

A Positive Transition

Navy Veteran faces rare case of cancer with the right attitude

By Daniel Shockley

As a veteran of 22 years in the Navy, I receive annual physical examinations at the Spark M. Matsunaga Veterans Affairs Medical Center (VAMC) in Hawaii. Dr. Laura Jones, VAMC, discussed the importance of having a colonoscopy once I reach 50. Leading up to my first colonoscopy, I considered myself to be in very good health, other than an unexpected 14lb weight loss during the course of the previous year. As a result, it was decided I should undergo an esophagogastroduodenoscopy (EGD) in conjunction with the colonoscopy.

Dr. Fernando Ona, VAMC, performed the procedures in May last year. Dr. Ona found at least 100 polyps throughout my colon, rectum and anus along with a large mass in the transverse colon causing an 80% blockage. I was referred to Certified Genetic Counselor Susan Donlon at the Tripler Army Medical Center (TAMC).

Inevitable Outcome

At this point, I realized surgery was inevitable and I was willing to accept the worst-case scenario. I tend not to think about medical issues I am unable to control. What I can control is my attitude. After 51 years on God's green earth, my positive attitude has brought me far in life. Why change now?

Counselor Donlon confirmed I have the gene mutation APC with the diagnosis of attenuated familial adenomatous polyposis (AFAP). Lt. Col. Ronald Gagliano, chief, colon and rectal surgery and director, surgical research, TAMC, was assigned my case. He informed me I would need a total proctocolectomy with ileostomy, which would remove the entire colon, rectum and anus.

It should be noted that while I had at least 100 polyps throughout my large intestine, this isn't always true with AFAP. There can be cases where there are only a few adenomatous polyps. Sometimes, these cases can be controlled with less drastic surgery. Someone with classical familial adenomatous polyposis (FAP), on the other hand, may have thousands of adenomatous polyps and these may start in childhood.

Dr. Gagliano encouraged me to read about AFAP and



Daniel Shockley with colorectal surgeon Dr. Gagliano of Tripler Army Medical Center. Photo provided by U. S. Army.

the surgical procedure. This would allow me to better familiarize myself with what is considered lifesaving surgery as well as a life-changing event. FAP accounts for fewer than 1% of all colorectal cancers, while Lynch syndrome, the most common hereditary colorectal cancer syndrome, is responsible for 2.8% colorectal cancer cases. On June, 29, 2012, Dr. Gagliano and Susan Donlon reviewed all the test results. My wife and daughter were present and based on the findings, I agreed to have the surgery.

The surgery was successfully performed by Dr.

Gagliano on July 13, 2012. After six hours of surgery, I spent 30 minutes in the recovery room. I had a 10-inch incision with 35 staples in my abdominal area and 13 staples where my anus was removed. Other than being weak, I felt fairly good for having gone through such an invasive surgery. I was on bed rest and encouraged to take a short walk after the third day after the surgery. Nina Lum, certified wound, ostomy and continence nurse (WOCN) TAMC provided my care and education on how to care for myself throughout my recovery.

The pathology report listed the large mass as a tumor 8cm and on the verge of turning into cancer within weeks. On July 24, 2012, I was discharged to begin my recovery at home. The TAMC team continued to express how amazed they were with my recovery. I responded that I am just as amazed if not more as everyone else.

I often reflect on the Norman Vincent Peale quote: "The person who sends out positive thoughts activates the world around him positively and draws back to himself positive thoughts." One thing I have learned through my experience is that attitude is 90% mental and 10% physical. I believe attitude determines the ability for a positive transition. Maintaining a sense of humor is also important. I like to reflect on the following Hugh Sidey quote: "A sense of humor... is needed armor. Joy in one's heart and some laughter on one's lips is a sign that the person down deep has a pretty good grasp of life."

Finding Support

During recovery, my focus was to keep my brain busy since I would be at home for the seven weeks. Hollister, Inc. provided a Secure Start new patient ostomy kit with tips on caring for my ostomy.

UOAA provided me with a copy of the *Ileostomy New Patient Guide*. The guide featured Robert (Bob) Cuyler, who is an Army helicopter pilot. I asked the Army if it would be possible to pass along my contact information to Bob. Later that day, I received a call from Bob and had a chance to talk about our experiences. The TAMC staff writer wrote a feature story about me that was published on October, 26, 2012. The WOCN society read the TAMC feature article. The society was interested in publishing an article on my experience. The article was published in the WOCN Spring Magazine.

As time went on, I reached out to the Colon Cancer Alliance and the Fight Colorectal Cancer organization. Jim Murray, UOAA board member, contacted me expressing interest in my experience. I continued to keep these groups updated on my happenings as I

sought out more information about AFAP.

The Fight Colorectal Cancer organization informed me they would be creating a new website in support of March being National Colorectal Cancer month and asked if I would contribute. My information debuted February 20, 2013, which is the same day I had the opportunity to meet Dr. Lynch in Hawaii at the University of Hawaii, Cancer Center.

Genetic Awareness

I accepted the AFAP diagnosis from the very beginning and my passion is to learn more about the disease and get the word out to the masses about my case. Especially when I was informed my case is listed as an unusual clinical presentation. I found out that my parents and siblings have no history of colon cancer. Dr. Henry Lynch informed me

that APC mutations are often "de novo" (new). There is a good chance that the mutation started with me. Possibly one-third of APC mutations are de novo.

My case was included in TAMC Hereditary Cancer Risk Assessment lectures. I attended these lectures as a "live case presentation." I enrolled in the Johns Hopkins Hospital Hereditary Colon Cancer Registry (HCCR) and the Family Registry of Hereditary Cancer at Creighton University which was founded by Dr. Henry T. Lynch, who is considered a pioneer in genetic research. My hope is that someday there will be a case study on me by Dr. Lynch and his team at Creighton University.

To date, I have a rather large following about my experience in which I continue to share as a source of encouragement and inspiration. I am an active patient advocate for AFAP.

Personal outreach

My outlook is: another day, another positive testimony. Having my information spread to the masses will hopefully be a source of encouragement and inspiration for bringing awareness to the importance of colorectal screening. I want to share my story with others on behalf of those patients that have gone before me and who were unable to share their story.

I highly encourage early detection by getting colonoscopies starting at age 50 unless family history indicates that they should be started sooner. My catchphrases are: "AFAP – Seize the disease!" and: "More about AFAP. Less about me!"

My mission in life is to share my experience in an effort of reminding everyone just how important having a colonoscopy at the 50 year mark really is. ☺

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