

Inherited Colorectal Cancer Registry

FALL 2013 NEWSLETTER

 Washington University in St. Louis

SCHOOL OF MEDICINE

COLORECTAL SURGERY & GASTROENTEROLOGY

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Our goal is to identify as many people with inherited colon cancer syndromes as possible so they can receive the appropriate cancer screening, treatment and education.
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Clinical Studies: FAP/AFAP

LOCATION: Huntsman Cancer Institute, University of Utah in Salt Lake City.

REQUIREMENTS: Individuals 18 to 69 years of age with a clinical or genetic diagnosis of familial adenomatous polyposis (FAP) or attenuated FAP (AFAP).

PURPOSE: Determine if the combination of the two study drugs (sulindac and erlotinib) can affect a significant decrease in duodenal and colorectal polyps in FAP and AFAP.

STUDY COST: Covered by the study.

If you would like to learn more about this clinical trial, contact: Therese Berry, Clinical Research Coordinator. Phone: 801-581-3917 (toll-free) 1-800-650-9071 E-mail: therese.berry@hci.utah.edu

Washington University Colon and Rectal Surgery is participating in an international **familial adenomatous polyposis (FAP) study** to assess an investigational agent to treat, delay and/or prevent the development of intestinal polyps. If you or a family member have FAP and wish to get more information or see if you qualify, please contact Nida Jamal at **314-362-0552**.

Paul Wise, MD, Named Director of Registry

Paul E. Wise, MD, joined the Section of Colon and Rectal Surgery at Washington University in St. Louis in August 2012 as an associate professor of surgery. He is the director of the Inherited Colorectal Cancer and Polyposis Registry, as well as the associate program director for the Colon and Rectal Surgery Residency.

Dr. Wise received his medical degree in 1996 from The Johns Hopkins University School of Medicine after which he did his residency training in surgery at Vanderbilt University Medical Center in Tennessee. He completed his fellowship training in colon and rectal surgery at



Washington University School of Medicine in St. Louis in 2004.

Dr. Wise has a special interest in hereditary colorectal cancer syndromes (Lynch syndrome, hereditary nonpolyposis colorectal cancer [HNPCC], familial adenomatous polyposis [FAP], polyposis syndromes). He served as president of the Collaborative Group of the Americas on Inherited Colorectal Cancer from 2011 to 2012.

Patient Profiles

Alissa Murphy

I was getting ready to go to a holiday party back in December of 2006 when I first noticed some rectal bleeding. Even though I felt fine, I knew that I had a family history of colorectal cancer on both sides, so I decided to get myself checked.

Initially I was seen by a gastroenterologist who did my colonoscopy. When I awoke from the anesthetic, I could tell by his expression the results were not good. He was surprised by what he found, said he would be doing a biopsy, and wanted me to follow up with a colorectal surgeon. He proceeded to say, "If it is cancer..." That's all I remember — along with my mom crying.

I couldn't understand how it could be cancer. I was only 36 years old. I was healthy, worked out regularly and felt fine. Surely, it couldn't be cancer.

Two days later, I met with the colorectal surgery chief at Washington University. I was diagnosed with stage 3 rectal cancer. My treatment consisted of one month of chemotherapy and radiation to shrink the 5 cm tumor in my rectum, followed by surgery, then six months of



follow-up chemotherapy and a final surgery to reverse my stoma. The treatments were long and challenging, both physically and mentally. I was very fortunate to have a tremendous amount of love and support from my family, friends and church and a tremendous team of doctors and staff, all working to heal me.

Because of my cancer diagnosis at a young age, it was recommended that my brother, who was 39, also get a colonoscopy. It was fortunate that he did because they found several adenomatous polyps, which were removed.

My mission has been to help create awareness of colorectal cancer, especially in younger patients. For this purpose, I speak about my cancer experience to the community and medical students. I am happy to say that this spring will mark six years that I have been cancer free!

Teri Griego

I started my journey with cancer on September 17, 2009. A colonoscopy revealed a mass, and then just a few hours later a CT scan revealed that the mass had metastasized to the liver. In the snap of a finger, I was diagnosed with stage IV colorectal cancer. This happened just two weeks after I had completed an Ironman event (2.4 mile swim, 112 mile bike, 26.2 mile run).



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Visit us at: www.colorectalregistry.wustl.edu

About us

The Washington University Inherited Colorectal Cancer Registry has been serving patients — such as Alissa Murphy and Teri Grieger — and their families with inherited colon cancer syndromes since the 1970s. Our goal is to identify as many people as possible with a predisposition for colon cancer so they can receive the appropriate cancer screenings and treatment. In the process, we hope that we can learn more about the hereditary syndromes and advance the knowledge and understanding of inherited colon cancer. Patients who have a history of multiple polyps on colonoscopy (FAP) or who present with features suggestive of HNPCC may be flagged for inclusion in our registry. They are referred to our genetic counselors at Washington University, who then gather a more detailed family history and arrange for genetic testing. Patients with inherited colon cancer syndromes such as hyperplastic polyposis syndrome, juvenile polyposis syndrome, and Peutz-Jeghers syndrome are also encouraged to participate in our registry.

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Since my diagnosis, I have worked diligently to maintain a rigorous training schedule while being treated for cancer. I have undergone radiation treatments, chemotherapy, surgeries and presently receive maintenance chemotherapy. I continue to train and participate in events from 5Ks to the Ironman World Championship in Kona, Hawaii; I am "Powered by Hope." It is my dream to see a world without cancer. Two weeks after I was diagnosed with colon cancer, two of my sisters had colonoscopies; one had precancerous polyps and the other stage III colon cancer. Shortly thereafter, two of my four nieces were found to have

precancerous polyps. From that day forward, I began a mission to spread awareness and inspiration about colon cancer. My family and friends are what motivates me; I pray they will never have to endure what I had to. I am determined to kick cancer for me, for them and for you. I cannot think of a better way than to share my story by participating in as many engagements and events as possible.

I swim-ride-run-raise-research-talk-share-support-inspire, all for a world without cancer.

With Gratitude, Teri
Powered By Hope
For more on my story please
visit my website terigrieger.com

Our multidisciplinary team includes our registry coordinator, colorectal surgeons, gastroenterologists, genetic counselors, nutritionists and enterostomal therapists. In addition to this, the Siteman Cancer Center is

expanding their genetic counseling services to accommodate a greater volume of patients. To find out more about the Inherited Colorectal Cancer Registry, please contact the registry coordinator, Nida Jamal, at 314-362-0552.



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Colorectal Cancer

Patient appointment or physician referral:
314-454-7177, option 2

www.colorectalregistry.wustl.edu