Young Dezi was more than a little anxious. You would be, too, if you were having your colon removed the Friday before Thanksgiving...at the age of 12!

Questions were swirling…

“What’s life going to be like afterwards?”

“How long until I can skateboard and ride my dirt bike again?”

(Side note: Ask Dezi about the dirt bike he’s building in his bedroom!)

“Will I be able to play basketball and baseball this year?”

“Will I still be able to eat my favorite foods?”

All legitimately serious questions by their own right, especially by a true dirt bike rider and skateboarder, but questions all the more imposing given his family’s history of young deaths caused by FAP.

With the thought of surgery bummering him out, Dezi’s mom, Stacie, took to action to cheer her son up.

**Step 1: Inspiration**

First things first: Dezi needed to know that a normal life, albeit a new normal, awaited him after after surgery. Doing so started with Stacie educating him on the ‘ins and outs’ of FAP so that he understood why he needed surgery. They also watched the video “Everyday” on HCCTakesGuts.org so that Dezi could see another previvor who hasn’t been slowed down by a colectomy. Dezi perked up watching the action shots of Travis snowboarding. Knowing that kick flips and allies (skateboard terms...look ‘em up!) was not too far in the distant future, Dezi’s fear was replaced with determination.

**Step 2: Community Support**

Dezi’s surgery required the family to travel from Minneapolis KS to Children’s Mercy Hospital in Kansas City, MO and Stacie would need to take time off of work. So she started the “Dezi Fund.” (Children’s Mercy Hospital hosts one of the nations few pediatric gastroenterologists specializing in FAP. Find Seth Septer, MD and many more specialists here.)

However, Dezi had other goals in mind... He proposed that half the money would help pay the family’s costs and the other half would be sent to support the Hereditary Colon Cancer Foundation.

(continued…)

**Attenuated FAP**

**Cowden Syndrome**

**Familial Adenomatous Polyposis**

**Gardner Syndrome**

**Hereditary Mixed Polyposis**

**Juvenile Polyposis Syndrome**

**Lynch Syndrome**

**Muir-Torre Syndrome**

**MYH-Associated Polyposis**

**Peutz-Jeghers Syndrome**

**Turcot Syndrome**
Dezi’s Story of Hope

Mom was supportive, “We can all agree that education is key and I feel that the focus and information through the Foundation is the best out there for those going through life with FAP, juvenile polyposis, or many other hereditary colon diseases.”

At a local bake sale, red velvet cake, trail mix, R2D2 cookies, coconut and chocolate cream pies, and banana bread, were donated by many family and friends including Dezi’s best friend, Hunter. Chili was also donated. While a chili cheese dog and a brownie would be enough to put a smile on most any kid’s face, Dezi received an added surprise. At the event he learned that one of his classmates also has FAP! Both kids had been dealing with it privately and out of the view of classmates, but now they’ll have each other. Dezi also decided to sell bracelets “to support his journey with his hereditary disease.” The bracelets were royal blue, the color associated with colon cancer with the Foundation’s slogan “it takes guts” in lime green, Dezi’s favorite color. (Looking at a bracelet, one would predict that Dezi is a Seattle Seahawks fan, but don’t be fooled! Dezi bleeds red and black for the Atlanta Falcons!)

For anyone who would like a bracelet, go to https://www.gofundme.com/DeziFAP, donate $5 and send your address in a message to Stacie.

Step 3: An Encouraging Chat

Travis was touched to tears by Dezi’s actions, “This is why I love my job!” And Dezi was inspired to talk to a person with his diasease and no colon and who rocks a snowboard. So the two had a video chat a few days before Dezi’s surgery discussing everything from what to expect after surgery to slaying dragons!

Step 4: An Early Thanksgiving

Since Dezi would still be recovering on Thanksgiving, his family celebrated a week early so he wouldn’t miss out on all the fun.

Step 5: A Class Full of Support

His entire 6th grade, teachers and students donned the Foundation’s “DNA Dude” tattoos on surgery day to honor what he was going through!

Step 6: A “Last Dinner”

When offered dinner at his place of choice in Kansas City, an internet search turned up Twin Peaks Sports Bar & Grill. Look them up online and you’ll see why a 12 year old boy would want his “Last Supper” here. Suffice it to say, this dining experience took his mind off of the surgery the next morning!

Step 7: The Man of Steel

Dezi entered the hospital sporting none other than Superman socks! It makes sense actually... what a brilliant way to take the strength of the man from Krypton into surgery!

Many things went into making Dezi’s surgery a success. The support of family and friends. The support of teachers and classmates. The support locally from the Minneapolis and Tescott, KS communities and online through Facebook. And the support of Dezi and Stacie’s new friends at the Hereditary Colon Cancer Foundation who can’t wait to see pictures of this inspiring, young man back on his skateboard and dirt bike!
What an eventful few months it has been! We are extremely grateful for your support in a variety of ways! Thank you to...

...all the providers who have shared “A Patient’s Guide to FAP” with your patients!

...all of the previvors and survivors for the kind words of encouragement you’ve provided in response to the Guide!

...Missy Barber, Wayne Barber, Rhonda Blender, Kelly Livingston, Marianne Lotito, Peg Moran, Kevin Myers, Carlton Myers, Sharon Perlman, and Jamie Willmott for volunteering your time at our events.

...the University of Chicago Medicine and Gilda’s Club teams for your collaboration in producing our premier Hereditary Colon Cancer Family Day.

...the dozens of providers who have joined us in planning amazing support events for our community in 2016!

...and, the donors who make this work possible!

We thoroughly enjoy the role we have in the hereditary colon cancer community. Thank you for bringing us into your families, and into your workspace.

Happy Holidays!

Shawnie & Travis Bray