



HPV & CERVICAL CANCER

STORIES FROM SURVIVORS
AND SUPPORTERS

FROM THE NATIONAL CERVICAL CANCER COALITION
A PROGRAM OF THE AMERICAN SEXUAL HEALTH ASSOCIATION



YOU ARE NOT ALONE

This year in the United States, more than 12,000 women will be diagnosed with cervical cancer. That's an average of more than 32 women every day.

Behind each of these women is a story.

A story that involves not just one woman and her battle against disease, but her support system of family, friends and healthcare providers that fights alongside her. At the National Cervical Cancer Coalition, we know the importance of these stories. They serve as a source of information and inspiration to patients and their families and offer a powerful message to those dealing with the impact of cervical cancer—you are not alone.

Not every story has a happy ending; more than 4,000 women in this country die each year from cervical cancer. But from both stories of these tragedies and the words of survivors come messages of hope—cervical cancer can be prevented. We can and should do more to raise awareness about ways to prevent cervical cancer so that no woman—no daughter, sister, mother, wife, friend—will die from this preventable disease.

We are grateful to the survivors and family members who have chosen to share their stories of pain, struggle, strength, and hope. We hope you will find inspiration in the stories here and will share the message of prevention.

ABOUT ASHA AND NCCC

ASHA is the American Sexual Health Association, an award-winning and trusted 501(c)(3) nonprofit organization that has advocated on behalf of those at risk for sexually transmitted infections (STIs) since 1914. ASHA's mission is to promote the sexual health of individuals, families and communities by advocating sound policies and practices and educating the public, professionals and policy makers, in order to foster healthy sexual behaviors and relationships and prevent adverse health outcomes.

The National Cervical Cancer Coalition (NCCC) is a program of the American Sexual Health Association. NCCC serves women across the country with, or at risk for, cervical cancer and HPV disease. The organization has local chapters across the U.S. that offer education and support to members. NCCC also offers other outreach services such as the Phone Pals program, the Quilt project, and online resources to raise awareness of cervical cancer and HPV disease.

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THE REASON I HAD CANCER

By Tina

I am fearless...well, I used to be. I have jumped off piers, photographed wild black bears, swam with wild manatees and flew an open-air biplane. I did not fear what others called dangerous ventures. I was crazy, I never thought once about death—until August 25, 2009, when I heard the words “you have cancer.”

At first I was shocked and confused, and then I was depressed and scared. I had never experienced this emotion before—this was fear. Fearing something that is inside your own body was a surreal experience.

When I was faced with never holding my sweet husband’s hand again or watching my daughters laugh, I realized life was indeed precious and fragile. I decided I was not going to let fear ruin my life. I decided to fight against all those killer cells. I had a radical hysterectomy two weeks later, underwent five weeks of radiation, and six months of chemotherapy. I struggled through it all. It was the scariest and hardest thing I had ever done in my 34 years of life. But it was all worth it—I can say I did it! I fought the battle of a lifetime and won—I am cancer free!!

Throughout my journey, I continuously looked for a reason why this happened to me. People told me, “sometimes things happened in life for NO reason.” That statement just didn’t settle with me. I decided to MAKE a reason. I wanted to tell my story hoping to raise awareness and save lives. If I help just one person and their life is spared in the face of cancer then I have found my reason!

From my chemo chair, I started a non-profit organization called **Walk of Women**. I saw a need to raise awareness for gynecological cancers. I want women to be aware of changes in their bodies and feel comfortable to talk to someone about these changes. Early detection is key to all cancers.

In three years I have hosted four fundraising walks, which has helped my mission to raise awareness of gynecological cancers and fund a program called Wellness of Women (WOW). The WOW program provides financial assistance for women that have been diagnosed with a gynecological cancer. We pay for medications, transportation, wigs, doctor’s appointments or anything else that will help make their cancer journey easier. We also host a monthly support group for patients and survivors called Words of Wisdom to inspire and empower one another. Women need to know where to turn when they are told they have cancer. WOW wants to help them feel connected and encouraged during their journey. We have raised \$52,000 and have helped over 85 women so far.

The reason I had cancer—to help other women fight during their battle to survivorship.



THE IMPORTANCE OF A SECOND OPINION

Anonymous

On August 14, 2012, a day after settling into the flat that my partner and I rented in Paris, I received a work email titled "Urgent Message," with verbiage something to the effect of: "Please call your doctor immediately." I had been working remotely and had not been accessible via phone, so my doctor had called my office. Of course, something had to be very wrong.

The conversation with my doctor was a blur, something about CIN3, high-risk, need a LEEP based on test results from two months before (still not sure why there was such a gap, but it happens). I scheduled the LEEP procedure a few days later, for six weeks ahead, when I'd be returning to the U.S.

Several days after my LEEP procedure, I received another nearly incoherent (to me) call that I had cervical cancer with dangerous invasive cells close to my uterus. The shock of that and the pain on my partner's face as I told him the news still haunts me and probably always will.

My first visit with my initial oncologist was awful, jarring and traumatizing—not just because of the nature of the discussion, but because the oncologist mentioned the word “death” several times as she rushed me to remove my cervix and uterus. At least if I “lived” I “could still adopt,” was her argument. She discouraged me from even exploring the fertility-sparing trachelectomy procedure, even though I was 32 and still wanted to have children. She was all too ready to schedule my hysterectomy right then and there, without further tests, with just my biopsy results and the results from the vaginal ultrasound that she had just done. I left sobbing uncontrollably, something I have done in public only once before, when I was a child.

That experience made me realize how important it is to get a second opinion. Thankfully, I was blessed with someone who connected me with a widely-respected oncologist. How different my first visit was with her. She genuinely wanted to learn about me and how I was doing. She gave me the space to make my own decisions. She arranged for me to meet with a fertility specialist before deciding on anything. The fertility specialist explained that exploring fertility options in advance has proven to largely impact survival and health for those in similar circumstances. That appointment was an opportunity to learn. My new understanding of what my specific scenario meant for my future and that sense of empowerment that came from feeling that I had options and choices helped to give me the peace that I desperately grasped for at that time.

After ordering and reviewing a PET scan and MRI, my oncologist decided that I was a candidate for a trachelectomy, though members of her team urged that I have the hysterectomy, since my tumor was in the upper cervical canal and was larger than two centimeters in diameter. The day of my trachelectomy, I was so little prepared. I hadn’t even packed an overnight bag, though I had been scheduled to stay in the hospital until the next evening. And that lack of preparedness, which really started before my LEEP procedure, carried through my recovery.

In the weeks leading up to the LEEP, I was in travel and exploration mode. Forget research or thinking about my high-risk cells. In the weeks leading up to my surgery, I was in a total daze, still fighting the great weight and fears that came from recognizing how incredibly vulnerable I was both physically and emotionally. I faced inevitable mortality in a way I never had before, and instead of coping, I was in a state of numb denial.

Being so ill prepared and so unwilling to face the cold hard truth, I had to learn things the hard way. But I am very happy to report that at the moment, 11 months post-surgery, I’m doing incredibly well. I can’t say that I’m “back to my old self” or back to “as good as new,” since my body has changed permanently in little ways that only I can perceive, but I can say that I’m almost as good as new. I’m in good health with clear results so far at every appointment, a new strength and perspective, and so much more thankful for every family member, true friend, blessing, moment than I ever was before.

My tips for the recovery phase are based purely on my own experiences and the struggles that came from my lack of preparedness and lack of foresight to ask my doctor every question I could think of pre-surgery. (I do recommend asking a lot of questions and taking good notes during all of your pre-surgery appointments):

- If you’re fortunate enough to have care at home during your recovery, take full advantage of it. Let yourself rest, I mean truly rest, without trying to pretend like you’re strong enough to do what you normally do. Sleep as much as you can after a relaxing read or movie, which will help your body heal and help lower the additional level of anxiety that your conscious pain could cause.

- If you have to be more self-reliant during your recovery, prepare your home in advance for your recovery period to avoid overexertion and heavy lifting. For instance, you can set out a huge supply of small water bottles in an easy to reach place in advance, so that you're not constantly refilling your giant filtered water pitcher or lugging around heavy two-gallon water jugs
- Prepare your wardrobe for recovery. You'll need a good supply of loose-fitting comfortable clothes. If you've had a laparoscopic trachelectomy, your belly button and middle abdomen will have wounds that need to heal, so your clothes should be able to sit comfortably below your midsection and loosely above. Soft, loose gowns are really useful for this period, especially if you have to wear a catheter for the first week.
- Eat well—high fiber, high nutrition meals with lots of fruits and veggies and lots of water. This is so very important because all of the pain medications, including the serious drugs you'll have injected into you during and just after surgery, may throw your body off. You'll get stool softeners and laxatives to combat the effects of the painkillers, but in the long run, it's important to help your system reset in a healthy way and have healthy bowel movements. Pushing is not good for you while you heal because it puts added pressure on your pelvic cavity, just as lifting does. Avoid both in the first days—weeks even—and ask your doctor for her/his take. I personally had major issues with digestive regularity, for a whole host of possible reasons: very low activity level, shock to my system from being so outside of my normal active routine, lack of sunlight from locking myself away and hiding from the world for an excessive length of time (studies link digestion, and in turn, bowel activity to serotonin, which is increased with higher levels of light). I still struggle to stay regular, a challenge I never faced before the surgery, though I eat very healthy and am very active.
- All throughout your recovery walk around as much as you can without overexerting yourself. It's so good to be outside and to get fresh air and sunlight throughout your recovery. And it's also good to have a solid routine, like daily morning or afternoon walks and a healthy meal and sleep schedule. A healthy routine will help your body regain balance.
- Surround yourself with hopeful, uplifting movies, books, music, art and people. This can be a very hard time emotionally and spiritually. Saying that it was a hard period for me is an understatement. The worst thing you can do when you're emotionally vulnerable to dark thoughts is watch depressing movies or listen to depressing songs. It makes such a difference to find reasons to laugh and smile and feel hopeful.

Good luck and know that you are not alone. There are hundreds of people out there who have experienced what you're going through and who would be more than happy to be a positive support system for you. You have so many reasons to be thankful and stay strong, and there will be a great bright light at the end of this difficult period. You just have to work towards it day by day. Take good care.



I MADE IT THROUGH

By Janet

My story starts on October 23, 2006. Three months after getting married, I had my annual Pap test done, which came back normal. My doctor decided to do a D&C, due to bleeding after sex and suffering severe abdominal pains and lower back aches. This procedure is what caught my cervical cancer. It was high up in the T-zone which is why the Pap did not pick it up. I was a stage 2b.

I started six weeks of chemo/radiation on Dec 6, 2006. I made it through fairly easily. Then I had to go through 60 hyperbaric treatments to try to shrink a lesion that was caused by the internal radiation. Eventually I had to have a radical hysterectomy and 3 inches of my colon removed due to damage from the radiation. In 2008, I had a bowel blockage, due also to internal radiation damage.


The biggest help to me was when my sister brought me meals twice a week during my chemo. I was brought my Cheez-It® crackers and mandarin oranges (the only thing that sat well with me) and popsicles. Just having people around me encouraged me that I would get through this. And guess what? I did!!

The effects of cervical cancer can be ongoing. In my case, I suffered from diarrhea after everything I ate, and after six years I decided to see a specialist. I was put on medicine which I call my miracle cure—it allows me now to eat and not get sick.

With the love of my husband, family and friends, I did make it through the whole ordeal and am now living a pretty much normal life. I stress to all my children the effects of HPV, that it can indeed cause cervical cancer! Please keep your yearly appointments with your doctor and if something doesn't feel right with your body, get it checked out.

IT HAPPENED TO ME

By Christine



It happened to me. I never thought it would. I was 31 years old when I went in for my Pap—just like I did every year for 13 years. This time it was different. My doc had me come back for a “closer look” with a colposcopy, then he took a few pieces to be biopsied, and then I got the phone call...

INVASIVE CERVICAL CANCER.

Ten days later, I was having a hysterectomy. One month later, I was having a laparoscopic surgery to move my ovaries up and out of the soon to be frying zone. A week after that, I started five weeks of daily pelvic radiation concurrent with four rounds of chemotherapy. After that, I had three rounds of internal radiation. Then I was done.

I was 31. I was sad and mad and confused. Why did this happen? How did this happen? All I knew was that it happened to me.

I started asking questions, got the answers and, inspired by a yellow umbrella, found my voice once again. I started to sing and talk and SCREAM because I realized I had something to SAY! I didn't know anything about cervical cancer before I had it, but I learned a lot very quickly. I learned that it is caused by this super common virus—HPV—and that all Pap tests are NOT created equal. I also learned that women 30 and older should always get an HPV test with their Pap to get the most accurate information. I wanted to tell EVERYone. So that's what I did.

I put together a concert and called it POP SMEAR. I got my talented friends to come and sing and play and help me spread the word, and it worked. It worked because the message is simple and clear.

CERVICAL CANCER IS PREVENTABLE! Talk to your doctor. Get the best Pap available. Get your HPV test if you are 30+. And (now!) boys and girls, get the HPV vaccine if you are 9-26 years old.

This is a cancer we CAN stop. We KNOW what causes it—HPV—and we have PREVENTION and DETECTION tools. All we have to do is use them—to save fertility and lives.

People heard the message loud and clear as I shared my story because NO ONE WANTS CANCER, or wants someone they love to get cancer. I am your next-door neighbor. I am your college roommate. I am your daughter. This happened to me and I don't want it to happen to anyone else.

The reality is that my cancer was missed for many years because the Pap is not a perfect test, and I fell through the cracks. Now, Pap tests are more accurate, HPV tests let women know if they are carrying the virus even before it starts changing cells on your cervix, and the HPV vaccine stops 70% of oncogenic (cancer-causing) HPV. It's incredible to see how far we've come in our knowledge and our technology. And yet, some doctors, labs, women don't take advantage of what we have at our fingertips, and as a result women are still losing their fertility and lives to this preventable cancer, and it breaks my heart.

Ultimately my story is a happy one—I'm a survivor. I KNOW how lucky I am, and that's why I never want to stop speaking, singing, shouting out to anyone who will listen. Over the past 10 years, I took my "singing to save the cervix" show on the road and called it The YELLOW UMBRELLA Tour, doing hundreds of gigs in clubs across the country. I've spoken at conferences, on Capitol Hill, and in classrooms. My new program, PAINT IT YELLOW, is a grassroots, community-based program that works with community leaders in the schools, health departments and family planning centers to create many events over multiple days in a variety of settings in an effort to reach an entire community with the message of HPV awareness and cervical cancer prevention. If we work together, we can and will make a difference in the lives of women.

Bottom line, people connect with people and people need to know that THIS can happen to ANYone. It happened to me. I started www.theYellowUmbrella.org to try to DO something about it. I hope YOU DO SOMETHING too.



Rock on and on and Save the HOOCH!

Read more about Christine Baze and the Yellow Umbrella Organization at www.theyellowumbrella.org.





MY SECOND OF THREE

By Kathleen

When I engage in cancer counseling or public speaking, I refer to my past experience with cervical cancer as quite the opposite of how others may remember it. I never intend flippancy, and I do regard any (and anyone's) cancer as a serious matter.

But in July of 1999, I had already undergone a mastectomy for breast cancer and was about to discover that I had advanced, terminal stomach cancer with a prognosis of less than six months left to live. So in between these two dramatic and panic-laden, paralyzing events, my short bout with cervical cancer was a picnic in Paris by comparison.

It helped that I had a kind and highly capable gynecologist, referred to in my memoir as "Dr. Crotchbuddy." His proactive and preventative orientation guided us in determining that, since my history with breast cancer now made me susceptible to ovarian cancer, a hysterectomy—and a total one at that—might be warranted. Factors in my favor were that I had become menopausal, due to the Tamoxifen medication I was taking then. I had long ago accepted my inability to bear children, and at 51 I was way past the age of bearing or caring.

Out they all came: uterus, cervix, tubes and ovaries. In came the incredible news a week later, over Dr. Crotchbuddy's personal phone call to me. The biopsy taken of tissue samples during my procedure revealed that I had early stage cervical cancer.

"So . . . doc," I dragged out words as I gulped a lot, "what does this mean? What do we do now?"

"Not a single thing, Kathleen. We got it all out. We got to the cancer in time."

In other words, my hysterectomy-as-prevention had been the cure as well. Dr. Crotchbuddy did go on to ask me if I had been "sexually active" in my youth. I guessed he was trying to figure out how I had gotten my cancer. I answered with something like, "To be perfectly honest, doc, I was a steadfast, thoroughly committed hippie, communes and all, back then." He said no more, and that was the end of that subject. But what wonderful news! It was the only time my husband Ed and I celebrated with champagne right after hearing the announcement that I had cancer.

That experience among others gave me the strength, gratitude, humor and opportunity years later to write and publish a memoir, *Becoming Warrior Woman: My Journey Through Three Cancers*. Today, as a freelance writer (my website is www.KathleenStatham.com) I am a fiercely proud survivor. I am pleased and honored to have shared my story, while adding it to the revelations from fellow cancer survivors in this book.



I M STRONGER BECAUSE OF THIS DISEASE

By Geneve

I was 20 years old and in a serious relationship with my boyfriend for almost a year. He was my first sexual partner and we used protection and both got tested and everything was fine. Or so I thought...

I had my first Pap smear that year and when the test results came back, my whole world changed. The doctor called me herself and let me know that I had HPV. She told me I had the high-risk strain that could potentially cause cervical cancer.

The next couple months were extremely hard on me. I was retested a few months later and found out there were abnormal cells on my cervix, and the doctor explained I needed to have the LEEP surgery because the abnormal cells were cancer cells. The LEEP surgery was one of the worst days of my life. I was in pain and I was alone. My boyfriend was not there for me and did not support me. I went through the surgery and the grief alone.

I made it through the surgery and I would have to see the gynecologist every three months to make sure there were no more cancer cells. I have had a couple Pap smears come back normal and recently my Pap smears have been coming back abnormal. I'm currently 26 years old and the virus still has not cleared from my body. I'm no longer with my boyfriend because he decided to leave me. He never took responsibility and was never there for me throughout the process.

I highly encourage every teenager or young adult to get the HPV vaccine. This is the most crucial shot you could possibly get. This will prevent you from getting many of the different strains of HPV. I wish I knew this when I was 20 years old, my life could be different.

I can say this—I've changed into a stronger woman because of this disease. I'm very careful with my sexual partners, and it's absolutely okay to share this information with a new partner. My partner now is extremely understanding and supportive.

I still get sad from time to time and wish this did not happen to me, and I pray to God I do not have to ever get the LEEP surgery ever again in my life. I believe this disease will clear from my body as long as I stay positive and strong and take care of myself. The most important thing is to make sure you get regular checkups/Pap smears from your doctor. Spread the word to your family and friends letting them know that getting the HPV vaccine can save you from many strains of this virus. If you are living with HPV, you will have a new normal one day. You can overcome this disease. I'm the living proof of it.



I SEE MY CANCER AS A BLESSING

By Cheryl

I left work on a hot, sunny Thursday in July with a plan to be back on Monday. I am a riding instructor and I was in my busy season and my job had never been better. I had never been so happy in my 40-year career. My riding program was thriving. I had a full roster. I had a waiting list. I could get extra hours working rodeos or holding a day camp. I loved my boss, my co-workers, and my customers. I loved my job. My dad once told me if your passion is your job, you never work a day of your life. That was how I felt, I was living it.

I finished my last lesson and left to have a cyst lanced the next day. I didn't teach another lesson until December.

My mother was the one that heard the news from the doctor first. Sitting in disbelief and anger, she tried to absorb the news of cancer in her child. We had lost my father to this terrible disease and it was just too much, too soon. My husband sat beside her trying to make sense of it all and he too felt betrayal and anger. They had many questions, but the doctor retreated behind a locked door and the questions would remain unanswered.

It was cancer. It was vulvar cancer. A rare cancer that no one in their 50s should get. I had HPV and was being watched closely. I had Pap tests every six months and cervical biopsies. The funny thing is, the cancer never went onto the cervix, but it was there all the same.

It sounded dirty.

I called my father's cancer doctor. He treated completely different cancers, but I knew I would feel safe with his advice. He looked at my CT scan and met with me. It was very serious. He began to describe the things that might be done to combat this cancer. He described that there would probably be radiation and maybe chemotherapy. He wondered if there was lymph involvement. He wondered if there would be radiation implants and described the many surgeries that I might have to go through. I broke down and my mother broke down. A friend in the room later admitted having the feeling of someone describing "gutting a fish."

We all stood in the waiting room and prayed. We prayed for a miracle, a total healing. The report came back and the cancer was contained. I would be going to Barnes-Jewish Hospital where they treated this type of cancer all the time.

I prepared for the trip in odd ways. A friend took me to their Wednesday night

prayer meeting. I was anointed with oil. Most of the congregation came up and laid their hands upon me and prayed for me. I kept hearing someone to the back and to the right of me thanking God for pulling the cancer off me even as we were praying.

Our dog groomer got me a special daily devotional book for patients; it became a lifeline for me. My mother-in-law brought me a blanket made for me by a lady that did not even know me!

My job had prevented me from hiding my illness. I had riders and explanations had to be made. The news was out. There was an outpouring of prayer—daily cards saying everyone was praying. Friends called and offered to help with the pets. They offered to stay with me and drive me to appointments. Strangers sent books, gift cards for gas and medical supplies. I felt ashamed that when these things presented themselves to me before that I had said that I would pray and not stepped up better. I felt awed that children were praying for me daily! I felt blessed!

I remember the first time I set a foot in the cancer center. If it has to do with cancer, they have it. If it is cutting edge, it is there. There are windows that run in a curve and extend upward about two stories high. I found myself sitting by these windows between treatments many times. I think the person that designed the center was a Child of God. I sat looking out those tall windows and past the high buildings, the buildings that were so tall my cell phone would hardly work. I had no service, but God had me on His call plan. He and I connected often in that place where a mere human had been thoughtful that I would want to see the sky. That I would need sunshine to stream on my face.

There is a rail that opens to the radiology department below. I later learned that it is open so that the sound of the treatment bell ringing can be heard, the bell that the patient rings at the end of their treatment. The bell that became my focus walking in and walking out every day. Each day in the door past the bell and back out the door. Longing for the moment that I would ring it. I did ring the bell! I remember ringing in and praising God while I did it! I remember friends and family coming to watch me ring it!

I have been in complete remission for two years and I am grateful for a cancer that opened my eyes and my heart to a new day. I look at my cancer as a blessing. I live each day to the fullest. I am broken from the treatments, but my body is repairing and I am grateful.

I know two things: One, God will hold onto you tight and never leave you. He was right there at each chemo and radiation treatment. And two, you are only as strong as the friends and family that are holding you up!



SHARING MY STORY TO ENCOURAGE OTHERS

By Laura

In October 1992, at age 36, I was diagnosed with cervical cancer. It was discovered during my routine annual gynecological exam, and was a shock, as I'd had no symptoms. I was immediately referred to an oncologist, and due to my size (I was about 100 pounds overweight), it was decided that I should have radiation therapy instead of a hysterectomy and/or chemotherapy.

Several days later I began a six-week course of radiation therapy. Every weekday, I was laid on a huge machine which rotated around me and shot 6"x6" square doses of radiation through my lower body. This was followed by a hospital stay, where a steel apparatus with cobalt radiation was inserted inside me. It was a crazy looking gizmo, which I nicknamed "Satellite Sputnik" when I saw the x-rays. It remained there for three-and-a-half days. Naturally, with all that radiation flying around, I was not able to have visitors. Nurses could only stay in my room for a couple minutes, and then they were wrapped in heavy lead protective vests. I wondered how I could survive with that much intense radiation. But thankfully, I did survive.

It has been over 20 years now, and though I'm THRILLED to be alive, it did not come without damaging health consequences. The first repercussion was that my vagina was seriously shortened (despite post-surgery treatments). A few years later, scar tissue was discovered in my bladder, and on several occasions it required surgery to remove. By 2009—unbeknownst to me—my bladder was in such bad shape that I wasn't able to eliminate all urine when I went to the bathroom (frequently!), and it began backing up into my ureters (the tubes that connect the kidneys to the bladder). Over the years, my kidneys were gradually poisoned, and I slowly became very ill and was eventually diagnosed with radiation cystitis of the bladder. My urologist said simply that my bladder was "kaput." It is now the size of a walnut, and hard like weathered leather, not soft and flexible like it should be. I was put on an indwelling Foley catheter 24/7, which was very uncomfortable and further damaged the inside of my bladder.

Last year, I was diagnosed with chronic and acute kidney disease, stage 4. Stents were inserted into my ureters to keep them open and let urine flow unimpeded. Hopefully, this will slow the steady march to needing dialysis and eventually a kidney transplant.

All these problems—and a few lesser ones—are the direct result of my having had radiation treatment for cervical cancer. I know that medical science has greatly evolved, and that the doses of radiation given today are much safer, but I am sharing my story to encourage others to get tested regularly and avail themselves of the HPV vaccination that might prevent this from happening to them.

A final note: I was never given an HPV test during my treatment days, and by the time I finally knew enough to request one, it was a decade later. By that time I tested negative for the virus.



HOW I BECAME A SURVIVOR

By Shauna



Life is never the same after you hear the “C” word. As the doctor shone the bright lights on my cervix, he noticed something bulging from it. At 31 years old, I just had a C-section with my second child nine months prior. I was healthy with perfect Pap smears for more than 15 years and no symptoms. The doctors called it a “fibroid” and I pushed for the mass to be removed. Baffled, the doctor sent it to the pathologist believing it wasn’t cancer.

The next day, I received the dreaded phone call to come in to speak with the doctor. That day my life went from B.C. (Before Cancer) to A.C. (After Cancer). As I heard the doctor saying “radical hysterectomy, radiation, chemo, adenocarcinoma cervical cancer,” I was in disbelief. That same day my Pap test arrived in the mail as NORMAL. Had the tumor not been bulging, they say I would have gone home and been dead within a year.

The next three months were a blur. I had my radical hysterectomy on August 19, 2005. They removed my cervix, uterus, a third of my vagina, appendix, and 44 clear lymph nodes. I also receive five weeks of IMRT (Intensity-modulated radiation therapy) that put me in a surgically-induced menopause. This was a very difficult time for me, as my two young children had to move in with my parents while I recovered.

I would like to say that once I beat the cancer it was over; however, the hard part came later. I must emphasize how important it is to deal with the emotional/hormonal/spiritual side of being a “survivor.” I mistakenly marched right past the survivor desk in the Cancer Treatment Center of my hospital.

Three years later, I suffered a breakdown. Was it hormones, exhaustion, depression, or ADHD? Why was the old Shawna not the same? After meeting with a psychiatrist specializing in cancer survivors, I was diagnosed with PTSD due to the cancer experience. This often mimics depression/ADHD. Discovering this was the beginning of my healing.

I worked feverishly to overcome my issues. After research, therapy, a year off from work, bio-identical hormones, support from those who loved me, and much prayer—I OVERCAME cancer. After a difficult divorce, I reconnected with my high school sweetheart whom I married in 2011. He loves me in spite of the cancer issues.

I want to support women and their partners as they navigate through the physical/sexual issues that can test a relationship. I remember feeling so unattractive, like a failure while adjusting to the physical side effects of cervical cancer. I feared I would never be the same. The sexual issues survivors face can be daunting.

Please know the value of networking with other survivors. While many won't experience PTSD or psychological issues from their cancer, be on the lookout for those who may develop these symptoms. With time, support, and prayer you can truly be a survivor with a story to tell.



OUR STORY

*By
Sandy and Lorrie*

Sandy: Life was going along as it was supposed to. I was at home taking care of my nine month old daughter when I got the phone call on a Friday in late August 2000. That's when I learned that I had precancerous cells on my cervix and was later diagnosed with severe cervical dysplasia. I had a LEEP procedure done, was told I would need to follow up every three months for a year and then every six months for four years. After that, I could return to an annual Pap schedule as long as all my Pap tests were clear.

They were all clear!

During my ordeal, I had alerted my sisters Donna, Lorrie, Debbie and Cary Anne what I had been diagnosed with and that they needed to make sure they had their Pap tests because if this could happen to me, this could happen to anyone. As far as I knew, they had been getting tested annually.

Lorrie: As a family, we were all scattered around in states of mind and location. But I had no doubt as I heard and felt Sandra's urgency to "Go get your Paps!" that all four of us girls she was pleading with did just that. How could anyone not hear the important information she was passing on to us? No doubt we all came together as sisters and had our Paps. Sandra was right that if it was happening to her, it could happen to anyone of us. I scheduled my (admittedly overdue) Pap. I was happy and excited to let Sandra know all is good here! I let her know I heard her and went. I felt proud that I had my Pap. Back in 1980, I had a scare with a bad Pap test result. I was the lucky one that my body fought the virus. What I did next was go on with life. I never educated myself more on cervical dysplasia or cervical cancer. I wish I did, so I could have been able to help my sisters—Sandra as she was going through her battle and later with Cary Anne.

Sandy: Fast forward to August 2007. My little sister Cary Anne was admitted into the hospital after she hemorrhaged during the night. She called me the next morning, told me where she was and that she would see me after I got off work. There was no reason for me to go to the hospital because they were just running tests and wouldn't know anything until then anyway.

Cary Anne had been complaining for months that she was having very unusual heavy periods, breakthrough bleeding, and was very anemic. She



The sisters: Debbie, Donna, Lorrie, Cary Anne and Sandy

was actually on Procrit® injections for iron, which I was administering for her. The doctors told us that it was probably fibroid cysts on her ovaries but they were running tests. I remember one doctor asking her when her last Pap smear was. Cary Ann then asked me when I had my ordeal and I answered 2000. She turned to the doctor and explained that was the last time she had a Pap test and my heart sank.

After an exploratory surgery, the doctor diagnosed her with a very advanced stage of cervical cancer. I did what I always do in these situations; I called each one of my sisters. I knew immediately the severity of the situation and knew that we had an uphill battle, one that I couldn't fight alone. My sisters all rallied around Cary Anne and did all we could to help.

Lorrie: Cary Anne used to call me every Sunday at 9:00 a.m. I'd hear the music of the CBS Sunday Morning Show and the phone would ring. I'd smile because I'd know it was Cary Anne waiting at work for her boss—our time to talk, even though we are 100 miles apart. She would talk about everything from her only son Tyler's school to what her and San (Sandra) were up to. She also mentioned heavy periods, backache and being tired. Cary Anne was 10 years younger than me and was where I had been—hard working, crazy mom, wife, sister and friend. We talked about her body changing, and how she should see her doctor with her period changes. But as we know now, some of us put everything else ahead of our health and our much needed doctor visits. It was 2007 when it all came together.

We did have one last week. I remember it like it was yesterday, the fun sister's weekend in Atlantic City! Cary Anne had been going to the doctor getting iron shots from San, but she was just in a bad spot and we all thought all was going to be okay. They would find out why she was so anemic. Life just keeps moving but after that weekend, it was all about to change, and states of mind and location would be together again.

Sandy: The diagnosis, as suspected, was not good—Cary Anne was going to be treated for pain management, but there was no chance for a cure. Her cancer was terminal and spreading rapidly. Cary Anne was diagnosed with stage 4b cervical cancer and there was almost nothing the doctors could do to help her.

We needed a plan, we needed help and we were just at such a loss and didn't know where to turn, so we did what we do best. We came together as a family and did the absolute best we could. My out-of-state sisters each rotated weeks to come to help care for our little sister, the baby of our family. She had one chemotherapy treatment and several radiation treatments before the cancer began to take over her liver.

She could no longer live on her own. She needed to leave her apartment and come live with my family, which she was not at all happy about. She wanted to remain independent, and viewed herself as a burden. This was not the case at all, and I wouldn't have had her go anywhere else. Cary Anne had a very close group of friends that totally stepped up to the plate and helped us in more ways than one. They were even able to pull off a very successful fundraiser to raise money for medical expenses.

Lorrie: Weekend after weekend making the exciting and scary trip up and down I-95 was what I lived for. The states were together, keeping busy taking her from radiation treatments to moving in with Sandra, and trying to maintain some type of normal. Our minds were all in the same state. Sisters, friends, all were for The Cause.

Sandy: The doctors explained to Cary Anne and I that we had come to a point that there was really nothing else that could be done. We were to go home and enjoy our time together. How do you do that? I had no idea.

The doctors told me that she had several months and that they really couldn't put a time on it. I had hospice come in, but Cary Anne was in denial and thought it was too early for all that. Everyone had returned to their own states though we'd stay in constant contact. She was released from her doctor's care just around Thanksgiving, and I told my sisters she will not make it to Christmas.

I knew in my heart that her will and fight was over and just like that within three weeks her health deteriorated. She became very confused and things were going downhill fast. I called my sisters one last time to make the trip back to New Jersey.

Lorrie: It all goes back to that Pap. If we only had known how long it had been. All four of her sisters cared for her in her last hours; we stayed with her until her last breath, just like she would have done for anyone of us.

Sandy: I miss my sister every day, I wish she was still here with me. But she isn't and the only thing that I can do at this point is to try to make sure no one else loses their sister to this deadly disease.

We need to bring awareness to HPV and cervical cancer. As a matter of fact, I have vaccinated my 13-year-old daughter and my 12-year-old son will be vaccinated this year during his annual checkup. I don't want another mother, grandmother, sister, aunt, daughter, niece, wife, or girlfriend to lose their battle to this very deadly but preventable disease.

Lorrie and Sandy: Now six years later, still in different states and minds, we do what we can do to spread awareness and prevention. Sandy joined the National Cervical Cancer Coalition (NCCC) in 2009 and is now the New Jersey Chapter leader for her third year. Lorrie started her North Carolina Chapter in 2012. Our goal is to tell anyone that will listen that HPV and cervical cancer are real and we need to educate our children before sexual activity. This is preventable and with a little bit of knowledge, we can save lives!

I personally thank Cristina Ryan, my sister's best friend who founded the New Jersey Chapter of NCCC back in 2009. Originally I didn't want to be involved; it was nothing I ever thought I would or could do, and it just wasn't on my radar. Today, two years later as Chapter Leader, I couldn't imagine not being involved and doing what I do. It's become our passion!



JOANNE S LAW: ADVOCATING FOR CHANGE

By Anne Marie



Joanne

Our lives changed forever when my sister, Joanne, was unexpectedly diagnosed with terminal, late-stage gynecologic cancer. We were devastated by the news and needed to make plans for Joanne's care as her health deteriorated quickly. In a very short period of time, Joanne needed around-the-clock care and we were forced to make tough decisions about her care. Joanne was not married, nor did she have any children. Our father is deceased and our mother is elderly with medical conditions of her own. Taking care of Joanne and getting her safely to all her chemotherapy treatments and doctor visits became difficult. We all have our jobs and our responsibilities, but this was one that I could not walk away from—this was family.

Terminal illness does not leave much time for research nor does it wait for any resolution to occur. I applied for Family Medical Leave at my place of employment; however, I was denied since Joanne was a sibling. Siblings are not covered as an eligible individual under the current law. Disappointed, but not giving up, I appealed that decision, citing 'in loco parentis' because of our family situation. However, it was denied once again. Having no other option, I made the difficult decision to voluntarily resign my position of 17 years to help take care of my sister until she passed

away. I do not regret this decision to resign and would certainly make the same decision all over again. For some people, though, the loss of employment would be devastating.

While I am not a nurse by trade, I accepted my new position as caregiver and was trained by critical care nurses in our home. Hospice was not an option for us due to Joanne's medical situation, so our family took care of her until she passed away on February 13, 2009.

As I thought about our experience, I realized that we cannot be the only family in Pennsylvania in this situation. No one single law can dictate who is considered "family" anymore. Death, divorce, separation, and single people all play a role in today's family unit. I felt that Pennsylvania law should be changed to include a provision to include siblings under special circumstances, like my sister's, as eligible individuals so that we may take protected leave from our jobs. I approached my state representative with draft legislation modeled after the several other states that have already passed similar statutes. I testified in our state capitol before the labor relations committee where the bill seems to stall with each introduction. We have official written support letters from reputable organizations that encourage this legislation and advocate for work, family, and life balance. They include: The National Partnership for Women and Families, Pathways PA, the Susan G Komen Pennsylvania Affiliate, the National Cervical Cancer Coalition, the American Cancer Society, and the Disability Rights Legal Center.

I often think, who would have taken care of Joanne if I had not sacrificed my livelihood and my job? Today's economy is not one in which anyone can afford to choose between taking care of a family member or keeping their job. Unfortunately for many Pennsylvanians, this is a harsh reality without this legislation. I continue each day to gain support from both our elected officials and from various family caregiving organizations. I know what's involved, from an insider's perspective, the challenges that families face and decisions that were made on behalf of my sister and my family. I am only one person but I know now I can make a difference for another Pennsylvania family facing similar challenges and, in doing so, honor Joanne's memory by getting "Joanne's Law" passed.



BATTLING A RARE CANCER

By Colleen

My story is different than most you will read here. My story isn't usually told by organizations like these. I am so happy and proud to be able to share with everyone, as I have worked tirelessly to spread awareness for several years and bring hope to other women suffering my same diagnosis. There are many more than you would think.

In 2006, at the age of 38, I was diagnosed with small cell neuroendocrine cervical cancer. I was at the time, and of course still am, a breast cancer survivor and come from a long line of women who have battled this disease. My annual Pap test was a given, not a choice. I never missed one. I had never had an abnormal Pap and in 2005 had been screened for HPV. I didn't have it.

At first I was diagnosed with squamous cell cervical cancer, the one that accounts for about 70 percent of invasive cervical cancer cases, is slow growing in nature, and caused by HPV. This is usually detected in pre-cancerous lesion stages. Yet in 10 short months, I somehow grew a seven centimeter tumor that covered my cervix. This didn't make sense to me.

How could I have a cancer that everyone says is caused by HPV? How could I have never had an abnormal Pap, including the one 10 months prior, and have squamous cell cancer? I persisted with these questions until finally my radiation oncologist listened. My biopsy was sent out again, and it came back as small cell cervical cancer (SCCC). To further my point, there was no HPV in the DNA of this tumor. Had I not pushed, I would have been treated for squamous cell and would not be here today. I often wonder how many others out there suffered this fate, especially the ones diagnosed during pregnancy and right after giving birth. No one saw the "slow-growing abnormalities?"

SCCC has a poor prognosis for survival. I had less than a 15 percent chance of surviving 18 months, less than that for a longer period and zero, zip, zilch if it ever came back. It did. In September 2013, I will be four years cancer-free from recurrence and I seven years from diagnosis.

Over the years I have found women from all over the world suffering this diagnosis and we all heave a collective groan when we read, "cervical cancer is caused by HPV." Listen to your body. Be proactive and be informed. Knowledge is power and the only true form of prevention out there...if there truly is such a thing as complete prevention of any cancer. I don't think there is. So, I say, trust your own instincts. No one knows you better than you. No matter what, get your annual "well woman" check-up. There is so much more to look for than just HPV and cervical cancer.

Editor's note: Small cell cervical cancer (SCCC) is a rare and aggressive type of cancer, accounting for less than one percent of all cervical cancers. While there is not a known association between SCCC and HPV, most women with cervical cancer will have either squamous cancer or adenocarcinoma, which account for more than 99 percent of cervical cancers and both of which are associated with HPV.



INTO HIS LOVING ARMS

By Janet

Bad things are not supposed to happen to good people, but they do, every single day. It is fair to say that even the most knowledgeable Christians do not always comprehend the powerful works of our Creator. I believe that all devout Christians have questioned something God has done at least once in his or her lifetime; therefore, I am not ashamed to admit to having questioned Him several times, when life just didn't seem fair. My Aunt Jolene's diagnosis of cervical cancer five years ago I count as one of those times, the most recent, in which I felt God was punishing an innocent woman, who had always followed Him faithfully, and loved Him completely.

Our family spent almost a year watching Jolene go through 25 rounds of radiation, followed by chemotherapy, then loss of hair, two separate surgeries to remove the cancer, and yet another to repair bodily damage from the radiation before I decided that instead of questioning God, I was going to start trusting him with my aunt's fate. Something inside me told me that if anything was going to be done for her, it had to pass by Him first anyway, because He is the ultimate healer.

Jolene's cancer returned only twelve months after what was to be her final radiation treatment. This time the cancer had spread in masses much larger than the tennis-ball size of the original mass. Since she had changed her diet, gotten more than her fair share of second opinions, exercised often, read at least fifteen books on curing cancer, and gone to church routinely, naturally our family was devastated. Jolene had done all of the right things, and God had done nothing—or so it appeared to me.

I continued to pray every night for Jolene's recovery, hoping that God was just taking His time, planning out His next miracle. But Jolene's health continued to decline, as she began to respond negatively to the chemotherapy. In spite of a desperate trip to the Dana-Farber Cancer Institute in Boston in 2006, Jolene returned within five days' time, having acquired no more information than she had received firsthand from her doctors in Indianapolis. Our family then counseled her, suggesting that maybe what she needed was to relax, spend time with her children, and let nature run its course.

Within months, Jolene's cancer went into remission again. By the summer of 2006, Jolene was healthy, in good spirits, and resuming her active lifestyle. Eager to take advantage of the revival that God

had granted her, Jolene did not waste a moment of that summer sitting at home; she exerted her athletic talents playing for her infamous community softball league, coaching youth softball and t-ball, spent the weekends traveling with her kids, and continued to entertain our family with her undying sense of humor.

But six months later, Jolene was informed for the third time in five years that her cancer had returned. I again asked God to give her the strength to fight it, one more time. Even though the cancer progressed fiercely throughout her body, she never let it poison her mind. Jolene was a woman of perseverance; the star competitor of her high school athletic teams, an intelligent mother of three beautiful children, and the strongest person I knew. Jo's role in my life had always been significant, and a good portion of my childhood was gladly spent under her care. Her passion for life was infectious to all that knew her.

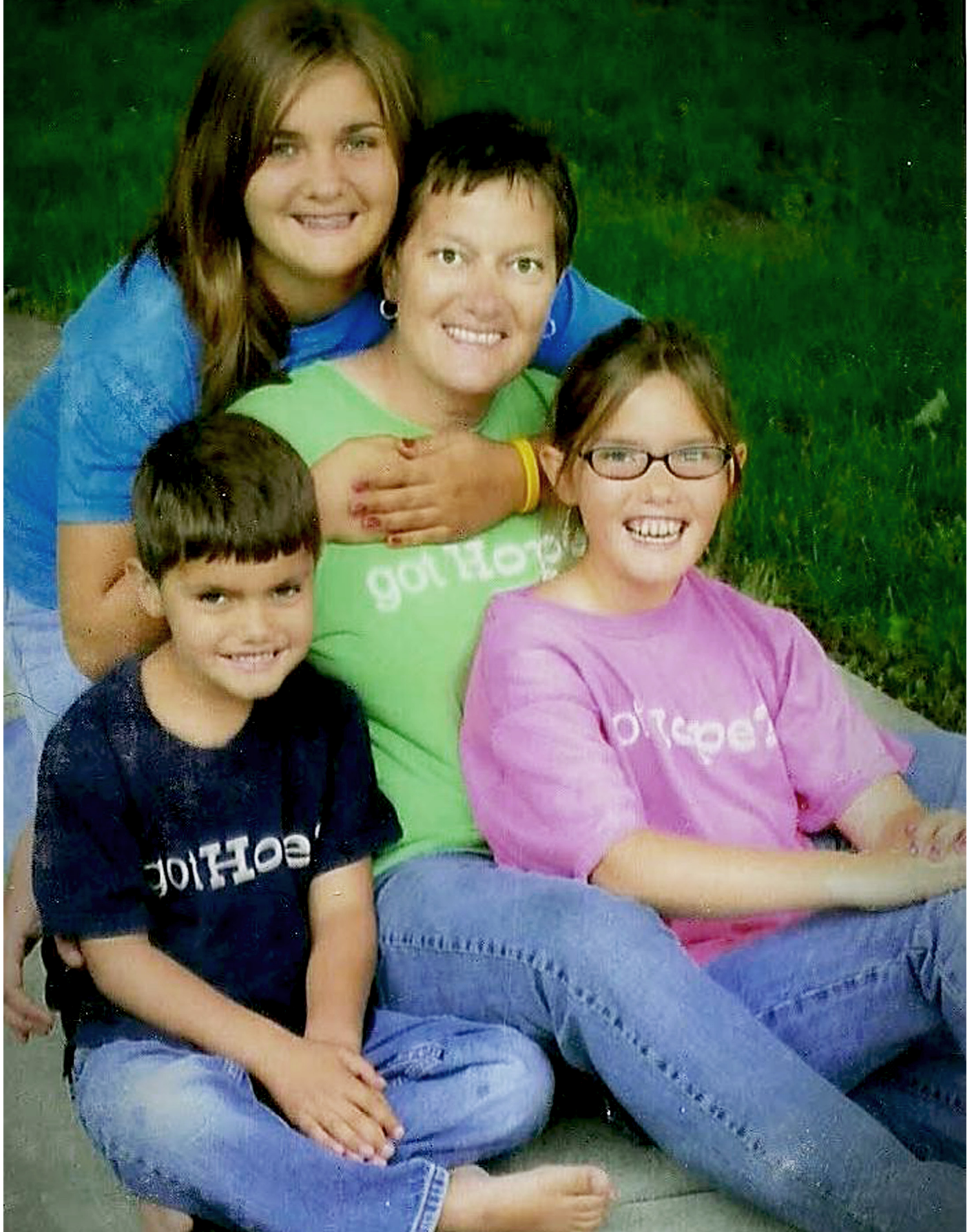
Although Jolene lost her battle with cancer, several valuable lessons can be learned from the way in which she fought her disease. She taught us how to persevere. Vitally ill, not once did her condition consume her spirit, even though it was persistently degrading her physically, mentally, and emotionally. Jolene tackled her struggles day to day, and when clouds formed she never gave up on the sun. She lived in a way that we all should strive to replicate—with no sense of time. Needless to say, her condition did not define her, she defined it. Slowing down was never an option to Jolene, she was always on the go, and it never really mattered what she was doing, she just wanted to be with her family, making them smile.

She taught us how to regard family. Even in her darkest hour, she was still our brightest light. Jo cherished her family above all else, and proved daily that there wasn't a thing that she wouldn't do for the people that she loved—especially her children.

She taught us how to love eternally. Jo was one of six beautiful sisters. Six sisters that come together to celebrate, to learn, to teach, to grow, to assist, to counsel, and now to grieve. Six sisters that could be counted on. Now that Jolene has passed, and their number lessened to five, the sisters will band even tighter. They are the strongest five women that I know, attributing a lot of that strength to what they learned from Jo. She was always the rock, and helped hold them up during her time here on Earth, and I have no doubt that she will continue to do the same now, only from the realms of heaven. Jolene passed in the comfort of knowing that she was leaving these five amazing individuals behind; Debbie, Janet, Jill, Missy, and Melanie.

More than anything she loved to travel with her family, and was continually plotting our next outing a year in advance. Having the privilege to travel with Jolene made each trip an experience of a lifetime, just because you could see how much time she put into making sure that every single person on the getaway had not just a great time—but one they would surely never forget. She also liked to travel in the car, no matter where it was—she liked to be on the road, just going.

Jolene was always in motion. For her kids, for her family, for her friends, for her co-workers, for people that she didn't even know at times. That was what she loved to do, and that will never change, she will continue to go, the single difference being her means of transportation. She has traded in her Saturn Outlook for a beautiful pair of wings, and now nothing can stand in Jo's way—peacefully into His loving arms.



Jo and kids



I THOUGHT HEALTHY PEOPLE DIDN T GET CANCER

By Sally

My name is Sally and I live in Harare, Zimbabwe. I was diagnosed with stage 2b cervical cancer in June 2012. I did not have regular Pap tests or other recommended tests because I believed cancer didn't happen to happy healthy people. I had no family history of cancer, I ate what I thought was healthily, only drank the occasional glass of wine and was fitter than most 60 year old women, having run six ultra-marathons and numerous 10k plus runs. I was running 100 and 200 meter sprints and did an 80 meter hurdles race in May 2012—a dream fulfilled.

I received my chemo treatments and radiation treatments in Johannesburg, South Africa. The treatment was easy for the first four weeks but on the fifth week I fell to pieces and it has taken a year plus to feel reasonably good again. I have had other traumas during the year and found everything very hard to deal with.

This year, I have run 16K and 21K runs and done a 42K progressive marathon. My advice to everyone is stay fit and healthy so when you get sick, whatever it is, you have the physical strength to deal with it. Learn to live in the moment, because I believe nothing lasts forever and have dealt with all the ups and downs believing that they would pass.

Be tested and use vaccines where possible and you don't have to even go down this road.

Editor's note: According to the World Health Organization, cervical cancer is the second most common cancer in women worldwide and the third most common cause of death from cancer in women. In developing countries, where more than 80 percent of all cervical cancer cases occur, it is often the most common cause of cancer-related death among women and a leading cause of death for women overall. In poorer nations, limited access to life-saving screening tools, such as Pap and HPV tests, means cervical cancer is often not diagnosed until the cancer has advanced to a later stage, and thus more women die as a result.



I WISH I WOULD HAVE KNOWN

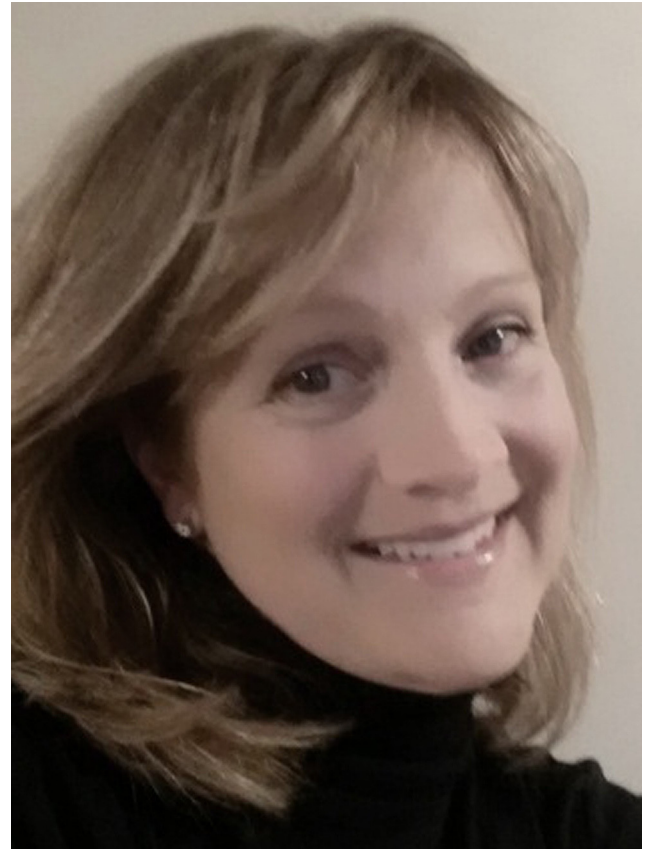
On June 13, 2012, I went in for my annual exam, which is both humbling and uncomfortable. It is something that girls are introduced to early in life and we learn to deal with it. Experts now say that if all of your Paps have been normal, you can actually go two or even three years between tests. I am here to tell you that I disagree with that position.

On June 20, exactly one week from my annual Pap smear, I got a frantic call from my doctor letting me know that my Pap result was “very abnormal.” The call itself was abnormal because up to this point, all of my annual Paps had been normal. I had missed a Pap during 2011 because I had my period, but that was just one missed year, so my thought was that it was probably nothing. That was the general consensus of my friends as well because, everyone has had an abnormal Pap, right?

I met with my OB/GYN on June 22 for my colposcopy. I was already running worst case scenarios in my head. She said that people don’t go from a lifetime of normal Pap tests to cancer, so I shouldn’t worry, just relax. So, I relaxed, as much as I could with a super-powered microscope looking into my cervix. Then she said this, and I quote, “your cervix is angry, you have a p.o’d cervix. We definitely need to do something.”

There were several options discussed, but the biopsy would ultimately tell the tale. When the results were in, I got the call and learned that not only was my cervix angry, I had cancer. And later I would learn I had HPV. My options for treatment went from many to one. At age 44, with one child, I had a radical hysterectomy. “Radical” means that they would remove the cervix, uterus, fallopian tubes and many lymph nodes. My ovaries scanned clean so they were saved and I did not go into surgical menopause. There were many scans and

By Jen



tests that led up to the surgery, but it was ultimately a success. My recovery, as hard as it was, was also successful.

I am a mother, wife, sister, daughter and friend. I work at a job I love, volunteer at my son's school and with his various teams and activities. I read as much as I can, talk much too much, laugh and most importantly, survive. I am cancer-free and I still have the HPV virus. The HPV is what caused my cancer. I didn't ask about it until after I'd done my own research. During one of my follow up visits I asked questions. What kind did I have? How long had I had the virus? I asked many other questions as well. Unfortunately for me, I developed cervical cancer which is quite possibly the worst side effect from the HPV virus. I wish I would have known that I had HPV and that there was something I could have done to prevent it.

Editor's note: Many women are used to getting screened once a year. However, newer research has found that in most cases it is not necessary to screen this often. So now you and your healthcare provider have options depending on your age and the screening tests used.

- *Women ages 21-29 should have a Pap test every three years*
- *Women ages 30-65 should have a Pap test along with an HPV test every five years (it's acceptable for women in this age range to have Paps alone every three years, though)*
- *With women over 30, healthcare providers may also use a newer genotyping test that checks specifically for the HPV types found in most cervical cancers.*

If you have questions about which tests are right for you, ask your healthcare provider. Even though screening for cervical cancer can occur less often, it is still important for you to see your healthcare provider annually for other female-related health care needs - ask your provider what he or she recommends.



STAND UP AND FIGHT AGAINST THIS

My name is Meghan and I've struggled with HPV since I was in my early 20s. I was devastated, and needless to say embarrassed, to learn that I had this sexually transmitted disease. While most strands of the virus go away on their own, or with little treatment, mine was one of the aggressive types that just kept recurring. I had at least eight to 10 colposcopies and two LEEP procedures over the course of four to five years in order to keep the intermediate stage, precancerous cells, under control.

A couple of years ago, I FINALLY received my first clear Pap test result in years, and I've had clear Paps ever since then. Not only was I blessed with the miracle of good health again, but I have since got married and will be delivering my first child this December!

I write this so that all the women out there who feel like they are in a place of hopelessness and helplessness will not despair, but rather stand up and fight against this disease. If it weren't for my will to overcome this condition, and the care and expertise of my doctors, I would not be here today. Not only did my doctors save my life, they made my new family possible! Never give up hope!

By Meghan



I AM BLESSED TO BE ALIVE

By Mary Jo

This story was first published in Your View in The Louisville Times on August 13, 1986.

This is not just another cancer story. It is my story—a personal event that threw me into experiences I never dreamt of having. I had always been very active and healthy. Yet in December 1985, I was diagnosed as having invasive cervical cancer.

I went through many different emotions when I learned this, but found the support I needed to face it. There were the nervous times when I was facing medical treatments and the pain involved in these procedures. There were calm times when I was alone, especially the night before my major eight-and-a-half hour surgery. When I reconciled myself to the necessity of this operation, I felt a powerful calmness within. The operation was the one main thing I needed to win my personal battle of life over death. Deep within, I did not feel I would die soon. Yet, I knew I had a disease that would eventually kill me if treatments weren't successful.

Lastly, I felt a strange excitement because I was facing the hardest challenge of my 38 years of life—to beat death—that inevitable, yet unknown, existence. We might say that every day one faces the game of winning life over death. Yet, when potential terminal illness strikes, normal life routine stops; control of taking care of one's body is altered and, in my case, drastic permanent physical changes were made.

Fortunately, I was blessed with a strong support system. I have only praise for the skill and excellence of my surgeons and their assistants. Their service to me was one of dedication, warmth and caring for my well-being. Also, the nurses and other staff members at Norton Hospital and the James Graham Brown Cancer Center were very caring people, and great contributors to my getting well. Louisville is truly fortunate to have facilities of this high caliber.

The continued strong support, both physical and spiritual, of my family, friends and associates at Ursuline-Pitt School was a powerful force in my healing

process. Ursuline-Pitt School, where I have taught for the past 13 years, serves children with special needs. I have become an adult with special needs, and I feel myself extremely blessed to know the bonds that exist among this select group of people.

Possibly, this bonding is the boundless strength of life itself, no matter what additional limits have been placed on one's physical body. It is in this strength among people with varying degrees of disabilities that an outgrowth of very positive energy can flow.

It is a gift we have been given. Let us use it!

Update 2013: Twenty-seven years ago after the first article, I am blessed to be alive and to be a productive member of society. This medical journey has often times been a lonely one because of the few isolated cases of pelvic exenteration patients. Support group attempts have not been successful. However, I have met some cervical cancer survivors and I keep in touch with them. The creation of NCCC is a most valuable resource and support system for cervical cancer patients.

In the early 1990s, I had two serious life-saving surgeries involving blocked ureters. These surgeries saved my kidneys. I traveled to Vanderbilt and to Massachusetts General to have the best surgeon perform this procedure.

I'm proud to say that I have continued my mission of working with people who have developmental and intellectual disabilities. Currently, my friend, an Ursuline sister and I, along with many others, are moving into a new school building for adults with special needs. This new one-floor facility is another dream come true for all of us involved in this project. These most special people inspire me to keep living and to keep dreaming.



MORE THAN MY BODY

By Natima

Experiencing multiple rapes, beginning at the tender age of nine, I struggled with my attempts to differentiate the act of sex from the meaning of love. Like a lot of rape victims, I initially blamed myself for the action of the rapists, had low self-esteem, and later became quite promiscuous.

At 17 years of age, I became a mother and thus filled the self-love void with the love of my newborn baby. Less than two years after the birth of my newborn, my son had a stepdad. Two years later, I was single again, but not for long.

This new guy seemed to be the perfect description of what a woman looks for in a good man—that is, until months later when he shared his STD with me. He was ashamed to admit he was living with a sexually transmitted disease. He continued to “live his life” and like many men his age, preferred sexual intercourse without the use of condoms. His view of me changed once I accepted his explanation as to how I could have gotten this STD during the course of our relationship, and so he began calling me “stupid” and “dumb.” I wish I could tell you that my journey of bad relationships ended there.

I eventually discovered that I was living a pattern, and that no matter my ending of previous relationships, I simply picked up a new abuse pattern at the beginning of the next. I also learned that I had HPV, and was at risk for cervical cancer. Somewhere along this destructive path, I adopted the belief that “if a man accepts me as I am and says that he loves me, surely it is true love.” For a short while, I too was ashamed of the STD I carried, and afraid of who wouldn’t accept me. I realized that there was nothing I could do about the STD, and that I needed to focus more on accepting myself.

When and how did I rise from the victim’s path, and onto the road of victory? I watched cervical cancer age and kill the body of one of my peers. I was determined that her death would not be in vain. I decided that no one else’s love for me was enough, not even that of my son. This did not happen overnight, and thus began a journey of my process of healing. No matter how lonely, no matter how deep the connection, I had to learn to love myself first.

Years ago, I began to tell it to myself regardless of whether I felt it. I spoke it into existence, and started following up my affirmations with actions, one behavior pattern at a time. I stopped being a victim and accepted my role in each situation. Once I realized and accepted that it was I who made the choice to be in situations and relationships that were hazardous to my mind, body and spirit, I felt free to let go. I changed my thoughts and standards and I left, even when it hurt to say goodbye.

With the changing of my standards, I also learned to stop pretending I was in relationships with those who were not in relationships with me. I ceased giving more into a situation than I was receiving. I made better choices for my body, mind and spiritual self. I married a man who is totally in love with me and my onerous self. The best news of all: My doctor advised that I was no longer at risk for cervical cancer.





MY MISSION IS TO SHARE MY STORY

By Michele

My experience begins in the usual way. Although screening guidelines today seem to be in constant flux, I represent generations of women who have followed the routine of the annual Pap smear. In 2008, when I was 33, it was time once again to take the annual pilgrimage to the gynecologist. My husband and I decided it was time to try for a baby and I wanted a doctor I could build a relationship with. A friend of mine loved her doctor so I made an appointment with her. After a run through of my and my husband's sexual and general health history, which was far from exciting, my new doctor advised co-testing just to be safe.

And this is where it got interesting and educational for me.

She asked what I knew about HPV and sadly all I could tell her was that it was an STD and there was a vaccine for it. But I knew I was too old for it, and I had never even heard of co-testing and specifically the HPV DNA test. And besides, I was in my 30s, and in a loving, monogamous marriage. I naively thought STDs are what young, single women in their 20s worry about. Since I entered my 20s a virgin and came out with just a handful of sexual partners, and a glowing, spotless Pap history, I was feeling pretty confident I had no concern for an STD.

I was someone who had never missed a Pap test, a graduate student at an Ivy League university, getting my doctoral degree in health education, the daughter of a doctor, someone who had always eaten well, been active, and knew very well the dos and don'ts of good health. But there I was, learning about an STD, and subsequent cancer risk, I had to be concerned about.

Although the doctor applauded me for my due diligence of getting my annual Pap, she also pointed out that it wasn't all I could be doing to protect myself. I of course eagerly agreed to co-testing and I am so grateful to her every day for suggesting and encouraging this.

Waiting a week for the results was a walk in the park. When my doctor called she told me my Pap was normal. I congratulated myself. With so many normal Paps under my belt, I always felt like I was winning some race, beating some record. But then that feeling quickly went up in smoke. She also told me I was positive for high-risk strains of HPV.

I was stunned. My mind raced. How could this be? My Paps have always been good. Wouldn't I know if I was carrying around something as dangerous as high-risk HPV?

And my husband? All I could think of was how much I love him and how awful I'd feel if I infected him. My doctor said I should tell my husband and she told me that women don't always share their HPV status because of the stigma. I was sure my husband would be supportive, but this was also the first time we'd had to deal with something like this, and to be honest, I was thinking how awkward it would be.

When I told my husband, his first words were, "I feel so badly. What if I gave this to you?" His second thoughts were, "Isn't there a vaccine we can get?" and "How do I get tested so we can treat it and get it out of our lives?" At the time the vaccine was not approved for men, and even if it had been, he would've been too old for it. And this is when we learned that there is no screening for asymptomatic men.

This led to us spending many hours learning all we could—that approximately 79 million people are infected with HPV at any given time, that it's easily transmitted, and that even abstaining from intercourse doesn't fully protect you. And we were feeling it can be so unfair that the combination of choices, bad luck, and lack of education from our previous lives can have the ability to so drastically affect our current life.

The results of that first round of co-testing led us to postpone starting a family, as my doctor told me to return in six months. Six months later, I was in the same spot—normal Pap, HPV positive. I was not fighting this off. We were all stumped by this. All the information out there about reasons you don't fight it off—poor diet, unhealthy weight, and smoking—didn't apply to me.

All my doctor could say was that stress lowers your body's ability to do its job and that HPV is very common. We were encouraged to just keep living our healthy lifestyle and advised that it would probably go away by the next follow-up. But six months later, at the second follow-up, my co-test showed low grade ASCUS and I was still HPV positive. I was still not fighting this off. In fact, just the opposite! It was getting worse.

My doctor didn't want to play the waiting game any longer. She referred me to a gynecologist that specialized in treating STDs. I had to wait three very long weeks for the appointment with the specialist. Although no one was sure how long I'd been carrying around this unwanted guest, now that we knew it was here, we couldn't wait to get rid of it.

Both my husband and I attended the appointment. She did a colposcopy and noted that a majority of my cervix turned white from the acetic solution. This led to a biopsy and she told us what next steps would be depending on the results, with the scale varied from watchful waiting to total hysterectomy.

You try not to think the worst, but in just 12 short months we'd gone from co-testing just to be safe, to follow-up, to low grade ASCUS to biopsy. It seemed we were pressing on full steam ahead in the wrong direction. My husband and I began to cry and think about where we'd want to see ourselves in 5, 10, 20 years. We talked about the children we didn't have yet, the doctoral program I hadn't finished, and how our lives would change if it really did turn out to be advanced cervical cancer.

When she called to give me the results she told me it was CIN III. I She cautioned me to not get wrapped up in the labels—even though some say it's stage 0—and that what was most important was that it was caught early. She said I should have a LEEP. I tell you, I couldn't schedule that appointment fast enough. It all seemed so precarious, one small sway of the wind and I'd be on the wrong side of the cancer fence.

How can someone go from over a decade of normal Paps to low grade ASCUS to CIN III, in just one year? And what about all those Paps I'd gotten? Were they always missing a spot? And then came the more logical questions. How did I not know about co-testing? I live in New York City. You can't walk one block without seeing a public health message for pretty much any ailment, but I'd never seen one for co-testing. And how about any doctor I'd ever been to? Why didn't they mention it to me? Did they even know about co-testing? And what really blew me away was that I seemed so healthy, so asymptomatic.

The LEEP went very well and she told me to come back in three months, and then again three months after that. It had now been six months since all this and we were given the go ahead to start trying for a baby. This was great news. And this is when I felt strong enough to take action and turn the hours of research and emotions that my husband and I stumbled through into leadership action because I don't want anyone else to have my experience.

As I got deeper in learning everything I could about HPV, I was fortunate enough to learn something that no other provider had mentioned – that two-thirds of women who present with high-risk cervical dysplasia also present with HPV strains on the anus. At my one-year post-LEEP appointment, I told my doctor about what I'd read and she said she knew about this, but felt I didn't meet the at-risk criteria because I had no history of anal sex. We did talk about the “superhighway of transmission” as she called it between a woman's front and backside, but even so, she really thought I had nothing to worry about. She must have asked me a half dozen times if I was sure I wanted the test. I think she was really more uncomfortable than I was. But since we all thought I'd fight off the cervical HPV after that first co-test, and I wound up with CIN III, I didn't want another surprise.

Waiting for the results was exhausting. Seven days later she phoned me and her first words were how sorry she was to tell me that my cervical Pap came back low grade ASCUS, and if that wasn't enough to stop me in my tracks, she said the anal co-test showed inconclusive Pap but HPV positive.

I was crushed. My cervical dysplasia came back. And now I had to deal with anal HPV? Then she told me that she was embarrassed for thinking I was nuts and “one of those patients” when I asked for the anal co-testing because I had taught her something. I have to tell you, as a health educator by training and profession, this was exhilarating—I had taught a doctor something! But as a patient, that's not what you want to hear.

Then she told me that she felt my bout with HPV was beyond her scope and it would be best if she referred me to a gynecological oncologist. She asked if I had a paper and pen to write down the information and when I didn't say anything she asked if I was still on the line. I had been walking down Fifth Avenue during rush hour and I had cut into Central Park to sit down. I can tell you exactly what I was wearing that day and that it was warm and

sunny. And even though the park was full; children playing after school, puppies and strollers at every turn, it was if someone had hit the mute button on the entire city. It was dream-like. All I could hear was the hollow din of the word “oncologist” ringing in my head.

I made that appointment in record time!

Two days later, when I noticed how late I was, I eagerly and apprehensively took a home pregnancy test. Eager because I so badly wanted it to be positive. Apprehensively because what if it was positive? Didn't we have enough going on right now? Within seconds the little plus sign appeared. I was officially, 100 percent pregnant. I screamed with delight. Finally! After seven months of trying. Success!!

That week is forever broken into two separate occasions for me. I'm referring you to an oncologist. I'm pregnant. I'd be hard pressed to think of two other words you'd least want to hear in the same sentence besides “pregnant” and “oncologist.”

At the oncology appointment she did a colposcopy and it did show one small spot that turned white, but she felt it was best to let it be until I delivered and that I should come back at the start of my second and third trimesters just to make sure it hadn't advanced. As for the results from the anal co-testing, she referred me to a general colorectal surgeon who couldn't see me for another month. It seemed like a long wait given how weak my body seemed at keeping the cervical dysplasia under control. But we also were clearly beginning to understand the passive-aggressive nature of HPV and how one month in “HPV years” is nothing.

Unfortunately, during that time, I miscarried at six weeks. We were assured that it was unrelated to the HPV and given all the research we had done, we were confident this was true. But we still couldn't help ourselves from bundling it all together as just one more low point.

On a bright note though, the miscarriage allowed for us to take a closer look at that small white spot on my cervix. Yet the follow-up colposcopy showed no signs of dysplasia. This was great news. Puzzling, but great.

Then it was the day of the appointment with the colorectal surgeon. He reviewed my health history and then the at-risk behaviors for anal disease, and strongly noted that I did not meet the criteria. When I mentioned what I had read about two-thirds of women who present with HPV on the cervix also present it with on the anus, he wasn't familiar with the literature, and again said he thought I had nothing to worry about. He performed a digital exam, found nothing, and told me to return in six months. Before leaving his office, I told him I'd had excessive anal itching off and on for the last couple years, that I had tried various over-the-counter itch creams, and often thought it must be from my desk job or the weather, or my bath or laundry soap, or being sweaty from a run outdoors or the gym. But now I had to wonder, did anal itching mean I had anal HPV? He said that my guesses were probably right, and he told me to use baby powder.

Although it was a relief he found nothing wrong, and I did feel good that he thought my guesses were right, the specificity of the HPV DNA test weighed on us. We were now devout believers in the HPV DNA test, so that this doctor seemed to wave it off didn't sit well with us. And baby powder? To tell a woman who just weeks earlier had miscarried, and just one year earlier was on the brink of staged cancer, to douse herself in a known carcinogen, well that just left me feeling this doctor wasn't for me.

But six months later, there I was, back in his office, having an identical visit. At the end of that visit, when it

seemed the feeling was mutual, he referred me to a colorectal surgeon that specializes in non-digestive anal disease.

With this new doctor, after explaining how I got to him, his first action was to do an anal colposcopy, something he said he was surprised hadn't been done yet. Now when a doctor quickly decides what he's going to do, and declares his surprise that no other doctor has done this yet, you find yourself second guessing pretty much every other patient-provider interaction you've ever had. Within seconds he spotted anal warts and commented how obvious the diagnosis was given my history of HPV-related cervical disease and excessive anal itching. And he also commented that baby powder was a bad idea because talc is a carcinogen and the scent and talc can be an irritant to anal warts.

His speedy diagnosis made me feel elated and sad. My first thought was "Finally, a doctor who knows what they are doing." My second thoughts were, "I have anal warts?" and "I feel so dirty and so comically jinxed." He had an opening in his schedule and said he could treat me that day. I called my husband to give him the news. We were laughing and crying. Laughing because of the craziness it took for us to get to a doctor that knew what he was doing. And more laughing because, well, as much as we try to normalize an experience and put it in a clinical perspective, we are weak to our social tendencies and anal warts are so embarrassing. But also we cried because it seemed like HPV was this third person in our marriage and it was so frustrating and scary that it just kept popping up.

What is most telling of my visit to him was that he said that although I don't fit the profile for non-digestive anal disease, my history of HPV-related cervical disease trumps any other index of measurement and that the persistent itching, even after changing soaps and using creams, was such an obvious sign of warts. I was so angry that the first anal disease doctor not only didn't know this, but also didn't think to do a colposcopy. Yet I don't solely place the onus on that first doctor. I couldn't help but wonder, why hadn't I pushed for an anal colposcopy? What stopped me from speaking up?

Throughout this journey there have been teaching moments on both sides of the exam table. But I also see missed opportunities for education. Maybe there is a gap between virologists and doctors and that's why doctors may not know about the value of lab tests and that they can be an aside to at-risk behavior. And providers need to follow a standardization of care.

Although I am diligent with follow-ups for the "front and back" as my husband and I say, and I am happy to say that I have no sign of disease, the 100 different ways my patient experience could have gone haunts me. If I hadn't started with a new provider, if she hadn't been educated about co-testing, if it weren't just anal warts and the wrong referral had delayed life-saving treatment, and that one provider thought to do an anal colposcopy when the other didn't...and I could go on.

All these what ifs is what drives me to become involved at the national level and local level and educate as many women as possible. Ultimately, my mission is to just keep telling my story. Because in some circles CIN III is also considered stage 0, and we live in a culture where the words "stage" and "cancer" in the same sentence sends chills up the spine.



A CERVICAL CANCER DIARY

*In memory of Jessika Macken Ritchie Morgan
3/19/1978 - 2/12/2011
My friend, my patient and sweet sister-in-law
Our journey together*

By Stacy

2010

March 7: Jessika had been having severe vaginal bleeding. I made her go to the ER that night because of the amount of bleeding, and she was examined and discharged with Provera. She was instructed to follow up with her OB/GYN.

March 11: She had endocervix curettage for the bleeding and because of the intuition and guidance God had given her doctor, several cervical biopsies were taken.

March 12: Jess, her husband Spence, and I were informed that she had squamous cell carcinoma of the cervix. We named her tumor "Miller" after the doctor who, just out of chance, biopsied her cervix.

March 19: Jess had her PET scan, her 32nd birthday.

March 22: PET results. Jess was diagnosed as having Stage IB1 cervical cancer with lympho-vascular space invasion. The retroperitoneal lymph nodes involving the left pelvis, the left iliac and left paraaortic nodes were involved.

April-June: Jess received chemo and radiation (brachytherapy). MRI showed positive response to chemo and radiation. Jess was discharged to follow up in three months. Her total weight loss was 12 pounds and she did not lose any hair. Overall, Jess did well, but did say she would never go through treatment again if she needed it.

July: Life is normal. Jess took a part time job, spent the summer with her children, went to the beach, etc.

August: Follow up with oncologist. Jess was given a referral to a gastroenterologist for mild nausea and vomiting. A PET scan was ordered. Follow up with the radiation oncologist. The PET scan results indicate a suspicious area to the right iliac chain along the lumbosacral level. The previous abdominal and pelvic retroperitoneal lymph nodes had "essentially resolved."

September 1: Visit with the gastroenterologist. He scheduled a gastric emptying study and placed her on a reflux med.

September 27: Jess had her PET scan follow up with an abdominal/pelvic CT scan. The following day, the radiation oncologist concluded that the suspicious area was post-radiation inflammation.

October 9: Jess gave my niece a birthday party and celebrated my brother's birthday as well. She looked pretty good that day and was as hyper as usual.

October 15: Jess started having worsening/uncontrollable nausea, vomiting and abdominal pain. She also started having mild back pain around this time.

October 25: Appointment with her oncologist. Jess had a normal urine test and was placed on Percocet® for her back pain and meds for her stomach issues.

October 26: Jess admitted to hospital for dehydration. Jess had an endoscopy with biopsies and was diagnosed with gastroparesis. She also had an MRI of her lower back which showed normal post-radiation changes with adenopathy. An MRI of her pelvis showed "no acute findings. No evidence of residual disease."

October 30: Jess had her gastric emptying study. She was diagnosed as having delay in gastric emptying related to the radiation she had been exposed to. Placed on Reglan®.

November 3: Follow up with radiation oncologist. Jess was instructed to increase her Reglan® and was referred to the pain clinic for "dependency related to the pain medications as well as concerns about psychological issues that may be playing into her use of the medications." He also wanted to "hold off on further imaging as she has just recently undergone repeat CT imaging" which had been "essentially unchanged" and suggested her oncologist consider a PET scan in January.

November 5 and 10: Jess went to hospital again for her symptoms and was admitted. Jess continued to lose weight and get weaker and sicker. We felt like she needed some form of supplemental nutrition but her doctors did not feel the same.

November 16: Jessika was extremely sick and I suggested she come to the hospital where I work an hour away. She had given up on getting answers and began to slowly lose her strength to fight.

November 16-December 13: Jess was admitted for malnutrition at the hospital where I work and was placed in room 319 (ironically, as her birthday is 3/19). Jessika had an excellent hospitalist who searched and searched for answers. She had more X-rays, CT scans, MRIs, endoscopies, an exploratory laparoscopy, a colonoscopy, another gastric emptying study, etc. Jess also had a feeding tube placed and was diagnosed and discharged as having severe malnutrition and failure to thrive.

December 14-23: Jessika stayed at her home and continued to have nausea and severe back pain and would vomit when she would eat. She had episodes of tightness or fullness in the center of her chest but overall as long as she did not eat her abdominal pain was tolerable. Jess also just used her feeding tube to take medicines. She started to develop lymphedema to her left leg and foot that her radiation oncologist felt was related to the previous radiation treatments. While she went to the local ER three times during this time, she was never admitted and was able to be there for her son's 11th birthday.

Pictured at right: Jessika with daughter Sydney and son Hunter



December 24: Jessika continued to be sick, so my brother brought her back to the ER where I work since she had been seen three times in nine days where they live. She had run out of her pain medicine five days prior to this visit and appeared to be in withdrawal. She was not dehydrated at this point so was not admitted, but was given a prescription for the pain medicine she had previously been prescribed. That night Jess and I stayed with my mom. Unfortunately, she was too ill to be home Christmas morning and slept through most of Christmas day.

December 26, 2010-January 19, 2011: Jessika lived with me and my girls. Jess, my brother and I felt that it was best for Jess to stay with me since he would not be home during the day to monitor her pain meds and care for her. He had to work and take care of their children and we did not want her children to continue to see her so sick.

Jess, Spence and I continued to feel as though something was being missed, but with all of the doctors that had taken care of her, our only option was to trust what was being said. I knew I had to help her get off her pain meds slowly to avoid withdrawal symptoms since Jess was already so fragile and her body could not take much more. I also knew we would not be able to get a doctor to prescribe more pain meds since all of her tests appeared to be normal.

Jess continued her tube feedings at night while attempting to increase her caloric intake during the day. Jess continued to have severe pain to the right side of her back. I can't tell you how many times a day I would rub a variety of back creams on her back to try to help her pain. I also used heat, muscle relaxers, anti-inflammatory meds, her pain medication and countless Epsom salt baths in an attempt to decrease her back pain.

As we attended follow up visits during the day and watched *Sex in the City* at night we became very close. Closeness I will never forget. We had bad days, fair days and even a good day here and there. We had a heck of a time keeping her feeding tube stitches in and even got to the point where we would laugh because we knew we would be in trouble by her doctor if they came out a third time.

2011

January 13: I began looking for resources for Spence and Jessika in an attempt to help with their overwhelming medical costs. I went to DSS and decided to submit an application to Medicaid for Jessika so that we could ask for assistance from the charity funds at the hospitals she had visited. While taking care of Jessika I realized how costly her medications, doctor co-pays and formula (not covered by insurance) was costing my brother. Unfortunately, Spence can't even put a dent in the nine months of medical bills he is and has been faced with.

January 14: I created a group on Facebook to keep Jessika's friends up to date on how she was doing while at my house. Jessika was typically too sick to keep in touch with her friends by phone.

January 17: Took Jessika to one of her many follow up doctor visits. I asked him if he would mind ordering her PET scan so that we would not have to drive to Charlotte to get it done and I had a fear her radiation oncologist would delay it again. Luckily, this doctor agreed to the PET scan and also wanted to repeat an endoscopy.

January 19: Jessika had the repeat endoscopy with biopsies. The results were abnormal and showed narrowing of her esophagus from the outside.

January 20: Jess had her second follow up PET scan and saw a kidney doctor for the severe right flank/back pain she had been having, as requested by the pain clinic. I mentioned to the doctor that she had just had a PET scan

and he looked up the results. He informed us that her right kidney was fine but the left kidney was blocked. He also mentioned that she had some fluid around her left lung. He did not feel intervention was needed unless she needed chemo at some point.

On the way home Jess decided she wanted Mexican food. I could not believe what I was hearing but was excited she wanted to try to eat real food. My mom was at my house waiting to see her so I dropped her off and went and got the chips and refried beans with cheese on top as she requested. The most I could ever get her to eat was broth, dry Cheerios®, Ensure® and milkshakes. My mom and I could not believe how she was going to town with the chips and dip. This was one of the funniest moments we had together.

However, this was the last moment we had together at my house. I walked my mom out to her car and then came in told Jess I was going to go get her pain medication. When I came back, I found her lying on the floor. She wasn't sure how she fell but after looking her over, checking her blood pressure and heart rate, I called EMS just to be safe and she ended up in the ER. While I was there, I was given the horrifying, unexpected news from the PET scan. Jessika had metastatic cancer throughout her body to include her spine and liver.

Since I was alone with Jess and my brother was an hour away, I told her she was being admitted for the fluid around her left lung. I could not tell her alone nor could I tell my brother on the phone. When she asked why I was crying I told her that my previous boyfriend and I had gotten into an argument. As I left the ER, Jessika said, "Well at least you don't have to get up with me tonight and you get to sleep in tomorrow." Little did Jessika know, I would rather do that for the rest of my life than to hear the news I had just heard.

I called my parents and they met me in Hickory so that we could go tell my brother in person. My best friend drove me and after avoiding a phone call and text from my brother, we arrived at his house around midnight. I know that he had the worst possible thought when the four of us showed up at his house, but I did not want to wait another moment to tell him. He was in shock as we all were, and shortly after we told him he went upstairs and got my six year old niece Sydney. He sat in a chair holding her like a baby as tears rolled down his face. I will never forget that night. This was the night that our lives completely changed.

Jessika was discharged home to hospice less than one week after getting the devastating news. Her esophageal biopsies from the endoscopy were positive and compatible with metastatic cancer from her primary (cervix) cancer. Treatment was not an option due to the severity of the cancer and the state her body was already in.

I went home with Jess to continue providing what was now called "comfort care." In shock, I went from keeping Jess on a very strict morphine-weaning schedule to giving her anything she needed to be comfortable. The weaning that I had been doing for over a month while she had cancer throughout her body has been one of the hardest things for me to accept. It is not in the nature of a nurse or family member to cause suffering and this is something that I have struggled with since getting the PET scan results.

February 12: After spending over three months away and less than two weeks home with her children, husband, family, and friends, Jess went home to be with the Lord February 12, 2011, just a little over one month shy of her 33rd birthday. She was diagnosed with cancer on March 12, 2010, which was exactly, to the day, 11 months prior to her passing.

I know God's plan was set the day Jessika came into this world and I am thankful she can rest in peace now. I pray that my family and I can accept this devastating event in our lives. I pray that our story will inspire others to

live each day as their last and I know that one day I will be healed from my guilt, anger, frustration and sadness. Jessika and her mother suffered from cervical cancer and I pray that there is a cure before my niece could be affected by this deadly beast too. As I continue forward on this journey I will use our story, my nursing career and guidance from God to celebrate Jessika's life while fighting back at this ugly thing called CANCER.

February 15: Visitation

February 16: Funeral

March 19: Jessika's 33rd birthday celebration was held at her gravesite. Messages were written on balloons and released up to her. It was a beautiful, sunny day as Jessika shined down.

April 15: We had a successful relay for life and raised more than \$2500 in memory of Jessika!

April 28: I was contacted by EmpowHER, a company that advocates for women's health. They wanted to spotlight Jessika's journey on their website in memory of her this Mother's Day! I am so excited and feel honored that they have asked to do this. Their website provides individuals access to women's health information and resources. It is also an online community of women who discuss their own health and wellness issues while sharing their stories.



FIND YOUR ALLIES

By Karen

Your inner core gets tested. I don't mean body parts, because I'm missing a lot of those. I mean who you really are. What makes you tick, what makes you, you.

I didn't really cry until six months after my radical hysterectomy for stage 1b cervical cancer. I don't recall being frightened that I could die. I simply knew that I'd be all right. Different, but all right.

I do know that I was exceptionally lucky with my early diagnosis at age 44. My annual Pap smear was damaged in transit to the laboratory, so I grouched and moaned but went back in for a second time. And this time when the sample was drawn, I started to bleed, which is something that had never happened. It struck me as odd, but I didn't worry.

I worry more about bad things happening to the people I love. I was 26 when I lost my father after a courageous but terrible battle with stomach cancer. When he was diagnosed, my mind whirled like broken film on a movie reel. I felt helpless and was horrified that I could not really help him. Each day of that journey was an exercise in compromise.

Then the call came. You know, the "you have cancer" call.

I must have an internal switch with a lot of insulation because I slept pretty well after being diagnosed. My family laughs a lot about serious stuff. It's wrong, but we make jokes to ease the stress. When my really cool gynecologic oncologist introduced himself and ask how I was, I replied by introducing myself and sharing that my mother had died just weeks before, and "other than this stupid cancer, I'm fine." He put his hands in his lap and laughed and said "Oh, you're going to be one of those." I knew I had found an ally.

And I did have allies. My sisters Mary Anne and Christine, tons of friends, my best friend Bob and my medical team. They were just great.

So six months after my surgery, I hurt. I mean my lower guts hurt and I had finally had enough. Sobbing into the phone, I said to one of my doctors, "Well it took six months, but you have finally made me cry." It felt good to cry. To finally let it out. Medication now makes my guts feel better. I make me feel better.

Now five years later, the medical team have become my friends. We laugh about a lot of things. My in-your-face approach forced them to treat me as a person not simply a patient. I've told them that many times, "I couldn't have done it without you." You'll find your allies. You'll beat this disease, don't let it beat you.

Scars and all, make sure to celebrate what makes you tick. Make sure you to tell people that you love them. Avoid idiots. Life is full of them. You'll make it. I did. Early detection saves lives. Save yours.



LEARN MORE

www.ashasexualhealth.org
www.nccc-online.org
www.quierosaber.org
(in Spanish)

HPV

HPV is human papillomavirus. HPV is a common virus—more than half of sexually active men and women are infected with HPV at some time. At any time there are approximately 79 million people in the U.S. with HPV.

Some types of HPV, called “low-risk” types, may cause symptoms like genital warts. Other “high-risk” types cause cervical lesions which, over a period of time, can develop into cancer if undetected and untreated. However, most people have no symptoms of HPV infection, which means they have no idea they have HPV. In most cases, HPV is harmless and the body clears most HPV infections naturally.

HPV AND CERVICAL CANCER

According to the National Cancer Institute, more than 12,000 women in the U.S. will be diagnosed cervical cancer this year and about 4,000 of these women will die. Most women with an HPV infection will not develop cervical cancer, but it’s very important to have regular screening tests, including Pap and HPV tests as recommended.

Cervical cancer is preventable if precancerous cell changes are detected and treated early, before cervical cancer develops. It usually takes years for cervical cell changes to develop into cervical cancer. This is why getting screened on a regular basis is important; screening can usually catch any potential problems before they progress.

PAP AND HPV TESTS

A Pap test is a test to find abnormal cell changes on the cervix (cervical dysplasia) before they have a chance to turn into cancer. A small brush or cotton tipped applicator will be used to take a sample of cervical cells. These cells are examined for abnormal cell changes. Experts recommend that Pap tests begin no earlier than age 21.

Unlike Pap tests, which look for abnormal cervical cell changes, an HPV test can detect “high-risk” types of HPV. “High risk” types of HPV can lead to cervical cancer and this test helps healthcare providers know which women are at greatest risk. Experts recommend using both the HPV test and Pap test with women ages 30-65. (HPV tests can also be used with younger women who have unclear Pap test results.) For women with normal Pap/HPV test results, co-testing should be repeated once every five years.

HPV VACCINES

HPV vaccines can help prevent infection from both high-risk HPV types that can lead to cervical cancer and low-risk types that cause genital warts.

Two HPV vaccines are currently on the market and both are approved for use with girls and young women. One vaccine is also approved for use with boys and young men. HPV vaccines are recommended for girls ages 11-12. Catch-up vaccination is recommended for girls and young women ages 13-26 who have not been previously vaccinated. Males are also at risk for a number of HPV diseases, so boys and young men ages 9-26 can also be vaccinated against HPV.

Being vaccinated against HPV makes it much less likely a woman will develop cervical cancer, or have precancerous cervical cell changes. HPV vaccines don't protect against all types of HPV, though, so women need to continue having Pap tests and, as appropriate, HPV tests even after being vaccinated for HPV.

TAKING CHARGE OF YOUR HEALTH

A majority of women diagnosed with cervical cancer either have never had a Pap test or did not have one in the previous five years. Cervical cancer is preventable if precancerous cell changes are detected and treated early, before cervical cancer develops. Regular Pap tests, supplemented by HPV testing, will detect virtually all precancerous changes and cervical cancers.

KEY POINTS

- HPV is very common. Most sexually active individuals have HPV at some point.
- HPV infections are usually harmless and most are cleared naturally by the body in a year or two.
- With regular screening (Pap and HPV tests) cervical cell changes can be found, treated (if needed), and cancer prevented.
- HPV vaccines are an important prevention tool. Experts recommend that all females between the ages of 9 and 26 get an HPV vaccine. Males between the ages of 9 and 26 should also get the vaccine to prevent genital warts and some cancers.



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