Special Edition

VACCINE-PREVENTABLE DISEASE

Human Papillomavirus (HPV)

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Emily Elliott distinctly remembers the day she found out she had HPV, the most common sexually transmitted infection which can cause genital warts, cervical cancer and other cancers. She was 26 years old, living alone in Denver, and she felt confused, anxious and afraid.

She soon underwent a cone biopsy procedure to remove abnormal tissue in her cervix. “I recall coming home and lying on the floor in pain. It was scary,” Emily said.

Although the procedure was a success, and Emily went on to get married and give birth to two healthy children without any complications from HPV, the infection resurfaced ten years after her initial diagnosis. Initially, Emily underwent cryotherapy – a procedure that destroys abnormal tissue by freezing it; however, the treatment was unsuccessful. After undergoing six weeks of topical chemotherapy, Emily’s Pap smears finally returned to normal. She now gets Pap smears every three to six months to ensure her cervical tissue remains healthy.

Emily hopes that sharing her story will help people realize how deeply HPV can affect one’s life. She also hopes to increase awareness of how common HPV is. Nearly 80 million Americans are currently infected with the virus.

Fortunately, HPV can now be prevented through vaccination. Several HPV vaccines are licensed in the U.S. which protect against 80-90 percent of cervical cancers. It is recommended that adolescents 11 to 12 years of age get vaccinated. Although the vaccine was not available for Emily, she plans to immunize both her children when the time is right.

“I never want my daughter to experience the heartache of cervical cancer.”

“I never want my daughter to experience the heartache of cervical cancer or of not being able to have a child because of complications from HPV,” Emily says. “And I never want my son to get HPV-related cancer or pass this disease to someone else. It’s my role as a parent to do everything I can to protect my children, and that means immunizing them against HPV and HPV-related disease.”
In September 2015, Jim Pyle, a healthy 65-year-old grandfather, discovered a lump in his neck. He was soon diagnosed with throat cancer caused by HPV. Jim underwent eight weeks of chemotherapy and nearly seven weeks of radiation at MD Anderson Cancer Center. “The treatment is tough to get through—it really beats you up.”

Less than a week after his last treatment, an infection spread in Jim’s mouth and the side effects from the treatments began. He suffered from severe facial swelling, thick choking mucous, painful ulcers on the inside of his mouth, skin burning and peeling, and dehydration. He was soon placed on a feeding tube due to his inability to swallow. In January 2016, another mouth infection occurred—this one worse than the first. Jim developed a large lump in his throat that became inflamed, painful and swollen. Doctors diagnosed Jim with MRSA, a serious bacterial infection, and he was hospitalized in isolation for three days.

Today, Jim is in remission but continues to suffer from painful ulcers on the inside of his mouth, swelling in his mouth and face, minimal taste function, potential long-term lung damage, and a loss of salivary gland function. Moreover, he’s lost nearly 25 pounds due to his inability to swallow. Jim will continue to be monitored every three to six months for the next six years, and doctors are hopeful that he will regain some of his taste and salivary gland function.

Until he was diagnosed with HPV-related throat cancer, Jim and his wife, Peggy, were unaware that HPV could have such a profound impact. “I thought to myself—is this it? Is this going to end my life? It’s scary. Very scary,” Jim shares. “And we were totally uneducated and unaware that HPV could cause cancer.”

Jim and Peggy now embrace the opportunity to use this experience as a lesson for their four adult children, their 3-year-old grandson, and any future grandchildren they may have. Furthermore, they hope to persuade other parents to vaccinate and protect their children from HPV-related diseases. “After you see people like me and many others go through this terrible experience, why would you risk it for your child? HPV will impact me for the rest of my life,” Jim says. “Please vaccinate your children—protect them from cancer.”
Jackie Golson has been living with the effects of HPV-related cervical cancer for nearly 30 years. First diagnosed with HPV at 30 years old, she underwent cryotherapy, a procedure that destroys abnormal cells by freezing them. Three years later, the HPV progressed to cervical cancer, and she had a radical hysterectomy.

Sadly, this treatment was also unsuccessful, and two years later, at the age of 35, Jackie was diagnosed with recurrent cervical cancer. Doctors discovered a small mass behind her kidney where the cancer had spread. Jackie underwent surgery again and, this time, radiation as well.

Now 60 years old, Jackie continues to deal with complications from the disease and treatment. She has had multiple subsequent surgeries including one to remove her rectum, which left her living with a colostomy bag. She has also suffered from two fistulas, a rare complication of advanced cervical cancer. One of the fistulas, or abnormal connections between two areas of the body, has leaked outwardly for the last seven years, severely limiting her ability to function normally. She was unable to continue working due to her health issues and recently retired from her career as a teacher.

As a single mother, the emotional and financial stress of Jackie’s experience was overwhelming. She has battled depression, suicidal thoughts and anger, seeking counseling to help manage her emotions. “My diagnosis with HPV and cervical cancer changed the trajectory of my life and continues to impact every aspect of it. My illness is always on my mind, and I will never be able to escape it.”

Having grown up in a period where polio, measles and mumps were widespread, Jackie strongly believes in the protection vaccines provide. “To me, protecting your children from HPV is no different than protecting them from those diseases.”

She also has an acute understanding of the risk parents take when they choose not to vaccinate their children against HPV. “I want parents to understand what can happen if their children are not protected against HPV. I wouldn’t wish my life on my worst enemy, and would do anything to be able to turn back time and have the chance to be vaccinated.”
A single mother, Fidencia Moctezuma was diligent in maintaining her health which included getting her annual Pap smear. Unfortunately, in 2013, when Fidencia went in for her annual Pap smear, her doctor noticed an abnormality in her cervix. She underwent an ultrasound, a biopsy and a Loop Electrosurgical Excision Procedure (LEEP) to remove the abnormal cervical tissue and provide further diagnosis. Soon after, Fidencia learned she had cervical cancer caused by HPV.

Fidencia was overwhelmed with fear and worry about what would happen to her 11-year-old daughter, Cassandra, if she was unable to care for her. She underwent a hysterectomy that resulted in a long and painful recovery during which she was unable to work for two months. Fidencia recalls the financial stress of not being able to work and wondering how she would support herself and her daughter. Fortunately, her older son was able to support them during this difficult time.

Unfortunately, however, Fidencia’s cancer diagnosis caused a great deal of stress on Cassandra. Following Fidencia’s surgery, doctors evaluated Cassandra and found she was experiencing trauma due to concern about her mother’s illness. Even today, two years after her mother’s diagnosis, Cassandra continues to struggle. She has difficulty concentrating in school, her grades have suffered, and she still worries about her mother’s health constantly despite her prognosis being good.

Fidencia shares her story with the hopes of helping others avoid her experience, particularly the impact it has had on her daughter. “Parents need to vaccinate their children so that they don’t have to go through what I did. Or what my daughter did in finding out that her mom had cancer.”

Since her diagnosis and surgery, Fidencia has worked hard to educate the women in her community about the devastating effects of HPV and the importance of the HPV vaccine. “There is a huge lack of information, and I don’t understand why more people aren’t talking about this,” she says. “We have a vaccine to prevent cancer. I vaccinated my daughter the first chance I had. Now she and her children will not suffer as I have.”
In July 2012, Sandy Wexler, a pediatric nurse, appeared to be in perfect health. But when she went for a routine dental visit, a large lump was discovered in her neck. Soon after, she was diagnosed with throat cancer caused by HPV. She underwent surgery to remove the lump, followed by six weeks of proton therapy, a form of radiation. She also underwent seven weeks of chemotherapy.

The treatment for throat cancer is severe, and the side effects are extremely painful. It caused the skin on Sandy’s neck to break down, resulting in painful sores and peeling. She also had extreme difficulty swallowing, leaving her badly dehydrated. She lost 25 pounds and needed frequent re-hydration treatments. In January 2013, Sandy was declared cancer-free, but she is still living with side effects of the cancer and its treatment. She has minimal taste function, extreme dry mouth, and a partial loss of salivary gland function. She will have to have check-ups every few months for the next couple of years.

“\[you never think it’s going to happen to you.\]”

Before her diagnosis, Sandy never had any symptoms, and didn’t know she had HPV. She and her husband, Michael, a pediatrician, recall being surprised to learn that her cancer was caused by HPV. Having both worked in pediatrics for 40 years, Sandy and Michael strongly believe that vaccines save lives and have spent their careers educating parents on the importance of vaccines. Now, having faced a cancer caused by a vaccine-preventable disease, they feel more strongly than ever that parents should protect their children.

“I don’t want any parent to one day watch their child go through what I’ve gone through when they could have prevented it. I wish I would have had the chance to be protected against this disease,” Sandy says.

She shares her story so that parents will understand the impact of HPV and that it can affect anyone. “You never think it’s going to happen to you. And it’s scary when it does.”

TEXAS CHILDREN’S HOSPITAL | HUMAN PAPILLOMAVIRUS (HPV)
Jerry Pillans will never forget when his wife, Kathleen, first reported feeling sick. A visit to her physician quickly escalated when a mass was discovered in her pelvic area. Soon after, Kathleen was diagnosed with advanced cervical cancer caused by HPV.

After being diagnosed in 2008, Kathleen underwent surgery to remove her bladder where the cancer had spread. Multiple surgeries, including a radical hysterectomy, as well as chemotherapy and radiation, followed. In 2009, Kathleen was briefly placed in remission, but by November of that year she found out that the cancer had returned and it had spread to her colon and rectum.

Kathleen spent the next 14 months undergoing more surgeries, chemotherapy and radiation. Jerry recalls what that time was like: “She was in a great deal of pain, and it was a tremendous struggle for all of us, but especially her.”

Tragically, on January 4, 2011, at 50 years old, Kathleen lost her battle with cervical cancer and passed away, leaving Jerry and their 19-year-old daughter, Kaitlyn, to mourn.

Kathleen never had an opportunity to receive the HPV vaccine. Today, Jerry believes that the HPV vaccine has the potential to save an entire generation from experiencing cervical cancer. “I think about what we went through and how young people today can avoid all of that if they simply get vaccinated. They would never have to worry about cervical cancer and all of the pain and suffering that it causes.”

Jerry’s memory of his wife’s experience has compelled him to urge parents to protect their children through vaccination. “Look at what we went through. Your children don’t have to go through any of that. Do not hesitate to get the vaccine. It saves lives.”

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