



# The Gut Check

*A quarterly newsletter serving the hereditary colorectal cancer community*

Issue No.3 - Winter 2014

## Story of Hope Spotlight on Dakota

In May 2011, Dakota Fisher-Vance was graduating from Bryn Mawr College with her B.A. in biology. While preparing to pursue medical school, she developed an interest in education. The intersection of these passions led her to a dream job in Boston, working with low functioning autistic children. Unfortunately, those children never had the benefit of knowing Dakota. Just before she was to begin her new career, a cancer diagnosis, followed by a proctocolectomy and three months with a leaking ostomy, forced her to pass on the job she was so excited to start.

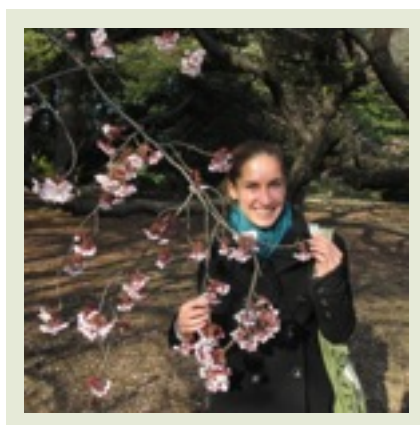
Two and a half years later, Dakota can say in retrospect that "everyone has their story...it could be a rare disease, it could be abuse." While this is true for everyone, and especially so in the hereditary colon cancer community, one cannot help but stand in awe of the juxtaposition.

The abrupt transition from being on the cusp of autonomy, progressing through her emerging adulthood, to dealing with the day-to-day struggles of cancer and surgery cannot be understated. The experience threw Dakota into a state of despair. Down and depressed for months, she reached a point where she rarely left her room, even during Thanksgiving.

"I had done everything right, but it didn't matter. This was something I could not have prepared for." Her supportive parents encouraged her to couple her passion for medicine with her new

diagnosis. Even the support of her teachers didn't ignite Dakota's interest. She made the mature decision to not let this disease infiltrate her life...

...until one particularly unnerving experience Googling "FAP." Fishing through countless pages of adult content before finding information pertaining to Familial Adenomatous Polyposis caused frustration to quickly evolve into anger.



The unfortunate truth is that, in the online community, 'FAP' is synonymous with male masturbation. "This is what they get?!? It's absurd and cruel! When someone looks for information, they should see a friendly face. They should find information that's relevant...not search through 20 Google pages of that!"

Thus began FAPulousTV, Dakota's YouTube based video blog. While she was hesitant about delving further into the FAP world and unsure what she could do globally for people with FAP, she felt compelled to push back against this perversity. Dakota has posted 25 vlogs ranging from "F.A.P.ology 101 to 'F.A.P. + Fertility'". (Story is continued on HCCtakesGuts.org)

## President's Letter

Dear Community Members,

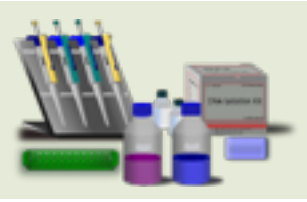
When we founded the Familial Adenomatous Polyposis Foundation in 2012, this name reflected our original knowledge and intentions. We have since been embraced by a larger community, comprised of patients, caregivers, and medical professional within the hereditary colon cancer syndromes (HCCS) community. On many occasions, we have been asked and encouraged to create resources that go beyond F.A.P.

We are pleased to announce that we are expanding our knowledge, and our team, to include patients and medical professionals who specialize in other forms of hereditary colon cancer. Additionally, we have filed the necessary state and federal paperwork to operate as the "Hereditary Colon Cancer Foundation." New resources are being developed that represent this expansion and we expect to begin releasing them in the spring. Watch your email for an official press release in the coming weeks!

If you are a patient advocate for any of the following syndromes, we would love your input and support. Please contact me at [TravisHBray@HCCtakesGuts.org](mailto:TravisHBray@HCCtakesGuts.org). Sincerely, Travis H. Bray, PhD

<b>Attenuated FAP</b>	<b>Lynch Syndrome</b>
<b>Cowden Syndrome</b>	<b>Muir-Torre Syndrome</b>
<b>Familial Adenomatous Polyposis</b>	<b>MYH-Associated Polyposis</b>
<b>Gardner Syndrome</b>	<b>Pautz-Jeghers Syndrome</b>
<b>Hereditary Mixed Polyposis</b>	<b>Turcot Syndrome</b>
<b>Juvenile Polyposis Syndrome</b>	

## A Clinical Trial for F.A.P.



Are you over 18 and have FAP? Have you had your colon removed and have an advanced form of FAP, OR are getting close to needing your colon removed? You may be interested in a clinical trial that has just started

recruiting participants in the U.S., Canada, and several countries in Europe. The trial is being sponsored by Cancer Prevention Pharmaceuticals.

This study combines two oral medications, Sulindac and Eflornithine, to explore and determine:

- 1) If combining these two drug treatments can prevent the disease from getting worse, and/or delay major surgery, better than each drug alone,
- 2) If the treatment can alter the course of the disease, and
- 3) How the medication might impact your quality of life.

What are these drugs?

Sulindac is a nonsteroidal anti-inflammatory drug (NSAID), similar to ibuprofen, that is used to treat pain, fever, and inflammation. Sulindac has also been used by doctors to manage polyp growth in FAP patients, although this use is not yet approved by the FDA. Eflornithine (CPP-1x) is a new drug, not yet for sale.

In combination, the drugs have been shown to significantly reduce polyps in patients with a history of large colon polyps but who did not have FAP. There are also studies that show a reduction in polyps in patients with FAP.

The first participants began the trial in December 2013 and will take the study medication for up to two years. Trial results will be submitted to the FDA. If approved, this would be the only approved medication for FAP on the market. To speak to someone and find out if you might be a candidate and for more information, go to [ClinicalTrials.gov](http://ClinicalTrials.gov) and search for study NCT01483144.

We encourage you to share the information about this study with friends and relatives that have FAP.

## New Guidelines for Lynch Screening

The National Comprehensive Cancer Network has released its 2014 Lynch Screening Guidelines. The guidelines, now posted on their website, include significant changes such as:

- High Risk/Familial Risk now has its own section and is not simply a part of the general colorectal screening guidelines
- Family history now recognized as an indication for Lynch
- Physicians should consider screening ALL Lynch Syndrome mutations at once rather than sequentially

Insurance companies look towards the NCCN to establish their policies. This is a massive stride towards having genetic testing covered. Go to [www.nccn.org](http://www.nccn.org) to learn more.

## March is Colon Cancer Awareness Month

Although many of us share tips on Facebook regularly, often the best recommendations get buried beneath new posts until the next time that same question is asked. So we created an archive of advice for patients, by patients. 'Words of Wisdom' from almost 100 people have been collected through a survey and will be shared daily throughout the month of March on Facebook and at [HCCtakesGuts.org](http://HCCtakesGuts.org).

## Empowering Patients with Knowledge

In November, we surveyed those with hereditary colon cancer about what they want to learn. Wow!...they sure did let their voices be heard! After receiving so many amazing responses, and great ideas, our Patient Education Committee is hard at work developing the following resources, some of which will be released in March:

### Online Resources:

- Screening Recommendations
- Treatment Options
- In-Depth Disease Answers
- Dietary Recommendations
- Genetic Counseling
- Patient Registries & Clinical Trials
- Communicating with Doctors & Insurance
- Child Friendly Information

### Webinars & Videos:

- Maximizing Health Insurance
- Communicating with Doctors

And... **Print Brochures** so those who are newly diagnosed know how to get more information!



## Medical Community Alliances



In addition to the resources we are creating to serve patients, we also serve medical professionals. Why? Because we're in it together! There are thousands of medical professionals and researchers across the world, committed to serving our community. We are working with them to improve the physical and mental health of those living with hereditary colon cancer syndromes. Our work would not be possible without the following individuals and organizations. Thank you all for collaborating with us and supporting our work. We look forward to all the future good we can accomplish together!

**Nicole Boice**, Global Genes Project

**Linda Bruzzone**, Lynch Syndrome International

**Randall Burt**, M.D. Huntsman Cancer Institute

**Carolyn Dumond**, Myriad Genetics

**Steven Erdman**, M.D., Nationwide Children's Hospital

**Carin Espenschied**, C.G.C., M.S., Ambry Genetics

**Eugene W. Gerner**, PhD, Cancer Prevention Pharmaceuticals

**Heather Hampel**, C.G.C., M.S., Ohio State University

**Erika Hanson Brown**, ColonTown

**Kory Jaspersen**, C.G.C., M.S., Huntsman Cancer Institute

**Sara C. Knapke**, C.G.C., M.S., National Society of Genetic Counselors

**Brandie Leach**, L.G.C., M.S., Cleveland Clinic

**Anna Leininger**, C.G.C., M.S., Minnesota Oncology Hematology PA

**Kate Mraz**, L.G.C., M.S., Sutter Pacific Medical Foundation

**Deborah Neklason**, Ph.D., Huntsman Cancer Institute

**Susan Peterson**, PhD, MPH, MD Anderson

**Sara Pirzadeh-Miller**, C.G.C., M.S., National Society of Genetic Counselors

**Jewel Samadder**, M.D., M.Sc., Huntsman Cancer Institute

**Michael Sapienza**, Chris4Life Colon Cancer Foundation

**Nicole Sheehan**, Colon Cancer Alliance

**Amber Trivedi**, C.G.C., M.S., Informed DNA

**Paul Wise**, M.D., Collaborative Group of the American on Inherited Colorectal Cancer

## Volunteers Needed for Research



Researchers at the University of Buffalo are working to link changes in the immune system to polyp growth. But, they need access to the medical records of FAP patients to do so. Foundation founder, Travis

Bray, has already joined the registry.

This study aims to identify signals from the immune system that correlate with polyp development. If successful, they may be able to develop methods that monitor FAP without colonoscopies. Someday, it may be possible to develop immune system therapies that prevent polyp growth.

Please read more about "Prognostic Markers for Early Disease Progression in Patients with Classical Familial Adenomatous Polyposis" and consider signing up!

### What is the purpose of the research study?

The purpose of their research is to:

- Describe and document early changes to the immune system during the development of intestinal polyposis, and
- Determine how these changes relate to the progression of polyps into intestinal cancer
- To identify new biological checkpoints in disease, and
- Develop targeted medical therapies to slow the development of polyps and/or intestinal cancer in FAP patients.

### What do they need?

If you decide to take part in this research study, you will not need to volunteer for any additional medical procedures. The study is largely retrospective, meaning that they seek only to access your past medical records and/or archived tissue samples, and to look for patterns associated with intestinal disease. All medical records and tissue specimens will be kept strictly confidential, and access to your medical information will be restricted to members of the research team. If you would normally undergo a colectomy for another medical indication, they will collect a portion of the removed intestine for research purposes.

To join, or for more information, please contact Allen Y. Chung, B.A., University at Buffalo, [allenchu@buffalo.edu](mailto:allenchu@buffalo.edu).





## Patient Events



Given the rarity of hereditary colon cancer syndromes, patients often experience their condition in isolation, never meeting anyone outside of their family who shares their disease. For Travis Bray, the first time he met someone outside of his family was 20 years after his diagnosis and colectomy. He describes meeting Jon Olis and Todd Spurrier as “cathartic.” It didn’t take long for these three men to compare scars and one up each other on medical stories!

We want others to have the same opportunity. To this end, we are working with Dakota Fisher-Vance, creator of Fapulous TV, an educational YouTube channel for those with F.A.P., to lead **HCCS Patient Days**. These events will include both education and empowering fun. Initial events will take place this summer in the U.S. with the goal of spreading them across the globe in 2015. Dates and locations for this summer’s events will be posted on our web site by April.

## Improving Quality of Care

Today, when patients are diagnosed with an HCCS, they will likely be cared for by a medical team whom has never treated a patient with their disease. Often, this medical team does not have access to correct and current screening and treatment guidelines. We are raising the level of care these patients receive by educating medical professionals on these rare diseases. The webinar topics listed on our calendar, were chosen by our Medical Professional Outreach Committee. Dates and times will be posted on [www.HCCTakesGuts.org](http://www.HCCTakesGuts.org) one month prior to each event.

## Sponsors



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## Support Us

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Please support our work by making  
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[www.HCCTakesGuts.org](http://www.HCCTakesGuts.org)

or by check:  
P.O. Box 2005  
Park City, UT 84060

## Foundation Calendar

### MARCH

- Education and Inspiration for CC Awareness Month
- New content on [HCCTakesGuts.org](http://HCCTakesGuts.org)

### APRIL

- Patient Webinar: Maximizing Health Insurance
- Non-polypoid content on [HCCTakesGuts.org](http://HCCTakesGuts.org)

### MAY

- Patient Webinar: Communicating with Doctors
- New content on [HCCTakesGuts.org](http://HCCTakesGuts.org)

### JUNE

- Patient Networking Events Begin

### JULY

- Medical Webinar: Genetic Diagnosis

### AUGUST

- Medical Webinar: Current Screening Protocols

### SEPTEMBER

- Medical Webinar: Successful Colectomies

### OCTOBER

- Medical Webinar: Upper GI Symptomology
- CGA-ICC Annual Meeting
- NSGC Annual Conference

### NOVEMBER

- Medical Webinar: Research Highlights

## Patient Support

We would like to thank the following patient advocates for reaching out to us, volunteering their time and/or providing inspiration and guidance in our work. If you are interested in helping us achieve our ambitious work, volunteer by contacting [ShawnieBray@HCCTakesGuts.org](mailto:ShawnieBray@HCCTakesGuts.org).

Tory Aldridge  
Danielle Brannan  
Tiffany Costello  
Jennifer Cross Johnson  
Dave Dubin  
Kasey Duffens  
Dakota Fisher-Vance

Erika Hanson Brown  
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Leanne Stinson  
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