



Sharing Experience and Action on Cervical Cancer Prevention: First Patient Education Conference Report¹

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¹Importante note: This report summarizes the presentations, discussions and collective views of a group of professionals, and does not represent any corporate or any organization's policy or decisions. The report was drafted by S. Pagliusi, on behalf of Eurogin, based on the notes taken during the conference, and it was circulated among all contributors for corrections and final agreement. We are grateful to Dr H. Lawson for critical review of the manuscript and valuable comments.

Preface

Despite the tremendous progress over the last ten years in prevention, diagnosis, and treatment, cervical neoplasias are still on the rise in many countries, and human papillomavirus (HPV) infections continue to cause significant morbidity worldwide.

The knowledge of HPV and its link with cervical cancer is essential for full participation of the public in the preventive measures offered by health professionals. However, the majority of the general public is still unaware of HPV infections, or the fact that cervical cancer has a viral aetiology. The complexity of the information makes it difficult to ensure that it is accessible and comprehensible to everyone.

The objectives of Public Health Education programs are three:

1. Increase the public knowledge and awareness of the diseases and their causes,
2. Clarify “at risk” personal behaviours within a culturally sensitive context, and
3. Motivate healthy people to participate in preventive programs.

Results of surveys and research indicate that women wish to know more about HPV and value information provided by health care providers.

The development of HPV vaccines has been accompanied by intensive HPV related educational and marketing campaigns directed towards parents, adolescents and healthcare providers. In addition, government and professional organizations have published guidelines and position statements.

Public education should also include a comprehensive program for improving knowledge among targeted populations, in close collaboration with health professionals. The role of the media is of particular importance in correcting misinformation, which eventually circulates on the Internet. Industry and advocacy groups are essential players in a global effort to end cervical cancer.

We need to define a program for public education on cervical cancer prevention, as well as to identify the shared opportunities, partnerships, roles, responsibilities and ethical issues of importance.

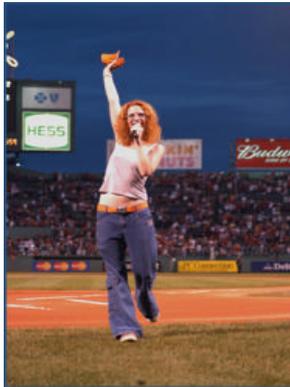
This conference is aimed at addressing these issues with a clear call for action, providing the ingredients of effective patient communication, and mobilization of stakeholders to take action on lessons learned and those values that are shared. The highlights of the meeting discussions are summarized in this report

We are grateful to all speakers, scientific societies, governmental and non-governmental institutions, representatives of patient groups throughout the world for their ongoing commitment, and the support from Qiagen/Digene, GSK and SPMSD for this event.

J. Monsonego
EUROGIN Chairman

I. Testimonials of Cancer Survivors

Christine Baze, a singer and cervical cancer survivor



C. Baze was 31 when she received a call from a doctor's practice to communicate a diagnosis of cervical cancer. Her world changed from being a young and active pop singer, to a patient suddenly confronted with medical terminology and procedures such as "diagnosis", "surgery", "radiation", "chemotherapy", "colposcopy", "Pap", "cytology", and HPV.

She was confused, and distressed, and sad. She never heard of HPV before. Her doctor explained to her that her previous control test, based on Pap cytology, was fine but it was not an accurate result, it was a false result. He told her that the cancer comes from an infection with HPV that lasts for a long time in the cells of the cervix, and year after year infects an increasing area of the tissue turning into a malignancy that spreads into the neighbouring tissues of the uterus, can spread to neighbouring organs, and later can spread over distant organs to become metastatic cancer.

Fortunately, today several life-saving tools are available to prevent this cancer: vaccination, cytology screening tests, HPV tests. "If you are young, ask for vaccination, and if you are over 30 ask for HPV testing", urges Christine. After a battle with therapies and depression, she returned to the stage as a happy cured singer, performing in concerts, where she takes the opportunity to talk to the public with simple words about HPV and cancer prevention.

A. Nightingale, a young mother and cancer survivor

LIFE BEFORE...



AND AFTER CANCER



"I'm so sorry, I'm afraid it is cancer..." are the words she was told when she was a mother of two small children, and went to a postnatal check-up. There was an abnormal growth that turned out to be a stage "1b" tumour. After physical healing there was an emotional turmoil. Following a hysterectomy she became depressed and struggled with questions as to whether cancer would come back, or whether her marriage would survive, and if she could be a good mother. Femininity was an issue. "Talking about cervical cancer was embarrassing because of its links with sex", said Mrs. Nightingale. She concluded stating that women confronted with a cervical disease need objective, expert and confidential medical advice, high quality and accurate information about their disease and treatment, and need to have a voice, be listened to, and be supported.

II. Current Knowledge of Cervical Cancer, HPV, and Prevention Strategies

The level of the public's knowledge of cervical cancer and human papillomavirus (HPV), as reported in the international literature, is still low, despite wide-spread awareness efforts over the last year or two, particularly focused in some specific geographical areas.

Recent articles focusing on HPV and HPV testing² suggest very low levels of knowledge about HPV infection, Pap and HPV testing, and the connection between HPV and cervical cancer. In addition, there is a need to communicate positive messages to minimize the shame, anxiety, stigmatization and fear of disclosure to partner, that often accompany a cervical disease diagnosis or a HPV positive test result.

Regarding HPV vaccination, acceptability is generally high among health care providers and consumers³, but actual practices of providers and vaccine uptake need to be monitored. Knowledge seems to correlate with acceptability--the more people know about HPV and cervical cancer the higher the acceptability of preventive actions. Thus, knowledge level can be regarded as a predictor of acceptability. While large amounts of data on attitudes of providers and consumers are available from Europe and North America, they are scant from other parts of the world, where HPV associated diseases and cancers are a serious problem, screening and clinical care are largely

absent, and health education is urgently needed.

Awareness of HPV, Cervical Diseases and Vaccination Among Adult Females in the U.S. An Internet-based survey, conducted in March-April 2007, showed that the awareness of cervical cancer and precursor diseases in the U.S. is high (95-100%) among adult females, while awareness of HPV as a necessary cause of cervical cancer is increasing (54-65%). To date, the majority of girls' mothers (aged 27 years old or more) and nearly half of young adult females (18-26 years old) identify HPV as the primary cause of cervical cancer. Awareness of genital warts is high among all surveyed women (almost 100%), but knowledge of the exact cause is lower than for cervical cancer. Knowledge of skin-to-skin contact as a risk for contracting genital diseases is relatively high, among young adult females (50%) and mothers (30%) who responded to the surveys. Knowledge about "cervical cancer vaccination" has increased by 44% among young adult females (18-26 years of age) and among parents of 11-26 years old girls, since June 2006, after licensure of the first HPV vaccine in the US, mostly through TV-, internet- and radio-driven consumer awareness campaigns. Vaccine acceptance is generally high among all adult females (~75%). Despite this, many respondents say that they are not yet ready for HPV vaccination, because they are too young, or not sexually active, or need more information.

Awareness of HPV, Cervical Cancer and HPV Testing Among Women Over 30 Years of Age in the U.S. and in Germany. Results of HPV awareness surveys conducted in 2006 among women over 30 years of age in the US and Germany were compared. Awareness of HPV was strong in the U.S., with 65% of surveyed women having heard about HPV, while in Germany only 15% reported the same. However, even among the U.S.

² Friedman & Sheppard (2007); Moreira et al. (2006); Tiro et al. (2007); Kahn et al. (2007); McCaffery et al. (2006); Perrin et al. (2006); Waller et al. (2007)

³ Brabin et al. (2007); Chan et al. (2007); Constantine & Jerman (2007); Dinh et al. (2007); Gerend et al. (2007); Hausdorf (2007); Hopenhayn et al. (2007); Lee et al. (2007); Lenselink et al. (in press); Marlow et al. (2007); Marshall et al. (2007); Stewart & O'Mahony (2007); Woodhall et al. (2007)

audience, where awareness of HPV is strong, in-depth knowledge about these viruses is still limited with 10 to 25% of respondents reporting they knew something about HPV, compared to 2-4% of respondents in Germany.

Once educated, agreement with the need for cervical cancer screening, in addition to vaccination, is high in both U.S. (85-100%) and Germany (54-92%). However, awareness of HPV testing among eligible women is only 39% in the US. and just 17% in Germany. The surveys indicate that the key to changes in health care behaviour is education. For example, by January of 2007, following extensive consumer education, the percentage of awareness of the HPV test had increased to 53% overall among women age 30 and over.

Communicating Sophisticated Science in Simple Messages: HPV Vaccination and Testing. Information on HPV and cancer can be difficult to understand and alarming -- raising concerns and fears about being diagnosed with HPV, as well as with getting vaccinated. In some instances, it could reduce participation in cervical cancer screening and HPV vaccination programs, putting women at greater risk for cancer. In large part, this is due to the linkage between two somewhat incongruent concepts -- one that attracts blame (sexually transmitted infections) and one that attracts pity (cancer). Perhaps as a consequence, public awareness of HPV in the UK is relatively low, with 25% of the general public reporting they've 'heard of' HPV, 10% agreeing with the statement 'HPV is a cause of cervical cancer,' and only 3% recalling that HPV is the cause of cervical cancer.

The challenges in providing HPV information to a large public audience include the complexity of the information http://us.mg2.mail.yahoo.com/dc/launch?.rand=bkgqniq9mmjku_ftn3#_ftn3 and the varying levels of

health literacy among the public. HPV information materials provided to the public need careful evaluation to avoid adverse effects on people's emotional wellbeing, compliance with cancer prevention programs, or risk-taking behaviours. In this context, a recent study in the UK evaluated the impact of seven key information points about HPV infection on cognitive, behavioural and emotional responses. The messages were tested among a sample of female students, in a randomized fashion, and the responses were compared to those for women exposed to information on breast cancer and a control group, who had recycling information. Interestingly, negative responses to cancer cues, in an information-processing task, were markedly reduced in the group presented with specific HPV information, as compared to the 2 other types of information, reflecting a decrease in cancer fear. Also, the perceived acceptability of HPV vaccination increased by 20% after exposure to specific information on the virus. In addition, the number of women planning to attend screening after receiving the 3 types of information increased by 15-20% after presentation of specific HPV information. This indicates a positive attitude towards participating in preventive programs following exposure to relevant health information.

In summary, it was recommended that the impact of HPV information be carefully evaluated, as well-designed information can reduce fear of cancer, promote engagement with cancer-prevention behaviours, and reduce disparities in cervical cancer incidence. Given the complexity of the material and the variety of needs, materials that present staged information, with a simple message with follow-up details, may be a useful approach.

III. Health Literacy, Psychological/Behavioural Barriers and Cultural Differences.

Despite inequalities in access to health interventions that exist today, successful experiences about increasing HPV awareness and implementation of public programs were shared among the participants in a round table discussion.

The German Green Cross Association has been involved with education and promotion of public vaccination programs since 1960. In promoting polio vaccination, for example, they used the slogan “vaccines are sweet, polio is bitter”. Presently, a working group on Cervical Cancer focuses on early diagnosis and prevention information for journalists, the general public, and medical circles, encouraging the dialogue between women and doctors to increase knowledge about cervical cancer, the risk factors, prevention, early detection, screening procedures and therapies. A hotline on vaccine information has been set up, TV spots targeting mothers of young girls have been disseminated, and a Questions and Answers email service has been made available to the public. For further information: www.zervita.de and www.dgk.de.

Studies in 2005, in Australia, indicated high levels of awareness of HPV. A study, based on telephone interviews, found 51% of women knew about HPV. Interestingly, this was before a government campaign that designated an HPV scientist as the Australian of the Year in 2006, and the open testimony of the prime minister’s wife about her experience with cervical cancer. Media attention to the existence of the HPV vaccines started during that study. Additionally, a school based vaccination program was introduced in 2007. It is

financed by the government and has been widely advertised, attracting the attention and engaging the general public in the discussion of HPV so the knowledge base should now be even greater. A recent survey on quality of life for HPV related infections and diseases indicated that high grade precancerous lesions and genital warts are rated as highly important health issues by Australian women. The Asian-Oceania Organization on Genital Infection and Neoplasias (AOGIN) a sister organization to EUROGIN, is also working towards communicating HPV messages in culturally sensitive and appropriate ways to the different health care settings throughout the region.

North Carolina in the U.S., is a state in which socioeconomic disparities have resulted in the existence of pockets of high cervical cancer incidence rates. The University Centre has launched activities aimed at reaching out to the most affected women in this state and has so far reported that older women are less likely to endorse vaccination.

IV. Role of Health Care Professionals

Health professionals often have the task of developing policies and advising political leaders; therefore it is very important to inform them about HPV. The main objectives of health education programs are to 1) increase the knowledge base, 2) increase public awareness of major health problems and their causes, 3) clarify at-risk personal behaviour and provide culturally sensitive and age appropriate sex education, and 4) motivate healthy people to participate in prevention programmes, such as screening and vaccination. The opportunity for comprehensive cervical cancer control is now at hand through the dual application of primary and secondary prevention tools, namely HPV vaccination and cervical cancer screening.

There is a call for establishing vaccination and monitoring programs in some

countries, while other countries need to strengthen screening programs as well. However, government officials, health professionals and communities are concerned about the outcomes of such programs, and about issues, such as viral replacement, potentially offsetting the beneficial impact of vaccination over time. In some countries decreased cervical cancer incidence has been observed and documented, after implementation of organized screening. Having similar evidence for vaccination programs, would provide assurance that there would be a positive impact on disease burden locally.

The organizations represented at the round table discussions need to coordinate efforts to effectively help women to win the battle against cervical cancer. As the Australian example illustrates, government support and organized programs are essential, as doctors and other health professionals alone cannot educate the public at large. In the U.S., the American Cancer Society (ACS) has implemented communication and education programs targeted to various groups including medical professionals, public health officials, and the public with special focused outreach to underserved populations. ACS also publishes national guidelines including guidelines for cancer screening and other health conditions that are widely accepted by health professionals and the public. Recently the ACS published guidelines for HPV vaccination.

We can't forget about the need to educate males, who play a vector-role in the spread of HPV related diseases. For instance, clinics and such venues can play an important role in implementing education programs, especially in developing countries. Male education programs should be considered whenever possible.

To date, adoption of vaccination against cervical cancer varies across European countries: some countries adopted and now

reimburse for vaccination of specific age groups while others have postponed decisions until later. The European Cancer Leagues Association facilitates exchange of information between national cancer leagues. The role of cancer leagues is to urge development of effective prevention programs at the national level, and that harmonized programs are implemented across Europe.

V. Role of Governmental and Public Health Agencies

Until recently the only evidence-based option for prevention of cervical cancer cases and deaths was screening of women for cervical cancer precursors, followed by effective treatment of detected lesions. The availability of vaccines to prevent infections with the oncogenic HPV types associated with the largest proportion of cervical cancer cases has the potential to be an effective primary prevention strategy to prevent precancerous lesions, invasive cervical cancer and cancer-related deaths.

There is now a need for evidence-based recommendations and consensus on comprehensive guidelines for cervical cancer prevention, that consider clinical and public health benefits, affordability and cost-effectiveness of these primary and secondary prevention strategies, when used alone or together. Examples from ongoing efforts from governmental organizations were discussed, as outlined below.

Guidelines have been developed by the European Union (EU) public Health Programme on the implementation of cervical cancer screening as a tool of cervical cancer control⁴. A new project has

⁴ Coleman D., Day N., Douglas G., Farmery E., Lynge E., Philip J., & Segnan N. (1993). European Guidelines for Quality Assurance in Cervical Cancer Screening. Europe against cancer programme. Eur.J.Cancer 29A Suppl 4, S1-S38. European Commission (in preparation) European Guidelines for quality assurance in cervical cancer

been initiated to update and expand these EU guidelines, taking into account current evidence and developments in HPV vaccination and testing.

The World Health Organization (WHO) provides guidance to hundreds of WHO Member States where patient education issues vary dramatically. WHO's experience with vaccination programs has shown that education campaigns influence awareness of vaccine-preventable diseases, adherence with vaccination and other interventions. HPV vaccination media campaigns have generated demand that calls for clear, non-biased, non-commercial client education, even in countries where vaccination is not yet available. WHO-recommendations about HPV education for various audiences can be found at www.who.int. WHO is closely following research in Peru, Uganda, India and Vietnam, conducted by PATH which is assessing various patient and parental education messages about HPV vaccination. Moreover, WHO is launching the HPV Community of Practice, an on-line forum for health professionals to exchange information about patient education efforts globally.

The International Agency for Research on Cancer has created a series of educational materials about HPV and cervical cancer prevention available on their website (www.iarc.fr). Specifically, there is mounting evidence about the effectiveness of certain screening methods in low resource settings: notably, the rapid and reliable use of visual inspection coupled with treatment (see and treat) has shown an impact on disease incidence.

The French National Cancer Institute, part of the Ministry of Health, is involved in creating policy and coordinating

stakeholders in four areas: prevention and screening, health quality control, research and public health information. Cervical cancer screening in France is recommended for women between 25 and 65 years of age, but is delivered in an opportunistic rather than an organized manner. Vaccination and screening are both public health interventions contributing to the same goal, and introduction of vaccination is an opportunity to strengthen information and interest in screening, with simple messages.

The US National Cancer Institute is involved in laboratory based research, epidemiological or behavioural studies, while the US Centres for Disease Control and Prevention (CDC) interfaces with the broader public health community and other governmental agencies. CDC has succeeded in bringing together subject matter experts from a variety of public health disciplines to coordinate the development of HPV and cervical cancer information for the public. CDC also funds individual states to create their own tailored information tools fitting the local needs, trying to leverage field work to decrease disparities/inequalities about disease issues in some micro-areas within the US that resemble developing countries.

VI. Role of Non-Governmental Organizations

So far excellent communication tools were developed, as exemplified by literature and internet surveys: with TV spots, radio information and press articles. A number of civil society organizations have also recently engaged in cervical cancer prevention and shared their actions at this conference:

screening – Second Edition. Arbyn M., Anttila A., Jordan J., Ronco G., Schenck U., Segnan N., Wiener H.G., Daniel J., Karsa von L. (eds)

Countless lives could be saved in France and elsewhere, and hundreds of thousands of women could avoid the physical and psychological suffering of a cervical cancer diagnosis. Along these lines, and upon the initiative of women touched themselves by these issues, an association has been created in France to save women's lives and avoid suffering, "1000 Femmes 1000 vies" ("thousand women thousand lives"). This initiative aims to increase the awareness of stakeholders in France about the fact that it is now possible to successfully prevent a cancer that affects a large number of women, and about the need to make cervical cancer screening and vaccination accessible to all women, as appropriate. Thousand women in France have already engaged in campaigning to prevent this cancer, and the movement should spread to other countries where cervical cancer is an even bigger problem for women, their families and their communities. www.1000femmes1000vies.org

Jo's Trust Fighting Cervical Cancer is a UK based registered charity dedicated to women and their families and friends affected by pre-cancer and cancer of the cervix. Jo's Trust was established by London businessman, James Maxwell in memory of his wife, Jo who died from cervical cancer at the age of 40. Following her diagnosis, Jo (and James) had difficulty finding good information about every aspect of cervical cancer: its causes, stages, prognosis, and availability of new drugs, surgical procedures, treatment options, research papers and clinical trials. It was their hope that one day everyone would have easy access to up-to-date information and medical advice, and the opportunity for women affected by the disease to communicate with others facing similar challenges. To ensure that women never feel alone in their cancer journey, the Trust provides easily accessed information, support and confidential medical advice free of charge 24 hours a day through www.jotrust.co.uk

The European Cervical Cancer Association (ECCA) is supporting the elimination of cervical cancer in Europe. The objectives are to raise awareness of cervical cancer and the benefits of effectively organised cervical cancer prevention programs, to ensure that the general public has a proper understanding of HPV, and to advocate for the implementation of organised prevention programmes equitably across Europe. ECCA has a network of 66 Institutional Members from 29 Countries in Europe, providing information for the general public, for health professionals, for policy makers and public health officials, advocacy and outreach. Together with the International Union Against Cancer (www.uicc.org) ECCA has launched the Stop Cervical Cancer Petition. ECCA has also launched European Cervical Cancer Week to promote cervical cancer prevention at the European Parliament, and the European Cervical Cancer Interest Group. www.ecca.info

Women In Government (WIG) is a U.S., non-profit, bi-partisan organization of women state legislators providing leadership opportunities, networking, expert forums, and educational resources to address and resolve complex public policy issues. WIG activities are educational conferences, public policy initiatives, HPV and cervical cancer policy resource centre, access to higher education policy research centre, kidney health policy resource centre, Medicare preventive services policy resource centre, publications and marketing, policy research, and State briefings. WIG created the Cervical Cancer & HPV Task Force, to ensure that all women are educated about cervical cancer and the virus that causes it, ensure access to effective screening and vaccination programs, and encourage the use of advanced technologies, and assist legislators in evaluating current practices and policy throughout the U.S. www.womeningovernment.org/prevention

"If we were to be so fortunate that all the laws were passed that enabled women and girls of all income levels to have access to vaccines and screenings that can prevent cervical cancer; and if all doctors and healthcare workers were all convinced that they need to inform and administer these interventions to their female patients, we would still fail in our fight to end this deadly disease if women themselves were not engaged in this fight. Women are the primary health decision makers for themselves, their families and often for their communities. Yet, in this whole effort at cervical cancer prevention, their voices are missing. The Global Summit of Women, an 18-year-old gathering of women leaders worldwide, is uniquely positioned to inform and to engage women globally in this struggle to end cervical cancer. With its wide network of 50 affiliated organizations from different parts of the world, the Summit launched a Global Consortium of Women to End Cervical Cancer at its Summit in Berlin last June. This was an unusual project for a largely business gathering, but the rationale for the Consortium was simple -- there is no economic opportunity available to any woman without a healthy body. The Summit will utilize its global network of women opinion leaders and influencers to leave a legacy of a cervical-cancer free generation by using existing organizational structures and their built-in dissemination systems to inform and to create awareness of the prevention strategies now available." www.globalsummitwomen.org

The Balm In Gilead is a not-for-profit, non-governmental organization whose mission is to improve the health status of people of the African Diaspora by building the capacity of faith communities to address life-threatening diseases, especially HIV/AIDS, and more recently HPV and cervical cancer. Indeed, the incidence rate of African Americans is 50% higher than that of white Americans. Therefore, the ISIS Project has been created as a national health initiative to increase public awareness about cervical cancer and HPV, the virus that causes cervical cancer. More information is available at <http://www.theisisproject.org/home.asp> and <http://www.balmingilead.org/home.asp>. The program named 'Spread The Word, Save Your Sister' (http://www.theisisproject.org/spread_the_word) is aimed at increasing the health seeking behaviour among African American women through self education tools available online, and ultimately decrease the incidence of disease among this population group.

Various initiatives such as "Popsmeat", "save a sister", "say something", and "tell her" websites have started. Organizations, such as Jo's trust, 1000 Femmes-1000 vies, Women in Government, Global Summit of Women, Balm in Gilead, ECCA, AOGIN, EUROGIN and others may now consider getting consensus messages to disseminate to women universally. "To know is not to fear", for instance, may be a useful campaign to highlight that HPV is common, that 90% of infections are asymptomatic and that most resolve spontaneously, with the intent of decreasing anxiety and stigmas linked to HPV and cancer.

A question arises about which groups would be best served with the information about preventive HPV and cervical cancer

vaccines. Nearly half of the cervical cancer disease burden occurs among women in Asia, where many women at risk do not have access to internet, TV or other communication media. Very simple messages, based on evidence, need to be designed and communicated to those women at highest risk. For instance, the use of visual inspection with acetic acid has been shown to be highly effective in reducing cervical cancer incidence, but the message about the value of visual inspection remains largely silent.

VII. Role of the Media

The introduction of HPV vaccination must be set within a wider context: The current anti-globalisation agenda, the widespread distrust of 'big pharma' and, in many

countries, concerns about vaccination and in particular fears of ‘vaccine overload’. These fears are amplified by the internet. More specifically, there is little understanding of HPV and its role in cervical cancer. There is little interest in the developing world where the need is greatest

HPV vaccination has all the ingredients that traditionally raise anxieties among the public with vaccines, such as long term safety, side effects and so on, but in addition HPV introduce an additional number of potential issues including sex, sexually transmitted infections, and corruption of childhood.

“In just little over a year, the HPV vaccine has been associated with at least five deaths, not to mention thousands of reports of adverse effects, hundreds deemed serious, and many that required hospitalization (www.LifeSiteNews.com).” Deaths Associated with HPV Vaccine Start Rolling In, Over 3500 Adverse Affects Reported, by John-Henry Westen “TORONTO, September 20, 2007 (LifeSiteNews.com) - As Canada, in large part due to aggressive behind the scenes lobbying, rolls out the not-comprehensively-tested Merck HPV vaccine for girls as young as nine, a look at developments on the vaccine south of the border should cause Canadians serious concern. In the United States a similar lobby campaign by the same company launched the mass HPV vaccination of girls beginning in June last year.”

The tendency of many professionals is to dismiss such challenges and refuse to engage with them. However, they need to keep talking and to engage wherever possible. For instance, continuing to stress how ubiquitous HPV infections are is important in dispelling the perception that only the promiscuous individuals are likely to be infected. Scientists and professionals need to improve their interactions with the media and to the wider public providing easily understood “sound bites”, and being available and passionate about the science. Problems arise when information gets out too late, not when information is provided up front in a timely manner.

Recently a news article stated that “new vaccines require virginity test”. Unfortunately, such misinformation is

The media are able to cover HPV related news, such as the introduction of new vaccination strategies or scientific developments, and personal stories about cervical cancer survivors. It has an additional role in questioning government about HPV vaccination policies. But the media should not be seen as a primary means of education.

A real concern is the misinformation being promoted on the internet. Below is a typical example of the type of misinformation seen on the Internet:

harmful and may impair the acceptance and hence the benefits of this life saving intervention. Events advocating for cervical cancer prevention need to occur in the developing countries and in this context women’s and international organizations will play a crucial role.

Vaccines are not tooth paste and careful marketing is needed to avoid damaging the confidence of the public, and avoiding misleading assumptions about the lack of need for continued cervical screening among vaccinated populations. Contradictory and confusing messages need to be avoided.

“Our girls aren’t guinea pigs” says another recent press article, illustrating that the public needs clear and correct

communication. Screening for cervical cancer remains a life saving intervention for women whether vaccinated or not. Communicating with transparency is crucial, which means communicating that vaccination presently does not confer 100% protection against cervical precursors and cancer, so that people can balance the risks by continuing to seek screening services. Vaccine manufacturers need to be proactive about communicating information about post-marketing activities informing and reassuring the public about vaccine safety and effectiveness, in consultation with regulatory authorities.

VIII. The role of Pharmaceutical companies and Industries

Industry, as the largest generator of data on products and their health outcomes, has a key role to play in providing information first to regulatory agencies, then to the scientific community through presentations in conferences and peer reviewed publications, and third, to health care professionals and the public through

provision of accurate educational materials and through the conduct of promotional activities, including marketing messages.

In Europe the health care arena is a highly regulated environment with strict rules to follow, such as the validation of messages before dissemination to health care professionals and the public. Direct to consumer advertising of prescription medical products is not allowed in the European Community, whereas in the US, advertisement of medical products is allowed, though also highly regulated.

The message of helping eliminate cervical cancer needs to be “centre stage”. Industry needs to build credibility, which can also be increased by adherence to guidelines as for example the code of practice on relationships between the pharmaceutical industry and patient associations recently issued by the European Federation of Pharmaceutical Industries and Associations (EFPIA). Five items have been identified as of particular interest.

This Code builds upon the following principles that EFPIA, together with pan-European patient organisations, last updated in September 2006:

1. The independence of patient organisations, in terms of their political judgement, policies and activities, shall be assured.
2. All partnerships between patient organisations and the pharmaceutical industry shall be based on mutual respect, with the views and decisions of each partner having equal value.
3. The pharmaceutical industry shall not request, nor shall patient organisations undertake, the promotion of a particular prescription-only medicine.
4. The objectives and scope of any partnership shall be transparent. Financial and non-financial support provided by the pharmaceutical industry shall always be clearly acknowledged.
5. The pharmaceutical industry welcomes broad funding of patient organisations from multiple sources.

Industry’s reputation strongly depends on the safety of the products; hence there is no reason for industry to take any risk. Therefore, providing clear and complete information to regulatory bodies is a duty, and most post-marketing surveillance studies are done in collaboration with partners of governmental or non-governmental agencies to ensure neutrality of reported outcomes.

IX. Conclusions and closing remarks

In general, there are four “best” tools for communicating with the public about improving health outcomes: 1) Communicate clearly about diseases and their causes; 2) take a holistic approach, and communicate about primary and secondary prevention strategies; 3) target specific populations and communicate in a culturally appropriate and sensitive manner; and 4) communication tools and messages need to be monitored and evaluated for both vaccination and screening.

The discussants proposed a top ten actions’ list to improve communication on cervical cancer prevention:

1. Women should be informed and have the right to choose among broad and specific ways of preventing disease, and should be free to make an informed choice on their own.
2. Competing priorities should be taken into account while implementing cervical cancer prevention programs to foster synergy among health promotion and prevention programs.
3. Political will is an important driving force. Communication with governing bodies about the health benefits of certain objectives for the entire community can go far to achieving these objectives.
4. Balanced, credible evidence based information about new tools and technologies should be provided, and made available by the media in a transparent manner.
5. Acceptability should be fostered rather than acceptance. Acceptability suggests buy-in based upon receiving credible information. Acceptance suggests passive approval
6. Gender equality should be a consideration of message development.
7. Advocacy groups should work together to create consensus and develop unified messages, avoiding interfering or confounding messages.
8. Awareness campaigns and events should be actively disseminated, and should include positive messages, and use materials that present staged information, with simple message with follow-up details to more complex issues.
9. The media should play a role in disseminating accurate and balanced information
10. Formative research, such as use of focus-groups, should be used where possible to test the acceptability of messaging for the public about HPV, associated disease and prevention strategies.

Inspiring ideas and examples of communication about HPV were presented and discussed throughout the conference. However it is apparent that the greatest expenditure for communicating about HPV diseases and prevention are implemented in countries that do not have the highest burden of disease. Stakeholders, players, constituencies, and scientists need to make sure that we are taking proper and equitable actions, not just devising messages that will never be available to women who bare the greatest risk for HPV-related cancers. A network, forged in this conference, but still a virtual one, should form a foundation to ensure that messages reach appropriate populations and cancer prevention programs become operational in places where prevention is most needed.