

# The Gut Check

*A quarterly newsletter serving the hereditary colorectal cancer community*

Issue No.4 - December 2014

## Enjoy a Healthy Holiday Season

There is much joy to be had during the holiday season. But an abundance of festivities and goodies can lead us to experience digestive pain, exhaustion, and even depression. Wouldn't it be wonderful to have the energy to thrive, not just survive, this holiday season? Following are just a few small changes that can help you enjoy this season.

### Plan for crazy busy days.

Don't leave yourself with a drive-thru as your best option. Instead, if you know that tomorrow, you'll need to run a gazillion errands, stock the fridge with a meal that requires no preparation.

### Cook once, eat twice.

There is no better time of year to start this habit. With gift shopping, card writing, and holiday parties to attend, you'll have less time to do everyday tasks. Make a humongous pot of your favorite stew and serve it two nights in a row!

### Pregame!

Not the way you might have in college, this time it's about setting yourself up to feel great the morning after. To prevent overindulging at a party, or eating foods your body can't handle, eat a nutrient dense small meal before



you leave home. You'll eat less at the party and will feel less guilty about the few treats you do consume. You'll likely sleep better and be less bloated too!

For wonderful recommendations on dealing with the emotional challenges of chronic illness during the holiday season, check out "13 Holiday Tips for Patients" from the Colon Cancer Alliance at <http://bit.ly/1Dp2dv5>.

## President's Letter

Dear Community Members,

Entering the season of gratitude, we would like to give thanks...

To the **patients** advocating for their care, searching for answers, and supporting one another... Thank you! YOU inspire and guide us!

To the **providers** who have voluntarily shared their contact information on [HCCTakesGuts.org](http://HCCTakesGuts.org), so that our patients can find quality care... Thank you!

To the **providers** who have spent hours expanding their knowledge through our "Preparing to Treat Polyposis" webinar series, to continue to deliver exceptional care... Thank you!

To our **donors**, our work wouldn't be possible without you. Thank you. Thank you. Thank you!!!

Sincerely,  
Shawnie & 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>Peutz-Jeghers Syndrome</b>
<b>Hereditary Mixed Polyposis</b>	<b>Turcot Syndrome</b>
<b>Juvenile Polyposis Syndrome</b>	

## "Best Practices in Treating Polyposis Conditions" - A Webinar Series

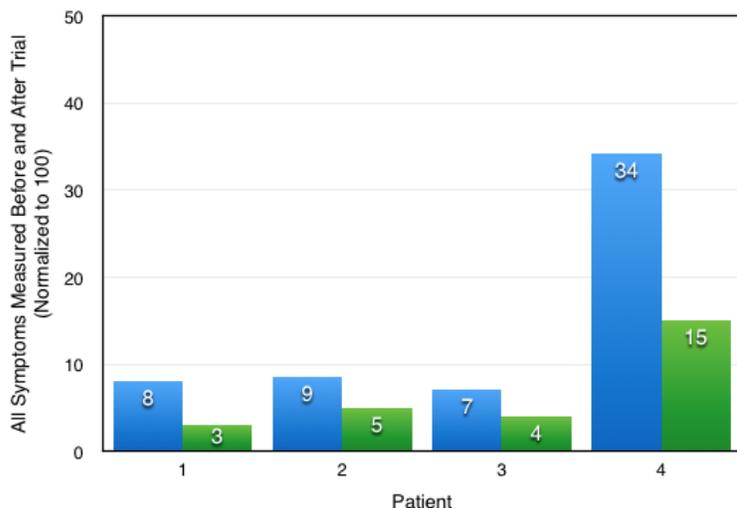


As part of the Hereditary Colon Cancer Foundation's commitment to improve the quality of care for our patient population, we hosted a live and on-demand webinar series discussing key issues

and best practices in treating polyposis conditions. Over 200 medical professionals have already attended and provided positive feedback about the speakers and the depth of content. Providers may still register to access the content at <http://bit.ly/1rCz711>.

### Diet for Bowel Diversions

Quality of life challenges faced by patients with bowel diversions are frequently related to nutrition. Shawnie Bray, VP at the Foundation and Integrative Nutrition Coach, recently lead a pilot study to assess if an anti-inflammatory diet could improve the quality of life for patients with bowel diversions. The results were promising indeed! We are very thankful for the efforts of our volunteers. More information can be found at <http://bit.ly/1woR86Q>.



We would like to thank our 2014 series presenters:

**Carol Burke, MD**, of the Cleveland Clinic

**Douglas Riegert-Johnson, MD**, at Mayo Clinic, Jacksonville, FL

**Michael Hall, MD, MS**, at the Fox Chase Cancer Center

**Brandie Leach, MS, LGC**, of the Cleveland Clinic

**Deb Neklason, PhD**, at the University of Utah Huntsman Cancer Institute

**Elena Stoffel, MD, MPH**, at the University of Michigan

**Paul Wise, MD**, at the Washington University - St. Louis

### 2015 Webinar Series "Treating Lynch Syndrome"

The Foundation is pleased to announce seven live, and subsequently on-demand, webinars to educate medical professionals about key issues and best practices in treating Lynch Syndrome. Presented by medical professionals with expertise in treating Lynch Syndrome, these webinars will start in March and run monthly through September 2015. The Lynch Syndrome webinar series will cover the following topics:

1. Defining Lynch Syndrome: An Overview
2. Universal Tumor Screening for Lynch Syndrome and the Impact on Colorectal Cancer Care
3. Gastrointestinal Manifestations in Lynch Syndrome
4. Gynecological Manifestations in Lynch Syndrome
5. Secondary Manifestations in Lynch Syndrome: Breast, Prostate, Sebaceous, and Other Tumors
6. Atypical Lynch and When it's Not Lynch
7. Lynch Syndrome: Patient Centered Care

More details will be released and registration will be open in January, 2015!

## Education & Support Groups



Would you like to be the HERO who starts the local chapter of the "HCC Takes Guts Education and Support" group in your area? We're looking for energetic, passionate individuals to work with us and start these groups nationwide.

Given the rare nature of hereditary colon cancer syndrome, patients are frequently diffusely dispersed and experience their condition in a vacuum. Peer-based support programs empower patients to improve the management of their health while providing them meaningful opportunities to help others facing similar challenges. The Foundation will work with motivated individuals, and in tandem with centers of excellence, to start local chapters of "HCC Takes Guts Education & Support Groups" across the U.S. In addition to providing patients opportunity to network, these groups will incorporate educational resources produced and/or presented by local specialists.

Contact [TravisHBray@HCCtakesGuts.org](mailto:TravisHBray@HCCtakesGuts.org) for more information!

## Help with Health Insurance



We are pleased to announce the release of an insurance video, recorded specifically to help those with a Hereditary Colon Cancer Syndrome understand your health insurance

policy, rights, and options. Presented by Michelle Sutter, AFAP patient advocate and President of Health & Benefit Operations at World Association Inc., this webinar will help patients and advocates:

### **Understand your policy.**

Deductible? Co-pay? Preventative care? We simplify it for you!

### **Get the care you deserve.**

Coverage denied? Pre-existing conditions? Need a referral? We help you know your rights.

### **Know your options.**

Affordable Health Care Act? Exchanges? Subsidies? We help you explore your choices.

To view now, go to <http://bit.ly/1w0wknL>.

## 2015-2016 Board of Directors

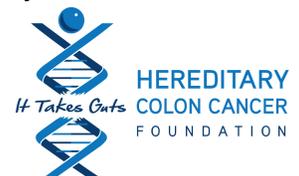
On December 9th, we had the honor of welcoming two new members to our Board of Directors for 2015-2016. We are excited to work with Kristen Truffa and Dr. James Church. Kristen Truffa, the Associate Director of Mid-Atlantic Network of Youth and Family Services, brings over 20 years of non-profit experience to the table. James Church, MD, is a world renowned colorectal surgeon specializing in hereditary colon cancer syndromes and has been the Director of the David G. Jagelman Inherited Colon Cancer Registries and the Head of the Section of Endoscopy, at Cleveland Clinic since 1989.

We are also very pleased to continue working with returning board members Michelle Beem, Joel

Glidden, and Beth Houck, who provide business insights, genetic counselor Brandie Leach, MS, LGC, physician specialist Randall Burt, MD, clinical researcher Deborah Neklason, PhD, and genetic counselor Kory Jasperson, MS, LGC.

Directors Travis and Shawnie Bray will be leaving their posts as President and Vice-President, respectively, to assume the roles of Foundation CEO and COO.

This diverse board presents the multifaceted expertise necessary to provide the greatest positive impact on the Hereditary Colon Cancer community.



## Your Feedback?



Have we earned your support in 2014? We provide education through social media every day and continually participate in discussions with patients

seeking advice. And, HCCtakesGuts.org receives over 1000 visitors every month! Please let us know how we've supported you, or someone you care for.

If we've earned it, please support us in one of two ways...

1) Make a donation. Every dollar counts! Your \$20 helps us support 5 patients and \$100 supports 25!

2) Share your story about your experience with the Foundation. Testimonials are extremely valuable and let donors know why they should keep supporting our work in 2015. Your words are pearls!

## Foundation Calendar

### DECEMBER

- Medical Webinar: Best Practices in Genetic Screening
- Fundraising for 2015 Patient Services

### JANUARY

- Medical Webinar: Multi-Gene Panel Testing
- Lynch Webinar Series Announced
- Volunteer Committees Set 2015 Goals

### FEBRUARY

- 2015 Patient Programs Announced

### MARCH

- Education and Inspiration for CC Awareness Month
- Lynch Webinar Series Begins

## It Takes Guts Wear



Order online at <http://bit.ly/1vM2X3k>

## Sponsors



## Support Us

Please support our work by making a tax-deductible donation online at [www.HCCTakesGuts.org](http://www.HCCTakesGuts.org).



Hereditary Colon Cancer Foundation is a GuideStar Exchange Gold Participant

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