



## MISSION STATEMENT

The Cervical Cancer Prevention Project is creating a national model to increase timely Pap screening and follow-up practices among low-income urban African American and rural Hispanic women.

tance. ASHA staff also presented preliminary data from a recent HPV-related Web survey posted on the ASHA Web site (please refer to the Web Survey section in this report for details).

Following a report from ASHA's Senior Director for Health Policy, Deborah Arrindell, participants also discussed the challenges and opportunities for HPV-related advocacy measures in reproductive health organizations and Congress. The advisory committee recognized that there is a disconnect between what many in the general public favor versus what policy-makers favor (for example, in regards to sexual health education within the public school system). In addition, HPV is often used by opponents of comprehensive sex education as an example of an STD for which no real protection exists. Advisors encouraged ASHA to continue working with various groups and organizations so that HPV does not remain vulnerable in message dissemination about STDs, and also in issues surrounding annual cervical screenings and exams.

Lastly, participants contributed significant input for ASHA staff on how to refine specific educational messages for patients on topics such as oral sex and HPV transmission, condoms and HPV transmission, partner communication, as well as changes in cervical cancer screening tests and intervals, and HPV vaccines. This information will be included in updated ASHA educational materials such as the *HPV in Perspective* booklet.

Meeting minutes are available by contacting Joanne Grosshans, HPV Resource Center Program Manager, at [joagro@ashastd.org](mailto:joagro@ashastd.org), or (919) 361-8485.

## NATIONAL HPV & Cervical Cancer Prevention RESOURCE CENTER

## MISSION STATEMENT

Addressing a lack of available resources for patients, health care providers, and policy makers, the National HPV and Cervical Cancer Prevention Resource Center will summarize and disseminate current data on both the clinical and psychosocial aspects of HPV infection, help to build communication skills for patients and providers, provide a forum for developing clinical guidelines, and promote relevant research and appropriate public policies.

# Quarterly Report

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## MEETING

On October 28, 2002, the HPV Resource Center held a meeting in North Carolina for its National Advisory Committee. The meeting, which marked the three-year anniversary of the Resource Center, provided an opportunity for over 30 participants to learn about the Resource Center's many accomplishments. ASHA staff also received guidance from committee members on the refinement of specific HPV educational messages. This input is necessary as revised medical guidelines, breakthrough research, the emergence of new technologies, and political setbacks will undoubtedly influence what the public, patients and clinicians need to understand about HPV,

cervical cancer prevention, and genital warts.

Tom Cox, MD, Executive Medical Director of the HPV Resource Center in 1999-2002, presented a brief overview of revised medical guidelines for cervical screening and management, as well as research advancements in areas such as epidemiology and diagnostics. Susan Rosenthal, PhD, University of Texas Medical Branch, shared data related to public acceptance of an HPV vaccine, such as the role of perceived susceptibility in accep-

American Social Health Association

## PUBLICITY

Syndicated columnist Carolyn Hax's February 2003 *Tell Me About It* advice column offered readers ASHA-approved information on genital warts. ASHA's Web site address (including the HPV pages) and the hotline number for the ASHA-operated CDC National STD and AIDS Hotlines were also included in the article. The column was syndicated in over 24 newspapers across the United States, including *The Washington Post* and *The Chicago Tribune*.

Over a year ago, ASHA assessed the commonly asked questions about HPV, and with scientific input from several HPV Resource Center advisors, provided succinct answers to these inquiries. All this work has culminated in the recent publication of a paper entitled, *Answering Frequently Asked Questions about HPV* in the March 2003 issue of the journal, *Sexually Transmitted Diseases*. Authors include Lisa Gilbert, PhD, Linda Alexander, PhD, Joanne Grosshans, and Leigh Jolley. This publication is yet another a tool available to assist clinicians in providing succinct answers on common HPV related questions that newly diagnosed patients might have.

## PATIENT OUTREACH

The HPV Resource Center temporarily has scaled back operating hours and staff on the National HPV Hotline and the HPV Chat Room due to funding renewals that are still pending thus far in calendar year 2003. Staffing levels were decreased from four health communication specialists taking hotline calls to one. The operating hours, which have been reduced by two hours per day on the hotline and one hour per day in the Chat Room, are now as follows:

### National HPV Hotline

1:00 p.m to 6:00 p.m, ET,  
Monday through Friday

### HPV Chat Room

5:00 p.m to 6:00 p.m, ET,  
Monday through Friday

In the year prior to this recent – and hopefully temporary – set back, the HPV Resource Center had successfully expanded its technology-based mechanisms for outreach, education and support. Below are quotes from users of HPVnet (e-mail service) and the HPV Chat Room, regarding these services:

- *I would like to say thank you for responding to my e-mail. It is nice to have a resource on this matter. Please keep this site for others who may need information concerning this issue. I appreciate your prompt response as well. I will tell my sister what she needs to know. Thank you for helping me find out what I can do to help her cope.*
- *Thank you very much for your advice and support. I will definitely pass this information on to my daughter. You are providing a very valuable service.*
- *I just wanted to thank you for having such an informative site. I've been diagnosed with HPV but didn't really understand what that meant. The doctors didn't really give me a good explanation of what it meant and your Web site and materials have really helped me to cope a little better. I'm 22 and not promiscuous, so this was quite a shock for me. Once again thank you so much for all of your help.*
- *Your Web site has been one of the most informative sites I have seen. I found that I had a lot of the emotional responses that were listed on your Web site and no one had really spoken to them before. I truly appreciate that.*

## HPV WEB SURVEY

At the National Advisory Committee meeting in October 2002, ASHA presented preliminary HPV Web Survey results. The purpose of this study, conducted in Fall 2002, was to begin investigating consumer opinions and preferences regarding three main areas of inquiry: (1) acceptability of a vaccine to prevent HPV; (2) preferences for

treatment of genital warts; and (3) knowledge and preferences regarding HPV and cervical cancer screening intervals. The surveys were posted for 17 days, and received an average of 770 valid respondents total.

The vaccine-related survey asked respondents what factors would influence their decisions about receiving immunization, if a vaccine were indeed available. Over 90% of the 272 respondents reported that health care professionals would play a role in their decision. Significant others, (same sex) friends, and family would also impact their choice. Specific factors that would encourage respondents to obtain the vaccine included the perceived safety and efficacy of the vaccine as well as the respondents' perceived risk for acquiring the virus in the first place. Issues that would discourage individuals from immunization included fear of getting sick or getting HPV symptoms from the vaccine, and also having to pay out of pocket for the vaccine. Most of the respondents also believed that that vaccination for HPV and other STDs was "very important," ranking at 91%, compared with 65% for biological hazards and 49% for adult diseases.

The survey on external genital warts (EGW) asked individuals to profile their health care experience when they were diagnosed and treated for symptoms. Nearly half of the 234 respondents were diagnosed in 2002. Questions were posed about treatments discussed with them by their health care providers, which treatments were used, and what factors influenced their preferences for treatment. Results also showed that not all treatment options seemed to have been discussed with patients. Over 25% of respondents reported receiving a prescription for imiquimod, and physician-applied treatments such as freezing and TCA/BCA were also reported at similar rates. Patients also stated that their providers used other wart-removal treatments, such as cauterization and surgery. While several treatment options may have been discussed with respondents,

further research is needed to find out the rationale for specific treatment preferences by providers and patients.

The final survey sought to determine respondents' knowledge and understanding about HPV testing used in cervical cancer screening. While most of the 268 respondents knew that HPV is an STD, only 70% realized that (some types of) HPV are linked with cervical cancer. Approximately 80% stated there is a specific test for HPV; however, when asked for further information about the kind of test available, only 16% identified the correct answer – a DNA test. Almost 100% knew the purpose of a conventional Pap test, and out of this, 83% reported that it should be performed once a year. When given an educational message about the purpose of an HPV DNA test and how it can be used in combination with a Pap test to increase the Pap's accuracy, most respondents reported they would like to obtain a combination Pap-DNA test but assumed that they would still be screened on a yearly basis.

Not surprisingly, the population surveyed had high knowledge scores regarding HPV in general; however, respondents indicated confusion about a variety of factors, including testing. Likewise, through the use of open-text responses, ASHA found that many in this cohort did not have positive experiences with their diagnosing clinicians. Respondents cited issues such as minimal communication and shared decision-making, as well as lack of compassion and inadequate information available. ASHA recognizes that the Web survey sample is not representative of all individuals who receive a clinical diagnosis; however, this survey represents a first step in understanding consumer and patient experiences and concerns.

## PROFESSIONAL EDUCATION/TRAINING

Two years ago, ASHA began to formulate the concept of Web-based

CME courses to educate providers about the complex issues surrounding HPV and cervical cancer prevention with the enthusiastic support of representatives from the American Society for Colposcopy and Cervical Pathology (ASCCP) and the U.S. Centers for Disease Control and Prevention (CDC). Tom Cox, MD, agreed to create multiple courses about the epidemiological, medical, and clinical aspects of HPV. ASCCP developed the infrastructure that supports the courses, tracks and monitors responses, and manages the site. The courses have been completed and are now available at: <http://cme.asccp.org>.

The two courses, *Understanding Cultural and Psychosocial Barriers to Pap-Testing* and *Follow-up after an Abnormal Pap: Addressing Barriers*, were formed using data from six focus groups conducted in Durham County (in African American women) and Chatham County (in Latinas) in North Carolina, from structured key informant and gatekeeper interviews and an extensive literature review. The courses are intended for licensed physicians and advanced practice clinicians seeking to increase Pap-testing and follow-up for under-screened women by augmenting providers' skills and knowledge of psychosocial and cultural barriers to Pap-testing.

In addition, an ASHA-sponsored monograph on HPV is now available through the Association of Professionals of Gynecology and Obstetrics (APGO) as a CME course. The publication is part of an educational series on STDs including herpes simplex virus and hepatitis B and C, and is valid for CME course credit until November 30, 2005. Specific information in the course booklet on HPV covers genital warts and cervical disease, diagnostics, clinical management, vaccines, and counseling messages. An adapted version of ASHA's answers to the most commonly asked questions about HPV is also included in the publication.

## LOOKING FORWARD

The HPV Resource Center has several projects under consideration at this time. Among these include:

- Design, produce, and develop content for an electronic newsletter that focuses on genital warts, HPV, and cervical cancer prevention. This will ensure that individuals seeking accurate and cutting-edge information are receiving it from a reliable source. Funding is actively being sought.
- Develop consensus questions and answers regarding the use of DNA testing in primary screening of cervical cancer from the patient and health care provider perspective. This project is made possible through an educational grant from Digene Corporation.

## ACKNOWLEDGEMENT

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*3M Pharmaceuticals* has provided quarterly grants to the Center for the years 1999, 2000, 2001, and 2002.

*Cytec Corporation* supported the Center with a one-time grant in 2001.

*Digene Corporation* has provided quarterly grants to the Center for the years 1999, 2000, 2001, and 2002, as well as a one-time grant in early 2003 for a specific project.

*The Merck Company Foundation* has provided funding to the Center for several projects in 2002.

*The National Cervical Cancer Coalition* has provided support to the Center for various months in 2001, 2002, and thus far in 2003.

*Roche Pharmaceuticals* supported the Center with a one-time grant in 2001.