

A recent study funded by the National Institutes of Health found that women of all ages and ethnicities suffer from vulvodynia. The following diverse group of courageous women are willing to share publicly their experience with vulvodynia and have agreed to be interviewed by the media. To arrange an interview, please contact the National Vulvodynia Association (NVA) at 401-398-0830 or chris@nva.org (or leave a message on 301-949-5114).



Yamalis, 26
Rochester, NY
**husband is willing to be interviewed*

As a Latina woman with vulvodynia, Yamalis has been faced with the challenge of stepping out of the accepted norm to be able to manage her vulvodynia. She believes that she has always had vulvodynia, but never knew what it was. She says, "As many Latina women who come from traditional backgrounds, I was always taught that premarital sex was wrong, that going to the gynecologist as a virgin was wrong to do and that a married woman's responsibility was to please the husband regardless of how the woman felt." Although she did not adhere to all the rules of her culture, Yamalis has never had vaginal sex because of the pain she experienced. At first she thought the pain was tied to feelings of guilt, so she dismissed it as "normal." After she married at age 24, the pain became too unbearable to stand and she knew there had to be something going on beyond guilt. It was then that she consulted a gynecologist and was diagnosed with vulvodynia. Since then, she has tried many medications, participated in research studies and then finally decided to have a surgical procedure in October 2006. Surgery improved her symptoms but was not a complete cure so she continues to try other therapies with the hope of being pain-free someday.

Christin, 32
NVA Associate Executive Director
Providence, RI
**husband is willing to be interviewed*



Christin was diagnosed with vulvodynia during her freshman year in college. Sitting, vaginal penetration and even wearing blue jeans all caused excruciating pain. At the height of its severity, Christin was unable to sit long enough to complete a mid-term exam, so she turned it in half-complete and drove straight to her physician's office. After being misled that nothing could be done to help her and that no specialists practiced in her state, she began her own quest for help and healing. She did research, located a physician at the university hospital and began volunteering for the newly-formed National Vulvodynia Association. In college, she became friends with Melvin, who soon became her greatest source of support. Melvin stood by her side, always encouraging her through years of painful days and a 7-year period of trying a laundry list of treatments, which only provided minimal relief. Friendship turned to love and Christin and Melvin were married. Shortly afterwards, she finally decided to try surgery for her condition. Two months later, they were able to have intercourse for the first time and a year later, they welcomed their first daughter, Grace, into the world. Since then, Christin has been virtually pain-free. In 2005, the couple was blessed with another addition to their family, their daughter Faith. Christin decided to transform her pain into a higher purpose and eventually became the Associate Executive Director of the National Vulvodynia Association. She says, "I feel fortunate to have found an answer for my pain, especially because so many other women do not. Those seven agonizing years compelled me to use my experience to help other women in pain. It is so important for women to educate themselves and become their own advocates and most importantly, to never give up hope!"



Karen, 41
Alexandria, VA
**husband willing to be interviewed*

Karen was 16 years old when she first knew something was "wrong." She has suffered for years with debilitating pain and has found little relief or support from the medical community. It took her 9 years to receive an accurate diagnosis. She says, "Finally having a name for this disorder let me know that I didn't suffer alone, but unfortunately, it hasn't led to a lasting cure for me." Vulvodynia has greatly diminished her quality of life, affecting her marriage, her energy level with her child and her ability to work. "I would like to see this disorder move to the forefront of medical research so that more effective treatments and knowledgeable physicians would be available for those women who are in need."



Emily, 30
New York, NY

Emily is a single Amerasian woman who started to experience vulvar pain during her senior year in college. She went to numerous doctor appointments and kept trying different medications to get rid of her pain. Although her boyfriend seemed understanding about her condition at first, the relationship eventually ended because of the strain it caused. One doctor told Emily that she “just needed to live with the pain,” another referred her to a therapist, saying that her pain was all in her head, and yet another told her that there was nothing more she could do for her. Emily didn’t give up and she finally found a specialist who diagnosed her condition. “To finally have someone not tell me that the pain was all in my head or something that I simply had to live with was such a relief!” she said. Since then Emily has been proactive by taking part in research studies to learn more about the condition. As a single woman, she continues to date and struggles in bringing up vulvodynia with a potential partner. “I hope that by sharing my story other women will see that they are not alone. I wouldn’t want anyone to go through what I’ve been through.”

Michele, 37
Hopewell, NJ



Even though Michele wasn’t officially diagnosed with vulvodynia until 2001, she has experienced vulvar pain since her very first gynecological exam. Like many women, she didn’t know that exams weren’t *supposed* to cause discomfort. After suffering for many years with painful symptoms, she knew that something wasn’t quite right and consulted four different medical professionals over a ten-year period before she was accurately diagnosed. She’s tried many different treatments, but nothing has really relieved the burning pain. She says, “My pain is very frustrating, and during the dark times, it often makes me question my womanhood.” She finds strength in her faith and is thankful that she has a very patient and caring partner. She hopes to marry and have children someday and knows that she has a lot of offer, despite her vulvodynia.



Nicole, 25
Chicago, IL

When Nicole was first diagnosed with vulvodynia, she had already spent a year being misdiagnosed by three different gynecologists. “Despite the constant physical pain and frustration of being a guinea pig for the first year, I considered myself lucky to find a doctor who had some real answers.” Since then she has tried many different treatment options and feels that her condition has improved on some level. “The hardest part of having vulvodynia is adjusting to a completely different lifestyle.” Nicole is no longer able to participate in activities she once loved without pain, like riding a bike, swimming, or running. She feels that maintaining current relationships or beginning new ones pose a challenge as well. Vulvodynia takes up such a large portion of her thoughts and actions that it’s hard for her to think of anything else. Nicole joined the NVA last year and began volunteering in January. “It is important for me to spread awareness of vulvodynia because I recognize firsthand how important it is to get this information out to the millions of suffering women and to the medical professionals still unaware of the condition.”

Amanda, 28
Denver, CO

****fiancé is willing to be interviewed***



Amanda is a Hispanic woman who has suffered from vulvodynia since age 19, when it came on suddenly after a vaginal procedure. After 5 years and countless doctors’ visits, she was finally diagnosed. “I’ve never felt like a fully functioning woman,” she says. She’s currently engaged to a very supportive man, but she would really like to be able to have intercourse without thinking about the horrible pain it causes. She’s tried many different treatments that have only been mildly successful and says that she often times feels like a “lab rat.” Vulvodynia has changed her life in many ways and she doesn’t know what it is like to think of sex without also thinking about pain. In addition, her partner avoids intimacy because he is concerned that it will hurt her. She plans to get married this May, but is very worried about her ability to have children in the future.



Phyllis, 58
NVA President & Executive Director
Potomac, MD

Phyllis is a 58 year old woman who has been married for 30 years. At age 25 she began teaching psychology, a job that she loved, and less than a year later, she started suffering from mild to moderate vulvar pain. “Neither my gynecologist nor dermatologist had any idea what was wrong with me. They prescribed cortisone cream, but that was it.” At age 40, the symptoms “exploded” and she was bedridden for six months with excruciating pain. Her family doctor began prescribing strong prescription pain-killers which worked pretty well for awhile. She continued to visit doctor after doctor in search of a diagnosis, but few knew about vulvodynia at that time. Desperate for permanent relief, Phyllis consulted a pain clinic and was given two nerve blocks which fortunately brought her pain down to a manageable level. She was able to resume what she calls “a semi-normal life.” Having baffled doctors for so many years, Phyllis had always felt completely alone in her suffering. When a doctor put her in touch with four other vulvodynia sufferers in the Washington, DC area, they decided to create the NVA, today the most prominent organization on vulvar pain in the world. What she didn’t expect was that research would find that there are *millions, rather than thousands, of women suffering from this hidden painful condition.* In spite of her own physical pain, Phyllis has served as executive director of NVA since 1996 and helped thousands of other women with vulvodynia.