

July Hero of the Month: AFAP Advocate Daniel Shockley

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/ by [Kate Brennan](#)



Each month, Be Seen, Get Screened features a member of the colon cancer screening community that has gone above and beyond to spread the word about colon cancer and the importance of screening. We call this Q&A session our [Hero of the Month](#) feature.

At the age of 51, Daniel Shockley received a life-changing diagnosis after having his first colonoscopy: he had Attenuated Familial Adenomatous Polyposis, or AFAP.

AFAP is a subtype of a condition known as familial adenomatous polyposis (FAP), which causes an increased number of colon polyps and therefore an increased risk of colon cancer in the

people who have it.

In this month's Q&A, Mr. Shockley tells us how he has used his life-altering experience with AFAP and military background to reach out to the AFAP and colon cancer communities to increase awareness of hereditary cancers.

BSGS: Tell us about your personal experience with [Attenuated Familial Adenomatous Polyposis \(AFAP\)](#).

Daniel Shockley: It was in May 2012, at the age of 51, when I first learned of Attenuated Familial Adenomatous Polyposis (AFAP) after my first colonoscopy. As a retired member of the Navy, the procedure was conducted by Dr. Fernando Ona of the Veteran Affairs Spark M. Matsunaga Medical Center (VAMC), Hawaii.

The outcome revealed a large mass in my colon and 100 polyps embedded throughout my colon, rectum and anus. Based on these findings I was immediately referred to the Tripler Army Medical Center (TAMC), Hawaii for a consultation with their Certified Genetic Counselor, Susan Donlon, in which DNA testing was conducted.

The DNA results revealed I had the gene mutation, Adenomatous Polyposis Coli (APC), confirming the diagnosis of AFAP which is estimated to affect less than 0.03% of the global population. I had numerous follow-ups with my surgeon, Dr. Ronald Gagliano, along with Susan Donlon and was encouraged to read about AFAP to better familiarize myself with this condition.

It was during these visits I was informed if the large mass and polyps are left unattended there is a 100% chance of them developing into colon cancer. It was determined, based on the best practices of medicine, that I would need total-proctocolectomy with ileostomy surgery. This type of surgery removes the entire colon, rectum and anus.

Leading up to my surgery I was conducting my own research on AFAP, the surgical procedure and life after surgery. The surgery was successfully conducted at TAMC July 2012. As a result, I have an ostomy pouching system, a prosthetic medical device that provides a means for the collection of waste.

I embraced being diagnosed with AFAP from the beginning and have undergone what is considered to be lifesaving and life changing surgery. My mindset from the onset can be best described as: I tend not to think about things I am unable to control. Medical issues I am unable to control.

What I can control is my positive attitude and after 51-years on God's green earth it has brought me this far, why change now. Therefore, I keep the faith, remain positive and overcome adversity each step of the way.

BSGS: How did your experience in the military help you deal with your diagnosis and treatment?

Daniel Shockley: During my 22-year Navy career I learned that mental and physical strength are important attributes to possess, especially in the face of personal or professional adversity. Maintaining a positive attitude while committed to the mission is instrumental in achieving success.

This was evident during my numerous deployments to the Persian Gulf prior to and during OPERATION ENDURING and IRAQI FREEDOM.

Preparation is significant in achieving mission readiness, utilizing the vast array of resources enhanced the opportunity for achieving success. While faced with many challenges, both professionally and physically, I maintained a positive attitude and utilized numerous resources that allowed me the opportunity for a better understanding of the situation.

To me, challenges are opportunities and being prepared along with retaining a positive outlook are key. It is also important to minimize any distractions that could have an impact on the outcome of the mission or challenge.

I am a firm believer that my faith and being able to plan for the worst and hope for the best allow me the opportunity for a success story.

BSGS: What are you doing to raise awareness of colon cancer and syndromes like AFAP?

Daniel Shockley: As an advocate in Hawaii for the [Colon Cancer Alliance \(CCA\)](#) and [Fight Colorectal Cancer](#) organizations I requested the Hawaii Governor and Mayor of Honolulu to proclaim March – National Colorectal Cancer Awareness in Hawaii 2014. The Governor and Mayor honored this request marking the first time Hawaii has had such a proclamation.

I also reached out to Hawaii Senator Brian Schatz and Congresswoman Colleen Hanabusa informing them of my local efforts bringing awareness to this campaign. They both joined this effort and provided their own personal letters acknowledging their support.

Also, my local employer, City Mill, Ltd., included my inputs and photo on a company-wide flyer showing support for the March campaign. Additionally, the local Hawaii newspaper, MidWeek, published an article in their May 7, 2014 edition under the “Good Neighbor” section mentioning my recent awareness involvement.

Furthermore, City Mill has joined forces this year with the American Cancer Society Relay for Life in Honolulu. The event is scheduled to take place 19 July, 2014 and I have been asked by the ACS to be part of their Survivor booth.

In closing, other awareness opportunities include sharing my experience with HCC Takes Guts, National Organization of Rare Disorders (NORD), Wound, Ostomy and Continence Nurse (WOCN) Society, United Ostomy Associations of America (UOAA), Chris4Life, Michael’s Mission and Hollister Inc.

BSGS: Why do you think there are so few resources out there for people with syndromes like

FAP, AFAP, and Lynch Syndrome?

Daniel Shockley: It appears there are a limited number of resources for people with all varieties of hereditary cancer. My hope is that one day my efforts as an advocate for colon cancer will add significantly to this deficit of education pertaining to these concerns.

BSGS: What do you say to others out there who may be battling colon cancer, AFAP, or another colorectal disease or syndrome?

Daniel Shockley: Understand your condition to the best of your ability, strive to overcome adversity, adapt to your condition, and as a result it will allow you the opportunity to press on with your life.

BSGS: What is one thing everyone should take away from your experience?

Daniel Shockley: Worrying did not cause my condition. Therefore, worrying will not make it go away.

BSGS: Do you have anything else to share with us?

Daniel Shockley: When faced with life's challenges I depend on my faith in God. After all, he is the Great Physician and Great Counselor.

I also utilize the numerous online cancer resources and have enrolled in the hereditary cancer registries at Creighton University and Johns Hopkins Hospital. These resources have been effective tools which allow me the opportunity to learn more about my condition and share my experience as a source of inspiration and encouragement.

This in turn allows me the opportunity to remain focused on overcoming adversity and pressing on with my life with a business as usual approach. In closing I would like to add as a result of my lifesaving surgery and life changing event my mindset can be best summed up as: Attitude determines the ability for a positive transition.