Patient Perspective and Personal Journey of Treating a “Rare Cancer”

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KEYWORDS

• Anal cancer • Anal cancer awareness • Anal cancer support • HPV vaccination

KEY POINTS

- The diagnosis of advanced stage anal cancer requires facing the challenges posed, including the search for expert care and the personal road to achieving a “no evidence of disease state.”
- There are difficulties in raising awareness of early detection for rare cancers, including care provider education for recognition and screening, and general population education.
- Researchers and pharmaceutical companies have refocused on improving treatment options for patients, especially those in the advanced stages of anal cancer.
- The lack of available resources must be recognized. Health care tools, support, and advocacy for the anal cancer community must be found.
- Topnotch care through networking support between larger and local cancer care centers must be provided. Prevention must be promoted through immunization and ending unwarranted stigma.

PERSONAL STORY: ANAL CANCER, ONLY “RARE” TO THOSE WHO DO NOT HAVE IT

I heard the words “you have cancer” just a few days after my 47th birthday. As shocking as those words are to the thousands that hear them each year, nothing on earth could prepare me for the statement that followed, “It’s anal cancer, stage IV.” How could this be? Up until that day I had been living an average and fulfilling life for a middle-aged female. I was happily married for 23 years, enjoyed my life as a wife and mother of 3, worked as a registered nurse, and was in good health and good shape. I am a nonsmoker, no history of known human papillomavirus (HPV) or positive Papanicolaou (Pap) smears. I always complied with yearly visits for well-woman assessment and mammography. And, aside from symptoms of recurrent anal itching and bleeding, which I regarded as a hemorrhoid, and my chronic sciatica,

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I was a typical Midwestern woman. That day in 2010 changed my life in ways I could never fathom.

My road to diagnosis began back in July of 2009 with what I thought was a fairly routine hemorrhoid flare up. I had struggled with them intermittently for about 16 years since the birth of my last child. This attack never really cleared up and I continued to treat it with over-the-counter medicines for several months. It was not until I started actively bleeding into the toilet and the itching became unbearable that I decided I must consult with a physician even though it felt embarrassing and awkward. I delayed this 2 additional months because my yearly gynecologic examination was scheduled for early January. I felt the least self-conscious with this physician, most likely due to the nature of the examination. This experience is not unique for anal cancer patients with my demographics. I dismissed symptoms for months, not realizing the life-threatening consequences of this 6-month delay. My gynecologist (GYN) was quick to recognize there was a problem when I complained about my hemorrhoid at that annual well-woman examination and asked him to check it for me. The color literally drained from his face when he was examining me and he saw the skin lesion. He had never seen anything like it before and did not know what it was. I was swab tested for a yeast infection and was immediately referred to a colorectal surgeon (CRS). I inquired about my increasing sciatica and he suggested that I follow up with my primary care physician (PCP) in regard to the pain. The next week I was examined by a CRS and he was also unclear about what the skin lesion was. He performed 3 biopsies under local anesthesia in the office that day. At that time, I again mentioned my sciatic pain and he concurred with my GYN and referred me back to my PCP to address it. My CRS diagnosed me with high-grade anal intraepithelial neoplasia (AIN) 3 days later, a colonoscopy was scheduled for the next week, and I was prescribed 5-fluorouracil (FU) cream.

Anxious to learn all I could about my diagnosis, the Internet seemed like a good place to start. Information and data available on AIN were scarce, and what was available was technical and frightening. The more I learned about it the more I came to understand that I was battling more than simply a rare form of carcinoma in situ. There is a stigma attached to this disease. The stigma of anal cancer can be paralyzing. The isolation is notable. However, as a health care professional, I was undaunted. I began a search for support, and reliable and relevant information about my currently prescribed treatment.

On further exploration by my PCP via MRI the following week, my continued sciatica was determined to be caused by a large lesion growing out of my sacral L1 vertebrae and compressing the nerve. This became the catalyst for my anal cancer diagnosis. I was referred to a neurosurgeon. In the meantime, the colonoscopy was done and, aside from seeing “much of the same” type of lesion just inside the entrance of my anus, which was also biopsied, the results were unremarkable and no further testing was recommended. I was instructed to continue with the 5-FU cream. I saw the neurosurgeon a few days later to discuss the tumor in my sacrum. A computed tomography (CT) scan was immediately scheduled, with surgery to follow. At first, there was significant doubt about any correlation with AIN. I even asked specifically if the tumor in my sacrum could be related to the AIN and both the CRS and neurosurgeon were dubious about whether the 2 were related. The neurosurgeon did not immediately recognize the type of cancer cells. An oncologist was consulted. The pathologist, together with my oncologist, finally fit all the pieces together. I had poorly differentiated stage IV anal canal carcinoma. I had 2 tumors at my anal opening with bone metastasis to my sacrum. A PET scan revealed no other distance sites. My prognosis was poor. I underwent treatment at my local cancer center. I received the standard Nigro protocol, with