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Herpes healing comes in numbers

Those afflicted with herpes or HPV

find plenty of support – and a path

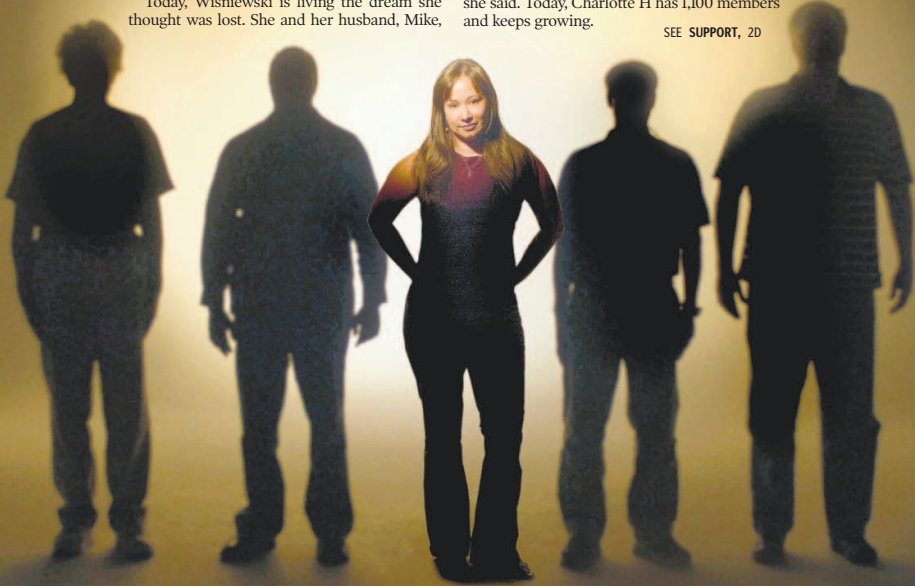
toward a happy, normal life

BY ALEXA GARCIA-DITTA
agarciaditta@charlotteobserver.com

Seven years ago, Pam Wisniewski stood in her doctor's office and got some news she thought would ruin her life. "You have genital herpes," a physician's assistant told her. Wisniewski started sobbing. "I felt like I was going to be alone for the rest of my life," she said. Her dream of marriage to the perfect man and children faded. "It was devastation at that point," she said. Today, Wisniewski is living the dream she thought was lost. She and her husband, Mike,

are approaching their one-year anniversary and plan on starting a family soon. And she's helping many others across Charlotte make the same transition. The 29-year-old UNC Charlotte doctorate student moved to Charlotte in 2005 and started a herpes and human papillomavirus, or HPV, support group. She thought it might end up as "a group of 50 people who went out to a movie now and then," she said. Today, Charlotte H has 1,100 members and keeps growing.

SEE SUPPORT, 2D



Pam Wisniewski, founder of the Charlotte H support group, lives a normal life with herpes. One out of five people in the U.S. have had the virus.

PHOTO ILLUSTRATION BY TODD SUMJIN - tsumjin@charlotteobserver.com

VIRUS BREAKDOWN

HERPES

The virus: Herpes simplex virus I and Herpes simplex virus II
The numbers: About 45 million people in the U.S. have had the virus. There are no breakdowns by state.

HPV (HUMAN PAPILLOMAVIRUS)

The virus: HPV, with up to 40 different types, is among the most common sexually transmitted infections.
The numbers: About 20 million people are infected. Fifty percent of sexually active people will contract HPV. Experts say most cases will go undetected.

MORE DETAILS ON PAGE 2D

SUPPORT

■ from ID

At least 45 million people in the United States have had Herpes simplex virus, and most don't know it, according to the federal Centers for Disease Control and Prevention. During an outbreak, patients can experience painful blisters and sometimes flulike symptoms early on.

The virus is transmitted through kissing, oral sex and intercourse. Herpes can even spread when a couple use a condom because the skin around the protected genital area could be infected.

About 20 million people have HPV, which causes benign warts in men and women and sometimes cervical cancer in women.

For those living with herpes or HPV, healing comes in numbers.

As support groups grow in Charlotte, members are transforming their experiences into lessons for the newly infected or longtime fighters suffering alone. For them, herpes or HPV aren't life-stoppers. Here are some of their stories.

Carla: The diagnosis

Carla, who requested her last name not be used, started dating a man she met in a divorce support group after her 10-year marriage ended.

Both had initially tested negative for sexually transmitted infections. But routine tests don't detect herpes unless a blood test is requested. Her partner, who did not have any symptoms, unknowingly gave her herpes even though they were using condoms.

Carla, 36, got tested for herpes when painful genital blisters erupted. The results were negative and she was sent home with a topical cream, but she tested positive after a second outbreak.

"It was a little bit to deal with coming off a marriage," she said. Dr. Lena White at the Mecklenburg County Health Department said a classic blister has a white head with a red halo around it. By the time many patients visit their doctors, the lesion may have subsided.

"Sometimes doctors don't have enough evidence to make the diagnosis," she said. Carla, an active member of the Charlotte-based Carolina H support group that started in March, is now in a long-term relationship. "The group keeps you grounded," she said.

John: Feeling trapped

John, 40, contracted herpes from his girlfriend, who hid her secret from him. He had a reaction many have when they're diagnosed: He thought he'd might as well marry her because no one else would want him. John also asked that his last name not be used.

"At that time, not knowing anything or without doing any research, I thought we were the only two within three states to have herpes," he said. In fact, a lot of people who are diagnosed limit their dating to stay within the herpes community.

John joined a support group after ending his relationship. He made friends quickly and is now dating a Carolina H group member.

"There's someone there that you're going to relate to and who can show you the ropes" on navigating a new life, he said.

Vicki: The isolation

Vicki, a 25-year-old decorator, finally feels free to hold her Halloween parties again. But after she was diagnosed at 23 with both viruses, she isolated herself.

She said she contracted HPV from her husband. Eventually, the marriage fell



TODD SUMLIN — tsumlin@charlotteobserver.com

Pam Wiesniewski started a herpes and human papillomavirus (HPV) support group in 2005. Today, Charlotte H has 1,100 members and keeps growing. Pam and her husband, Mike, hope to start a family soon.

apart, they divorced and she lived like a "hermit" for seven months after moving back in with her parents.

"My dad was even trying to get me out of the house," she recalled.

One day, Vicki said she woke up and was ready to move on. When she disclosed her condition to her family, she felt instant relief.

"This is me," she said. "Being open with my family made me feel so good." She got her own apartment and slowly started socializing. She posted profiles on dating sites and joined online support groups. Hesitant to go on dates, Vicki stuck to online chatting, but soon that wasn't enough.

Vicki said she finds Carolina H meetings and outings therapeutic. "Suddenly, I wasn't the new kid at the lunch table eating by myself," she said. She's dating a group member and it's getting serious.

Nadine: The talk

Nadine Murchison, 36, takes a self-proclaimed "radical" approach when disclosing her infection to dating partners.

She puts her herpes management book on the coffee table, alongside her suppression medication, for her date to see right when he walks in the door.

"I figure it's a part of who I am," she said. "If you're going to get to know me, you're going to find out one way or the other."

Disclosing the news, known as "the talk," can be just as emotionally taxing as the diagnosis itself, group members agree. Experts advocate having the talk early in a relationship to avoid transmission.

Murchison has told several people since she contracted herpes in 1998, but no talk has been more important than that with her children. She told each when they were in fifth grade.

"I wanted them to understand that not everybody (who gets infected) is sleeping around or using drugs," she said.

The mother of two and Charlotte H member said her daughter was very sympathetic, while her son was curious and had a lot of questions. They looked at photos online and read personal stories together. Murchison stopped hiding her suppression medication.

"I wanted to be an example," she said. "When you're trying to disclose your story, you have to be comfortable within yourself before you can tell other people."

Strength in numbers

For members, support groups are a chance for lessons and friendships. Some meetings are more social; others are educational. Charlotte H and Carolina H have scheduled gatherings or activities a few times a month.

"Sometimes we talk about it maybe one percent of the time," said Kirk, a Carolina H leader. "We talk about our group of friends probably two or three times a day."

Virus breakdown

HERPES

The virus: Herpes simplex virus I and Herpes simplex virus II

Symptoms: Both viruses can produce oral, genital or rectal blisters that look like white bumps surrounded by a red halo. Blisters can commonly be mistaken for ingrown hairs or razor burn.

Transmission: HSV-1 can be transmitted through kissing or sexual contact. HSV-2 is commonly transmitted through intercourse.

Testing: Herpes screening is not included in an STD test. If a patient has an active blister, a physician can do a culture. If a patient has concerns about herpes, a blood test can be specially requested.

Prevention: Abstaining from kissing and sexual contact during an outbreak of the blisters reduces the transmission risk.

Treatment: Daily suppression medications like Valtrex, Famvir and Acyclovir can reduce the severity and frequency of outbreaks, or blisters that can spread the virus.

Be aware: Condoms don't necessarily prevent transmission. The viruses are transmitted through skin contact and can be spread through the exposed genital-area skin.

HPV (HUMAN PAPILLOMAVIRUS)

The virus: HPV, with up to 40 different types, is among the most common sexually transmitted infections.

Symptoms: Most strains of HPV have no symptoms. Men and women infected with low-risk HPV may get genital or rectal warts. High-risk HPV can cause cervical cancer in women and other rare forms of cancer.

Transmission: Sexual contact.

Testing: Regular Pap smears can detect high-risk HPV and cancerous cells in women. There is no test for men.

Treatment: There is no treatment for low-risk HPV. The body's immune system will fight and clear infections from 90% of cases.

Prevention: The Gardasil vaccine protects women against four types of HPV, including cancer-causing strains. There are no effective preventive measures for men.

Be aware: The myth that men don't show symptoms is wrong; they get warts, just like women. Condoms do not necessarily prevent transmission.

— SOURCES: CENTERS FOR DISEASE CONTROL AND PREVENTION; AMERICAN SOCIAL HEALTH ASSOCIATION

H support groups

NORTH CAROLINA

- **Charlotte H Club:** www.charlotteh.com
- **Carolina H:** www.carolinah.net
- **North Carolina H:** health.groups.yahoo.com/group/nchgroup2

SOUTH CAROLINA

- **Carolina H Group:** <http://health.groups.yahoo.com/group/carolinagroup>
- **People of Color Social Networking of South Carolina:** <http://health.groups.yahoo.com/group/POCSC>
- **South Carolina H Friends:** <http://health.groups.yahoo.com/group/southcarolinahfriends>

HERPES HEALING COMES IN NUMBERS by Alexa Garcia-Ditta

I spent most of the summer working on this story. After checking archives and reading national numbers, I noticed that chronic sexually transmitted diseases hadn't been reported on as much as HIV/AIDS. I found two support groups in Charlotte and started contacting the leaders within the first week of my internship. I was prepared for the reporting to take a long time and prepared to talk with sources that may not be willing to use their names since herpes and HPV have such strong social stigmas attached to them. Fortunately the leader of one group was very willing to share her experience, and after a two-hour-long interview with her my story started taking shape. I interviewed a total of six people, most of whom were willing to use their full names, even though we decided not to run their last names for other reasons. The story ran at the end of the summer after careful writing and editing. I wanted this story to heal some stigma and embarrassment so many people with these infections are suffering from. Each source shared their experience in order to help others heal. They illustrate the truth that being diagnosed with something such as herpes or HPV doesn't have to take away other joys in life. It does take time to accept, but it's something that one can overcome.

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