

## DANIEL SHOCKLEY'S STORY



# Veteran Responds to Rare Genetic Mutation with Positivity

**S**tarting at age 50, it's encouraged that individuals get regular colonoscopies to screen for colon cancer. At the age of 51, Daniel Shockley went to his gastroenterologist for his first colonoscopy. 100 polyps were discovered throughout Dan's colon, rectum and anus, along with a large mass in the ascending colon causing an 80% blockage. Dan was diagnosed with Attenuated Familial Adenomatous Polyposis (AFAP), a rare mutation and a subvariant of Familial Adenomatous Polyposis (FAP), which affects approximately 0.3% of the population and increases the risk of colon cancer. Unlike most people when given a bleak diagnosis, Dan was not scared. He embraced the diagnosis from the onset and did everything he could to learn about this mutation, a process that provided a lot of comfort to him.

Two months after his diagnosis, Dan underwent surgery to remove his entire colon. Seven months after his successful surgery, Dan met Dr. Lynch—the father of hereditary cancer research who discovered the AFAP mutation in 1992. Dan was honored to have had the opportunity to meet Dr. Lynch to share his journey with him, and to receive his world-renowned expertise. The two bonded over the rare condition and their military backgrounds and kept in touch over the years.

Seven years after receiving his diagnosis and undergoing surgery, Dan is living his best life and is fully retired after serving in the Navy for 22 years. Just because Dan is retired doesn't mean he's not busy! He devotes almost all his time to spreading awareness



**ABOVE:** Dan served in the U.S. Navy from 1981–2003 until his retirement.

**BELOW:** On June 2, 2019, National Cancer Survivors Day, Dr. Lynch passed away at the age of 91. Because Dan has the mutation that Dr. Lynch discovered, Dan feels it's his duty to continue to share his journey with the medical community and the masses pertaining to his mutation and stressing the importance of early detection.



**LEFT:** Dan with his dog Sam, an adorable chihuahua-dachshund mix

**ABOVE:** Dan and his dog Sam stopped at Continental Divide, New Mexico, on their road trip from Texas to California.

about his mutation. Dan's purpose is to educate the world about his mutation, being a hereditary colon cancer survivor, and the importance of early detection. He speaks at various support groups and educational events around the country, where he shares his journey, discusses the mutation, stresses the importance of early detection, and talks about how both the mutation and early detection have impacted his life.

One way that Dan spreads awareness about his mutation is through public policy. During his time in Hawaii, Dan reached out to Governor Neil Abercrombie, Senator Brian Schats, Representative Colleen Hanabusa and Honolulu Mayor Kirk Caldwell to proclaim March National Colon Cancer Awareness Month in Hawaii. Dan received proclamations from all four of them in support of the campaign. Hear from Dan's certified wound, ostomy and continence (WOC) nurses about the impact Dan had on local ostomy communities:

*"Almost 5 years ago, a small group of ostomates got together with a strong WOC nurse in our community and started a support group...One of our former members was Daniel Shockley, who contributed in many ways. Not only to the support group but also to the entire state through a proclamation from our governor related to rare diseases. Although Daniel relocated to the mainland, he continues to provide guidance, connects people to resources and others living with similar conditions, helps those affected by rare conditions and continent diversions and their loved ones with practical support, and advocates on their behalf. We in Hawaii miss Daniel's physical presence but knowing that he's only a "click" away is very reassuring.*

*Aloha,  
Doreen Akamine, CWOCN*

*Daniel Shockley was involved for a short time in our Boise Idaho Ostomy Support Group until he left us for more adventures in Texas. He was such a positive influence on our members, and even presented his story to our group. He did a great job discussing his rare disease and sharing how he was able to cope and "forge ahead with purpose". I appreciated his work to designate a "rare disease day" for the state of Idaho as well. What Daniel is dealing with is a very serious form of FAP that has affected his colon and various other organs in his body as well. His example of maintaining a positive attitude and helping others is commendable. I also admire his persistence in educating himself and reaching out to experts in the field to help him to better understand and manage his illness. Thank you so much Daniel for leaving a positive footprint in the great state of Idaho!!*

*— Julie Olson, RN, CWOCN*