

ONE STEP AT
A TIME

One Step at a Time: A Patient's Story

BY EMILY FEST, MEMBERSHIP COORDINATOR, WOCN SOCIETY

When most people are faced with a bleak medical diagnosis, it's difficult to maintain a positive attitude. However, in the case of Daniel Shockley, who was diagnosed with Attenuated Familial Adenomatous Polyposis (AFAP), he proved anything but defeated. Because of the guidance and support of his medical team at Tripler Army Medical Center (TAMC) in Hawaii, he was able to keep a level head and marvel at his own body's resilience.

The retired sailor had no indication that there was anything medically wrong when he went for his first colonoscopy scheduled by the Spark M. Matsunaga Veterans Affairs Medical Center, Hawaii. Dr. Fernando Ona of the VA Center performed the procedure at the Hawaii Pacific Health Clinic in May 2012. Aside from some weight loss, he thought he was perfectly healthy.

What Dr. Ona found, however, was anything but "normal." Daniel had 100 polyps embedded throughout his colon, rectum, and anus. He also had a large tumor at his transverse colon, the junction between the large and small intestines. This accounted for an 80 percent blockage. Needless to say, they needed to act quickly.

Shockley was referred to Tripler Army Medical Center's General Surgery Clinic for further evaluation. His appointment with Tripler's certified genetic counselor, Susan Donlon, was the following week. To familiarize himself with the clinic's location he decided to visit it in advance. When he entered the General Surgery Clinic waiting room, he saw pictures hanging on the wall of some of the staff. One face he recognized was Chief of Surgery Dr. Ian Freeman. Although Shockley was retired, he worked various jobs, one of which was at a local hardware store. Dr. Freeman was a frequent customer of Shockley's and had become friendly with him over the years. At the moment he saw Dr. Freeman's picture he knew he would be in good hands; the calm that overcame him was reassuring.

DNA testing was performed during his genetic consultation with Susan. The screening revealed that he had a gene mutation known as Adenomatous Polyposis Coli, which increases a person's risk of developing colorectal cancer. This led to the ultimate diagnoses of Attenuated Familial Adenomatous Polyposis (AFAP), a rare condition in which many polyps form mainly in the large intestine.

Daniel knew then that surgery was inevitable. "I was ready for the worst case scenario," he said.

His case was assigned to Lt. Col. Ronald Gagliano, chief, Colon and Rectal Surgery and director, Surgical Research at TAMC.



DANIEL SHOCKLEY (LEFT)
AND DR. HENRY T. LYNCH

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Gagliano and his team took the time to explain his condition and what to expect from what Daniel would later describe as a "life changing event."

In July 2012, Shockley underwent a total proctocolectomy with ileostomy surgery which took six hours. This removed portions of his large intestine including the colon, rectum, and anus. He would need to wear a pouching system for the rest of his life.

Following the surgery he was cared for each step of the way by Tripler's WOC nurse, Nina Lum, who educated him about his ostomy. She provided a Hollister ostomy instructional DVD for his wife and daughter to view during their visit. In addition, Lum explained the pouching system and how to care for it, as well as body image and embarrassment issues. By the end of Daniel's twelfth inpatient day, he was able to change the bags himself.

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Most people who knew Shockley before the surgery couldn't tell that he now had this medical device. He credits much of his success to his outlook. "Attitude determines the ability for a positive transition," said Shockley. "It's 90 percent mental and 10 percent physical."

Since then, he has been a patient advocate for AFAP, the United Ostomy Association of America (UOAA), and Hollister ostomy products. He is also an ambassador for colon cancer awareness. Shockley is enrolled in both the Johns Hopkins Hospital Hereditary Colon Cancer Registry and Creighton University Family Studies of Hereditary Cancer study. He's even created his own catchphrases, "AFAP—Seize the disease!" and "More about AFAP. Less about me!" Daniel encourages early detection by getting colonoscopies starting at age 50.

Daniel shares his experience and diagnosis with the medical community as there is little information about AFAP. In January 2013 he was invited to be the first ever "live case presentation" for two of Tripler Medical Center's Academic Cancer Genetics Risk Assessment Conferences. He also shared his story as a part of Fight Colorectal Cancer's "One Million Strong" campaign, which kicked off March as Colorectal Awareness Month. Shockley was especially excited about recently meeting with the doctor credited with discovering AFAP, Dr. Henry T. Lynch, in Hawaii. Dr. Lynch is one of the founding fathers of genetic research and is the chairman of Prevention Medicine, Public Health Professor of Medicine and director of Creighton's Hereditary Cancer Center in Omaha, Nebraska.

When blindsided by a medical anomaly, Shockley learned to adapt and remain positive. His doctors credit much of his recovery to his philosophy of not worrying about things out of his control. His best advice: "Take one step at a time."

CORPORATE MEMBER NEWS

HDIS, Inc. Named Provider of the Month by the National Multiple Sclerosis Society

The National Multiple Sclerosis Society named Home Delivery Incontinent Supplies Co., (HDIS) its Nationwide Service Provider of the Month for December 2012. HDIS, a corporate member of the WOCN Society, was chosen out of 160 MS Society-approved providers for the company's product knowledge, customer relations, and service excellence.

HDIS is one of the nation's largest providers of incontinence supplies to agencies and seniors at home. As a Provider of the Month, HDIS is promoted by the MS Society and staff is encouraged to refer new clients to HDIS for the month.

The MS Society created a nationwide provider list as a service to their clients. This group of vetted providers offers services, resources, professional advice, products, and expert opinions regarding multiple sclerosis. Each month, the MS Society solicits suggestions from their nationwide staff regarding which provider should be chosen that month. Submissions come in from staff in the home office, the national call center and the 46 chapters. ♦

If you have Corporate Member news that you'd like to share, reach out to us at share@wocn.org.