



## THE HPV AND ANAL CANCER FOUNDATION

Testimony submitted by The HPV and Anal Cancer Foundation  
To the New York City Council Committees on Health and Women's Issues  
January 8, 2015

We thank the members of the Health and Women's Issues committees for the opportunity to speak today. My name is Justine Almada, and I am the executive director of The HPV and Anal Cancer Foundation, a non-profit organization that I co-founded with my siblings in 2010.

Our story is reflective of the larger issue.

In March 2008, while I worked at the New York City Council, my mom gathered my siblings and I together, and told us she had cancer. Her telling was a little different though because she prefaced the name of the illness with this. She said, "I have cancer, and it's not a very nice sounding kind."

At 51, she had just been diagnosed with stage IV anal cancer. As we fought alongside my mom over the next two years, we soon learned that not only is the virus a stigma but the stigma is a virus. There is a wealth of misinformation about this cancer – because it's not a very "nice sounding kind" and because it's caused by HPV. This stigma has stalled advances in medicine and resources for the disease.

The drug treatments for anal cancer have not changed since the 1970's, and there were limited medical networks and patient advocates. No one screened my mom for this cancer even though she had a risk factor – HPV – in her twenties.

My mom died in April 2010.

After her death, my brother, sister and I have endeavored to change this experience for other families, and founded The HPV and Anal Cancer Foundation. To achieve our mission, we focus on prevention through immunization and screening, work to build the scientific and medical infrastructure to find better cures, and empower anal cancer patients so they don't feel so alone.

We commend the Council for holding a hearing on preventing HPV and the cancers it causes, and for the attention the Department of Health and Mental Hygiene has given the issue through its current public health campaign.

HPV is a carcinogen. It causes six different cancers in men and women amounting to 5% of the world's cancer burden. Currently 79 million Americans or 1 in 4 have HPV. It is a sexually transmitted infection spread through skin contact, and nearly every person will be infected at some point in their life. Most people's immune systems will fight it off, but tens of thousands will develop a cancer and millions will develop a complication from the virus.

Despite these sobering facts, vaccination rates for females are very low, and rates for males are even lower, even though there are strong recommendations from the Centers for Disease Control and Prevention, American Medical Association, American Academy of Pediatrics and other medical associations.

Unfortunately, there is a lot of misinformation in the medical community and general public about this vaccine. In light of this, we must work together to educate these communities about the vaccine to prevent the next generation of men and women from facing these cancers.

### **Why Eliminating HPV is Necessary**

- **The HPV malignancy and cancer burden is significant. HPV causes at least six different cancers, and affects men, women and children.** HPV causes cancer in over 26,000 American women and men each year. These cancers include cervical, anal, vulvar, vaginal, penile and oral cancers. In addition to cervical cancer, women are also at risk for anal, oral, vulvar and vaginal cancers. Men are at risk for oral, anal and penile cancers. HPV can also cause recurrent respiratory papillomatosis (RRP) in children. The President's Cancer Panel states that HPV causes 93% of anal cancer, 96% of cervical cancer, 63% of oropharyngeal cancer, 36% of penile cancer, 64% of vaginal cancer, and 51% of vulvar cancer.
- **HPV causes precancer, warts and other conditions in nearly 2 million men and women in the U.S. every year.** It leads to about 360,000 cases of warts and 820 RRP cases. HPV also causes cervical lesions in women every year, including approximately 1.2 million low-grade and 300,000 high-grade lesions. It is estimated that in 2020, more boys than girls will have an HPV-related cancer.
- **According to the NCI, HPV-related cancers are on the rise.** In the National Cancer Institute's 2013 Report to the Nation, overall cancer death rates continued to decline in the United States among both men and women, among all major racial and ethnic groups, and for all of the most common cancer sites, including lung, colon and rectum, female breast, and prostate. Incidence rates of HPV-related oral and anal cancers, however, are increasing.
- **Current screening protocols are not enough to prevent HPV-related cancers. Of the six cancers that are caused by HPV, only one – cervical cancer - has an effective screening protocol. Despite this, people are still diagnosed with cervical cancer. The vaccine provides the best mechanism to prevent HPV-related cancers and precancers.** We do not have effective or standardized screening protocols for anal, penile, vulvar, vaginal and HPV-related oral cancer as we do for cervical cancer, and thus are left vulnerable to these HPV-related cancers. Even with the benefits of the standard screening protocol for cervical cancer, over 11,000 women a year are diagnosed with the illness.

- **Once you are diagnosed with an HPV-related cancer, treatments are antiquated, toxic and difficult.** I am going to speak to the treatment for anal cancer, which was developed 40 years ago. Treatment for stages I to III involves 6 weeks of 5 day a week radiation to your pelvis in addition to chemotherapy. This treatment to a very sensitive part of the body can cause diarrhea, changed sexual functioning, extreme burns, bleeding and long-term gastrointestinal, urinary and sexual complications. The person also often experiences prolonged fatigue, extreme nausea, and debilitating chronic pain. Treatment for other HPV-associated cancers often also involves surgery, radiation and chemotherapy. With a vaccine available to prevent this difficult illness, we have the opportunity to improve the lives of thousands of people, and to save lives that might otherwise be cut short from anal cancer and the other HPV-related cancers.
- **Vaccination rates for females are very low, and rates for males are even lower, despite strong recommendations from the Centers for Disease Control and Prevention, American Medical Association, American Academy of Pediatrics and a number of other medical organizations.** In 2013, 38% of girls and 14% of boys received the full dose series nationwide. In New York City in 2013, CDC estimates that 45% of girls and 30% of boys aged 13-17 received all 3 doses of vaccine. This is in contrast to the 91% of the same young New Yorkers who received the MMR and 90% who received the Tdap vaccines.
- **Anal cancer and the other cancers caused by HPV are highly stigmatized.** Anal cancer is a difficult disease for patients to openly discuss with their doctors, colleagues and loved ones, a challenge that makes dealing with this cancer even more difficult than its physical burden alone. Other HPV-related cancers also face stigma preventing equitable conversation, education and resources for the patients who are dealing with these conditions.

### **How Can We Eradicate HPV?**

The best route for increasing uptake is to educate the medical and parent communities about the vaccine and its importance. This will take a concerted effort on behalf of multiple stakeholders at the local, state and national level. New York can take steps to increase vaccination uptake by:

- (1) Working with health agencies and medical associations to educate every doctor, nurse, and provider about the importance of routinely vaccinating all children.
- (2) Working with education agencies and parent organizations to educate parents about the availability and importance of this cancer prevention vaccine for both their boys and girls.
- (3) Supporting the fight against stigma by speaking openly about HPV and the cancers it causes in both men and women, and helping the public to understand its importance. Nearly everyone will encounter this virus during their lifetime.

New York has a phenomenal opportunity to lead the way in preventing painful cancers in its population with a simple 3 dose shot. There are over 468,000 boys and girls aged 10-14 in New York City alone, and we can protect them from potentially excruciating physical and socially isolating conditions. Make New York the leader of the nation by having a 100% vaccination rate for boys and girls. We urge you to consider the impact you will have on future generations of Americans and their families by supporting education and awareness efforts to increase the uptake of this life saving vaccine.

We are ready to work with New York and the Council in support of ending 5% of cancer. We invite everyone to reach out to us regarding initiatives, awareness campaigns, fact sheets or resources about HPV and cancer.

Thank you for the opportunity to testify today.