

DNA spells Dan

One New Braunfels man has re-framed a rare genetic disorder as an opportunity to encourage others and save lives by raising awareness

By Lauren Corbell
Submitted photos

In 2012, Dan Shockley received a diagnosis that would change not only his life but possibly the lives of people throughout the U.S. — and beyond.

Shockley was 51 and seemingly healthy when he went to the Gastrointestinal Clinic at Spark M. Matsunaga Veterans Affairs Medical Center in Hawaii, where he lived at that time, for his first and only colonoscopy. He knew he was the age at which the procedure is recommended, and he thought nothing of heading to the clinic to check off the task from his to-do list.

What he didn't realize was about 100 polyps were lurking throughout his colon, rectum



and anus. Not only that, but a large mass had developed in his ascending colon creating an 80-percent blockage.

He had no pain and no symptoms, but the findings were alarming. Suspecting a gene mutation might be to blame, his doctor, Dr. Fernando Ona, immediately referred Shockley to Certified Genetic Counselor Susan Donlon at Tripler Army Medical Center who gathered DNA samples.

Within three weeks of his

routine colonoscopy, the retired Navy veteran who served in Operation Desert Storm, Operation Enduring and Iraqi Freedom learned he has Attenuated Familial Adenomatous Polyposis.

"It was a relief to have a diagnosis — no more wondering," he said.

If you've never heard of AFAP, you're not alone. In fact, chances are good you've never met anyone who has it, as the genetic disease is estimated to only affect roughly .03 percent

of the global population.

"I haven't met anyone else who has it," Shockley said. "I know they're out there, but our paths have never crossed. It's something a lot of people don't want to talk about."

AFAP has no cure and no tell-tale symptoms. Instead, it is characterized by about 10 to 100 colorectal polyps, a mean age of 44 for polyp diagnosis and cancer at a mean age of 56 years.

"It's a lot to digest," Shockley said, chuckling at the pun.

In July 2012, just two months after going in for a routine colonoscopy, Shockley was in the operating room to have his rectum, anus and entire colon removed. He had already begun researching his condition on his doctors' recommendation, so he could familiarize himself with what was happening and what to expect.

"AFAP is an inherited disorder but to the best of my knowledge, no one else in my family has had it — which means it's possible it started with me," Shockley said. "I don't have kids, so that means it will end with me; I'm the end of the line."

Shockley has a rare disease that could turn into cancer, but despite the potentially ominous future, he doesn't let the disease get the best of him. In fact, if you met him, you likely would be overcome by his enthusiasm, optimism and positivity. He said he sees having AFAP as a challenge rather than an obstacle.

"I've embraced the diagnosis from the onset," he said. "My mindset is I don't think about the things I can't control, such as medical conditions. After five decades on God's green earth, my positive attitude has brought me this far — why stop now? Worrying didn't cause this and worrying won't fix it."

Instead, he views his rare disease as a unique opportunity to raise awareness and promote screening and early detection. It's a chance, he explained, to positively impact the lives of people near and far by raising awareness and understanding in both the general population



A frozen section image shows a closeup view of the 8cm cancer tumor that was removed from Dan's colon in 2012.

and the medical community.

"I maintain a positive attitude and share my journey as a source of inspiration and encouragement on the importance of early detection," Shockley said. "Education is the first step."

In the seven years since his diagnosis, he has talked to numerous organizations to share his experience. Among his public speaking events since moving to New Braunfels a few years ago to be with his girlfriend, Donna Desoto, he has been a live case study at University of Texas at Houston where he spoke to 225 medical



ABOVE: Shockley speaks to New Braunfels Mayor Barron Casteel during a city council meeting in February, when he was granted a proclamation naming the fourth week of March Hereditary Colon Cancer Awareness Week. ABOVE RIGHT AND RIGHT: Shockley shows off similar proclamations he received in Honolulu in 2016 and Elk Grove, California, in 2017.

Dan Shockley loves uplifting acronyms and wordplay. He is quick to point out that the letters of his name, if rearranged, spell DNA. Here are a few of his favorite words of encouragement:

- **FAITH:** Firm Assurance Influenced Through Hope
- **ADAPT:** Attitude Determines the Ability for a Positive Transition
- **AFAP:** Always Forge Ahead with a Purpose
- **Attitude is 100 percent:** If the letter A represents 1 and the letter Z represents 26, take the letters of ATTITUDE and add them up. ATTITUDE = 100



students and he was the colon cancer warrior guest speaker at the opening ceremony at Colon Cancer Coalition's Get Your Rear in Gear 5K. In February, he obtained proclamations endorsed by New Braunfels City Council and Comal County commissioners naming the fourth week of March 2019 as Hereditary Colon Cancer Awareness Week. The proclamations say they "encourage all individuals to work together to promote awareness, understanding and the need for screening to

eradicate the disease."

"This is huge," he said of the proclamations. "This gets the word out there."

Shockley already has pursued similar proclamations in other states, and he plans to continue until proclamations are made at least on national scale.

"It will take a few years, but eventually Hereditary Colon Cancer Awareness Week will be known throughout the U.S., Puerto Rico and Guam," he said.

Aside from using an ostomy

to collect his waste and having routine medical surveillance of his stomach, intestines and left eye — places where the gene mutation has spread — Shockley appears in perfect

Dr. Henry T. Lynch, Creighton's Hereditary Cancer Center, Department of Preventive Medicine, is one of the founding fathers of genetic research. He is credited with the discovery of AFAP.

health. He is sprightly, passionate, radiates positivity and encourages others to embrace their challenges.

"I believe attitude is permanent and mood is temporary," Shockley wrote in a blog post in 2015. "It is possible to have a positive attitude and be in a bad mood. However, by maintaining a positive attitude it will have a direct impact on your mood and the outcome of your life. Do not let a bad mood affect your attitude. I remind myself of this daily and try to remain positive while pressing on with my life." +

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