**Story of Hope**

**Spotlight on Grayson**

What would inspire a mother to hand sew super-hero capes? Meet Danielle Brannan and her son Grayson. At the age of three, Grayson has already been diagnosed with Gardner Syndrome (GS), has had six sebaceous cysts extracted from his head, and an abscess removed from the base of his skull.

When the surgery to remove the abscess was approaching, Danielle, who is also facing her own challenges with GS, asked Grayson what she could do to make things better for him. “Make me a superhero cape,” Grayson says. “When I wear a cape nothing hurts me. I want to wear it in my surgery.” If that is not cool enough, Grayson asked Danielle to “make one for dad to keep him brave, too.” (From the mouths of babes, right?!?)

Danielle has coupled Grayson’s request with her own passion to raise awareness about GS to create “Capes for Grayson”. Danielle makes and sells capes so others can be a superhero for Grayson. The scrapbook she keeps holds pictures of Grayson’s fans wearing her handmade capes and “remind[s] [Grayson] of everyone praying for him and supporting him.”

Presently, the young lad has a tumor actively growing around his carotid artery, requiring testing every three months to monitor its growth. Proceeds from the sales of Capes for Grayson help defer the cost of their medical expenses.

These include frequent testing, which cost ~$100 each, co-pays for office visits, and travel expenses. She also has ambitions to donate towards pediatric research.

To order a customized cape for yourself or a loved one, search “Capes for Grayson” on Facebook or email CapesforGrayson@yahoo.com. The suggested donation is only $10 per cape.

PS. If you have a young one with a Familial Adenomatous Polyposis, we highly recommend picking up FAP & Me from the National Society of Genetic Counselors. Also, Visit HCCTakesGuts.org to find forums, support groups, and support organizations for young people dealing with a hereditary colon cancer.

**********************************************

A final note about Danielle. She first became symptomatic of colon cancer 12 years ago at the age of seventeen. While exhibiting digestive problems like bleeding, her GI diagnosed her with hemorrhoids. I have heard of this happening all too frequently, but what makes things worse is that she sought a 2nd and 3rd opinion. Both confirmed only hemorrhoids.

Danielle was finally diagnosed with Gardner Syndrome about two years ago, when Grayson was six months old, after she was found to have a tumor on her adrenal gland. The surgeon had the wherewithal to recognize that these types of tumors are rarely an isolated symptom and subsequently scheduled a colonoscopy. Thankfully, prophylactic removal of her colon was still available to her. Danielle, along with the Familial Adenomatous Polyposis Foundation, is highly motivated to reduce the instance of misdiagnoses. Check out our “Hereditary Colon Cancer is Preventable” campaign for more information.

Danielle Brannan joined the Board of Directors of the Familial Adenomatous Polyposis Foundation for the 2013-2014 fiscal year.

The Familial Adenomatous Polyposis Foundation’s vision is to be a beacon of light - extending life expectancy, enhancing life quality, and instilling hope in those born with Familial Adenomatous Polyposis and other hereditary colon cancer syndromes.

(c) 2013 Familial Adenomatous Polyposis Foundation. Familial Adenomatous Polyposis Foundation is a registered charitable organization in Illinois and Utah, and tax-exempt under Internal Revenue Code Section 501(c)(3).
Medical Professionals Meet to Discuss
Hereditary Colon Cancer Research Results

Shawnie and Travis Bray recently attended the 17th Annual meeting of the Collaborative Group of the Americas on Inherited Colorectal Cancer’s (CGA-ICC) in Anaheim, CA. As the leaders of a patient advocacy organization, they arrived at the CGA-IICC meeting knowing patients want access to resources that will improve their ability to manage their health and wellness. They departed acutely aware that the medical professionals focusing on hereditary CRC are equally interested in creating a platform to empower patients with information and tools to improve their quality of life.

The following three points, gleaned from oral and poster presentations, as well as individual conversations, will influence the work of Foundation in the coming year:

• Most general gastroenterologists treat very few patients with hereditary colon cancer (HCC) in their career and are therefore not well versed on current treatment protocols, such as the Bethesda or Amsterdam Guidelines. The Foundation can help by developing a central hub that will provide efficient access to pertinent information on diagnosis methods, treatment protocols, and a conduit to joint health care management supported by HCC genetic counselors and physician specialists.

• Many GIs only have access to inconsistent and/or outdated clinical decision processes. As such, it is common for them to overlook the critical need for early colonoscopies when caring for those with a familial history of CRC.

• The ability to assess and treat family members of those previously diagnosed poses perhaps the greatest challenge to early diagnosis and prophylactic treatment. HIPPA regulations force medical professionals to rely on intrafamilial communication as the path for reaching additional potential carriers. The emotionally charged nature of a HCC patient’s initial diagnosis appointment often makes it difficult for patients to fully absorb and retain all of the follow up recommendations. This ultimately presents an additional barrier to future screening and treatment. Providing diagnosed individuals with patient-friendly language and tools would be of great value to the HCC community.

The diversity, depth, and sheer quantity of research currently underway is staggering. Scientists around the globe are working to better understand and/or address a myriad of issues plaguing the hereditary colon cancer community. Research summaries of a few selected domestic and international projects/results can be found on our website.

Expert Directory

Living with a hereditary colon cancer syndrome (HCCS) can be extremely difficult, especially when you need to see a specialist and cannot find one. Until recently, no comprehensive list of physician specialists and institutes was available for the HCCS community. We are very excited that this list of Expert Care Facilities was developed in collaboration with Dr. Jewel Samadder, MD, MSc. at the Huntsman Cancer Institute. With his help, we now provide a list of 53 medical professionals working at 41 institutes in 22 states and 5 foreign countries. Please contact us at Info@FAPFoundation.org with additions/omissions.

Webinar for GIs

The Foundation was pleased to host its first webinar, entitled “How to Defy a Hereditary Predisposition and Prevent Colon Cancer,” on October 30 at 5:30 PM ET. Drs. Randy Burt and Jewel Samadder of the Huntsman Cancer Clinic covered key points every GI and GI-trainee should be know when providing care to patients with FAP, Attenuated FAP, or MUYTH-Associated Polyposis (MAP). Sponsored by Myriad Genetics and Genentech, this webinar was our first step towards increasing the quality of care HCC patients can expect to receive from their local GI. Look for the webinar on our website as it may be a useful tool you can use to educate your GI.
Making a Change “Takes Guts”

October 20, 2013 marked Day 1 of the inaugural It Takes Guts! 21 Day Challenge. Unlike your typical 5k event, the ITG 21 Day Challenge was designed to be accessible to anyone regardless of health status or capability. Participants chose their individual health goal from over 30 challenges or, in some cases, devised their own custom goal. Instead of meeting at the startling line, the ITG participants met online and supporting each other over the 21-day period. By November 9th, the challengers proactively improved their health while supporting our mission to develop educational and social resources for the HCC community. If you’d like to view their progress, like us on Facebook and root these brave individuals on as they take back control of their health!

We would like to thank the people who have been instrumental in making the It Takes Guts! 21 Day Challenge what it is. We could not have pulled this event off without the help of volunteers Jennifer Cross Johnson and Wendi Mohseni, and Board Directors Danielle Brannan and Alyssa Ziegler. Their passion for the cause is evident in the amazing energy that guides their work and their ideas have been critical to our success.

Clinical Trial Begins

Cancer Prevention Pharmaceuticals recently launched clinical trials at several research institutes in the U.S. and Canada to study the efficacy of a Sulindac/DMFO drug pairing in delaying the first occurrence of any FAP-related event. This clinical trial is built upon 30 years of research into the effects of Sulindac on reducing polyps size and preventing polyp growth.

The clinical trial research is underway at the following institutions: Dana Farber Cancer Institute (Boston, MA), University of Michigan (Ann Arbor, MI), Mayo Clinic (Rochester, MN), Cleveland Clinic (Cleveland, OH), Washington University (St. Louis, MO), MD Anderson Cancer Clinic (Houston, TX), or Zane Cohen Centre for Digestive Diseases (Ontario, Canada). For more information on this clinical trial, go to ClinicalTrial.gov and search for study NCT01483144.

2013-2014 Board of Directors

On September 30th, we had the honor of welcoming our new Board of Directors for the 2013-2014 fiscal year. This diverse board brings much needed insight into the Hereditary Colon Cancer community from both a patient and professional point of view. Our newly elected directors include physician specialists Randy Burt, MD and Jewel Samadder, MD, clinical researcher Deborah Neklason, PhD, and genetic counselor Kory Jaspersen, --- from the Huntsman Cancer Institute, genetic counselor Brandi Leach from Cleveland Clinic, and patient advocates Danielle Brannan (Founder, Capes for Grayson) and Alyssa Ziegler (Author of The Waves of Life: Going Against the Tide). We are pleased to be able to continue working with incumbent Board Members Michelle Beem, Joel Glidden, and Beth Houck who bring extensive business expertise to the table.

Westward Bound

On June 27th, Shawnie and Travis Bray had the distinguished honor of meeting with Dr. Randall Burt and his amazing team of gastroenterologists, genetic counselors, researchers, and coordinators at the Huntsman Cancer Institute. It quickly became clear how aligned our goals are for supporting patients and educating GIs and a partnership took seed immediately. Not only did several medical professionals accept our invitation to join our Board of Directors, but they have also volunteered to lead our first webinars. Additionally, Travis has also been given the opportunity to put his PhD back to work; discussions are underway for collaboration with Dr. Therese Touhy to utilize ‘molecular genealogy’ to search for, and reach out to, undiagnosed patients who carry the APC gene mutation by starting with a single diagnosed patient.

The patient registry at the Huntsman Cancer Institute’s High Risk Colon Cancer Clinic holds over 600 individuals with F.A.P. alone! Our relationship with Dr. Burt’s team at the Clinic is an amazing opportunity to interact with these patients. This opportunity, coupled with a concentration of board members in the Salt Lake City area, motivated us to make the bold decision to relocate our office to Park City, UT in September. If you find yourself visiting HCI, please let us know. We would love to meet you and discuss how we can better support you!
Being diagnosed with a genetic condition is unlike any other singular diagnosis. Patients turn to their doctors and medical web sites for clinical information. However, in between the major symptoms and prognoses lies a nebulous space full of uncertainty, and patients often struggle to find care and information that is inclusive of all their needs.

Our HCC Takes Guts patient portal was created by, and for, those diagnosed with a genetic colorectal cancer syndrome. Here patients will be supported by a community that includes survivors, medical specialists, dietitians, surgeons, researchers, therapists, family planners and alternative medical practitioners. Ultimately, our goal is that patients, along with their loved ones and medical care givers, will feel empowered. Together, they will be able to make informed decisions. They will read inspiring stories and interact with other survivors. They will be filled with hope, knowing that they can lead active, joyful lives and can in-turn inspire others to do the same.

Contact us at P.O. Box 2005, Park City, UT 84060 or info@FAPFoundation.org