

# LIVING WITH A RARE DISORDER

## *Attenuated Familial Adenomatous Polyposis*

**M**y name is Daniel Shockley, retired U.S. Navy, Operation Desert Storm; Operation Enduring Freedom and Operation Iraqi Freedom veteran. I am a colon cancer survivor, have a rare gene mutation and an ostomy. At the age of 51, I received a life-changing diagnosis after having my first and only colonoscopy: I was diagnosed with 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. I'll explain how I used my life-altering experience with AFAP and military background to reach out to the AFAP and colon cancer communities to increase awareness of hereditary cancers. It was in May 2012, at the age of 51, when I first learned of AFAP after my first and only colonoscopy. As a retired member of the U.S. Navy, the procedure was conducted by the GI Clinic, 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, 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 <0.03% of the global population. I had numerous follow-ups with my colorectal surgeon along with my genetic counselor and was encouraged to read about AFAP to better familiarize myself with this condition. It was dur-

ing 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 as an ostomate. 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 a 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 especially medical issues I am unable to control. What I can control is my positive attitude and after five decades 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. Here's how my experience in the military helped me deal with my diagnosis and treatment. 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 in direct support of Operation Desert Storm; Operation Enduring Freedom and Operation 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 a 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. Since my diagnosis and surgery my life is in "pay it forward" mode. I'm sharing my journey as a source of inspiration and encouragement and importance of early detection. Here are some advocacy efforts I'm involved in to raise awareness of ostomates, colon cancer, and syndromes like AFAP. As an advocate in Hawaii, 2013-2016, I represented the Colon Cancer Alliance (CCA); National Organization for Rare Disorders (NORD) Rare Disease Day (RDD) and United Ostomy Associations of America (UOAA) organizations requesting the Hawaii Governor and Mayor of Honolulu to proclaim March – National Colorectal Cancer Awareness; 28 February, Rare Disease Day and the 1st Saturday of October as Ostomy Awareness Day in Hawaii. The Governor and Mayor honored these requests marking the first time Hawaii has had such a proclamations. I've recently relocated to Idaho and will continue with these advocacy efforts here in the Gem State. Additionally, other awareness opportunities include sharing my experience with FAP Gene Support Group, based in England; HCC It Takes Guts; Wound, Ostomy and Continence Nurse (WOCN) Society; Hollister Inc; Stealth Belt ostomy products and H2ORS. Here are some thoughts on the importance of my advocacy efforts and

why I think there are so few resources out there for people with syndromes like FAP, AFAP, and Lynch Syndrome. 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 ostomates, rare disease and colon cancer will add significantly to this deficit of education pertaining to these concerns. Here is what I say to others out there who may be battling colon cancer, AFAP, or another colorectal disease or syndrome. 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. 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. Here is one thing everyone should take away from my experience. Worrying did not cause my condition. Therefore, worrying will not make it

go away. Adapt, Improvise and Overcome as I was equipped to do in the military. Furthermore, here's something I'd like to share. I read about a sermon G. Lee Avery made in 1958 pertaining to attitude: "The medical profession is filled w/stress and adversity - especially w/the current health-care crisis. One doctor, though, found a way to handle some of the occupational hazards that accompany the medical community. When asked how he could carry a smile in the midst of so much suffering and disease, he replied 'I always look upon disease from the curative standpoint.' Christian's gain, and maintain, higher levels of effectiveness when they view themselves as carriers of the cure - Jesus Christ. It is easier to look around and curse the darkness, but it is far more helpful to light a candle and become curative." In closing, sharing how my positive attitude, strong faith, ability to adapt to life as an ostomate and share my journey as a source of inspiration and encouragement is important to me. I'm also devoted to being a live case presentation and sharing the importance of early detection and how it saved my life. My mantra is: Always forge ahead with a purpose!

The city of Caldwell joined a nationwide effort to observe Feb. 28, 2018, as Rare Disease Day. A rare disease is defined as a condition that affects fewer than 200,000 people, according to Genetic and Rare Diseases Information Center. The local effort was brought forth by a retired U.S. Navy veteran and Caldwell resident Daniel Shockley. Shockley retired in 2003 after more than 20 years of active military duty.

The objective of Rare Disease Day is to raise awareness about rare diseases and their impact on patients' lives. **OC**

*Editor's note: In Canada the Familial Gastrointestinal Cancer Registry (FGICR) is located in the Zane Cohen Centre at Mount Sinai Hospital in Toronto. Dr. Cohen began the registry in 1980 and was involved for many years as it developed. Information is available on [www.zanecohencentre.com/fgicr](http://www.zanecohencentre.com/fgicr). The FAQ section is very detailed and informative. If you or one of your family members may meet some of the criteria relating to the genetic component of FAP we encourage you to reach out to the Centre directly or with the help of your physician.*

# Osto-EZ-Vent®

#1 preferred venting device for any Ostomy pouch

**The classic Osto-EZ-Vent® with a refreshed design!**

Pinch the new Osto-EZ-Vent® Glides for easier opening. The Glides push against the OEV™ base to help lift and open the Osto-EZ-Vent®.

- Easy to Attach, Open & Close.
- Convenient and Simple
- Attaches to Any Pouch
- Provides Comfort, Relief, & Confidence.

[www.kemOnline.com](http://www.kemOnline.com)

CANADIAN DISTRIBUTOR  
 1-800-567-2881  
[www.coopermedical.ca](http://www.coopermedical.ca)

Call 888-562-8802  
 Manufactured by KEM in the U.S.A.