile Polyposis
Cowden Syndrome	Lynch Syndrome
Familial Adenomatous Polyposis	Muir-Torre Syndrome
Gardner Syndrome	MYH-Associated Polyposis
Hereditary Mixed Polyposis	Peutz-Jeghers Syndrome
	Turcot Syndrome

Founders' Letter

How fast does time fly? The Hereditary Colon Cancer Foundation turns three years old in July! This is a big deal for us. A ridiculous percentage of businesses, especially those in the not-for-profit sector, fail in the first three years. To be honest, there were times along the way when we were afraid we would fall into this category. Yet here we are... not merely surviving, but growing!

Last fall we made some tough financial choices and invested in the infrastructure of the organization. Thankfully, the sacrifice is paying off. Less than a year later, the Foundation is on solid ground and we are developing several amazing new patient programs! We are seriously stoked, at not only how far we've come, but what the future holds.

Read on to learn about our continuing and upcoming programs. If you agree that our work is important, please make a donation and help us continue to serve this community! We love what we do, but we CANNOT do it without you!

Cheers,
Travis & Shawnie Bray, Founders

New Patient Resources

Thanks to a generous grant from Myriad Genetics, we have begun production of patient-friendly guides for families effected by Familial Adenomatous Polyposis and Lynch Syndrome. These guides will answer frequently asked questions about diagnosis, screening, treatment, and genetics. Our goal is to have these resources available for download by October, 2015!



Education and Support Groups

May saw the start of our first Patient Education & Support Group in Ann Arbor, MI. The event was a smashing success as patients and extended family members learned about "The Role of Genetics and Strategies for Cancer Prevention" from Dr. Elena Stoffel of the University of Michigan. We're looking forward to the next support session on June 18th lead by Kevin Myers (patient ambassador) and the Cancer Support Community of Greater Ann Arbor!

Interested in joining or starting a Patient Education & Support Group? If you live near Chicago, IL, Cleveland, OH, Danville, PA, Duarte, CA, New York, NY, Salt Lake City, UT, please contact TravisBray@HCCtakesGuts.org or (334) 740-8657.



Support Via Social Media

Every day, we support patients seeking advice via social media. By participating in 41 groups, and interacting with an audience of over 10,000 patients, we observe recurring questions including:

- "Should I seek a second opinion?"
- "Is there an experienced doctor near me?"
- "Should I have a hysterectomy?"
- "How can I reduce bowel movements?"
- "Should I have a genetic test?"

If you would like to join the conversations and lend your advice, you can find us on Facebook and Twitter @HCCtakesGuts!

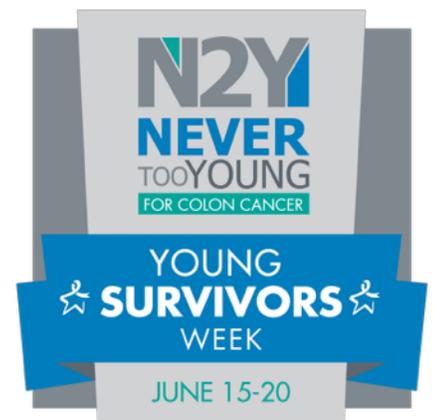


Colon Cancer Podcasts

Have you heard about the Colon Cancer Podcasts? These audio interviews allow us to get to know the intimate and heartwarming stories of cancer warriors. Three of the most recent stories featured those with hereditary syndromes: Travis Bray, Georgia Hurst, & Daniel Shockley. Check them out on iTunes by searching for "Colon Cancer Podcast."

Never Too Young Coalition

In the hereditary colon cancer community, being diagnosed at a young age can actually PREVENT cancer. We are pleased to announce our participation in the "Never Too Young Coalition." Partnering with 26 patient advocacy organizations amplifies our collective voice as we spread the importance of knowing one's family history and the early warning signs of colon cancer. To learn more, check out www.nevertooyoung.org.



Support Us

Please support our work by making a tax-deductible donation online at www.HCCtakesGuts.org or by check:
P.O. Box 2005
Park City, UT 84060

