

**Christin Veasley, NVA Associate Executive Director  
Launch of NIH Vulvodynia Awareness Campaign  
National Press Club  
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On behalf of the millions of women who suffer with this life-altering pain condition, I would like to thank Dr. Pinn and her entire staff for their exemplary effort in planning and executing this long-deserved campaign.

Thirty years ago, we reached a milestone when women were encouraged to openly discuss menstrual issues; twenty years ago, it became okay to discuss breast cancer... and ten years ago, women could finally discuss menopause openly without embarrassment.

Genital conditions, like vulvodynia, are still a “taboo” topic in our society and I commend Dr. Pinn for helping to bring them to the forefront of discussion through this campaign.

I stand before you today as both an advocate and representative of the National Vulvodynia Association and also as a former vulvodynia sufferer.

My vulvar pain came on very suddenly when I was 18 years old. I had never had any symptoms like this before so I thought, like most of us, that I would go to the doctor, get a prescription for whatever was wrong and that I would be feeling better in a day or two.

I only wish that were the case!

I kept going back... and going back... and going back... and when my provider told me that I had vulvodynia, my reply to her was very similar to that of HBO’s Sex and the City character Carrie Bradshaw when her friend Charlotte disclosed to her in a 2001 episode that she had vulvodynia.

Carrie said, “Vulvo-what-ia?”

I thought, “What in the world is vulvodynia?” “Is that even a word?” I couldn’t spell it. I couldn’t even say it.

A similar reaction was recently brought forth on an episode of ABC’s new hit show, Private Practice. When Dr. Addison Montgomery, played by Kate Walsh, told her colleague that she figured out that the cause of her patient’s pain with sex was one of the subtypes of vulvodynia – vulvar vestibulitis – her colleague replied, “Huh? Shis-ti-kin-itis?”

Few people, including those who are newly diagnosed, have heard of this condition, which is why an awareness campaign of this type is so vital.

When I learned that: 1) my pain would not go away in a few days like I thought, but rather I had a chronic pain condition; 2) the medical community didn’t really know what caused it; and 3) there was no cure, I had absolutely NO idea what I was up against in the months and years ahead.

While 60% of women visit upwards of three healthcare providers to obtain a diagnosis, which can take years, I consider myself fortunate that the very first provider I consulted was able to diagnose my condition after only a few months.

But I was floored when she told me, incorrectly I soon learned, that while I now had a name for my condition, there really weren’t any treatments for it nor were there any specialists around who knew anything about it.

At that time, I was a full-time pre-med college student working part-time at a restaurant. My genital area was burning all of the time, literally feeling as if someone was pouring acid into an open cut on my skin or

rubbing tiny shards of glass on the area. I could not wear jeans or any kind of pants and I could hardly sit through class.

When the pain was at its very worst, I vividly remember being in the middle of a physics final, when I had to get up and turn it in half-complete because I was hurting so badly that I couldn't sit and couldn't concentrate on what I was doing.

Imagine being in pain this severe and having your complaint dismissed by your doctor as "psychological" or being told that you should "try to relax or have a little wine before attempting to have intercourse next time." Women... now...today...in 2007, are told these things all of the time.

Having a name for my condition WAS half the battle. I could now focus on solving the problem instead of figuring out what was wrong. But after my provider told me that there wasn't anything she could do for me, I did what the majority of women still have to do today – I became my own educator, my own advocate and I started researching for myself.

I went to the medical library and probably drove the librarians crazy with all the articles I requested. I searched the University hospital for a physician who was at least somewhat knowledgeable about the condition and by far the most valuable thing I did was to contact the NVA, request all of their information and start volunteering. At a time when I had no hope, this organization provided me with the resources I needed to take my life back and go on to have the family I've always wanted.

Because there are almost no studies that have researched the effectiveness of treatments that are prescribed for this type of pain, it took me 7 years of trying a laundry list of different treatments, until I found one that was successful. Even though it took me 7 years, I consider myself very fortunate, as most women continue to live with some degree of pain for the rest of their lives.

It's been almost 8 years since I had surgery for my vulvodynia – a procedure that has afforded me the gift of two beautiful daughters. Today, my vulvodynia is 95% better – almost non-existent, but I do continue to live with chronic back and neck pain that was most likely caused by a car accident I was in when I was 15. However, with all of the excruciating physical pain I've experienced from this car accident, related surgeries and chronic pain since, nothing compares to the 7 years that I suffered with vulvodynia.

I say that not only because of the severity and chronic, unrelenting nature of vulvar pain, but because of the area of the body vulvodynia affects. Women with vulvodynia are embarrassed, ashamed and as a result are isolated. Talking to someone about your genital pain IS NOT the same as talking to them about headache, arthritis or back pain. These conditions don't have an associated "stigma" attached to them like vulvodynia does. The NVA conducted a survey of over 2000 women with vulvodynia and 75% report feeling uncomfortable discussing their condition with even their closest female friends. This unnecessary embarrassment causes women to remain silent, in fear of misunderstanding and judgment.

Like the women from our survey, it took me years to confide in close friends and family about my condition. I still remember the very first time I spoke to another sufferer on the phone. The comfort that conversation provided was immeasurable. To finally be able to speak to another woman who knew exactly what I was going through was life-changing for me.

And that is what this campaign is all about – reaching out to those who are silently suffering, who don't know what is wrong with their bodies – to let them know that they are not alone, that there is hope and that there are resources available to help them.

In the press kit you will find the stories of eight self-less women who have pushed through the embarrassment we've all experienced for a greater purpose – to raise awareness of this condition by openly sharing their stories with you.

They are a diverse group of women, representing four ethnicities, ranging in age from 20 to 60.

I encourage you to read their stories to get a sense of the many different faces of vulvodynia. Some are single. Others are married. Some are mothers.... But they all share a common experience – everyday, they courageously fight to overcome their pain and the debilitating effects of this disorder.

Vulvodynia impairs a woman's ability to function in everyday life, to have a family, if she chooses, and to take care of her children, if she is able to have them. It threatens her ability to contribute to our society and economy and vulvodynia not only desperately needs but deserves increased attention.

So, today, I'm proud to be part of the first step in doing just that. Finally, the millions of women with vulvodynia now have a voice. And with your help, their stories will both be told and heard. And this is the catalyst to change.

Ghandi once said, "We must become the change we want to see."

These women are courageously doing so. Please help us share their stories in an effort to change the lives of millions of women who are needlessly suffering in silence with vulvodynia.