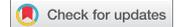




COMMENTARY



## Engaging parents around vaccine confidence: proceedings from the National HPV Vaccination Roundtable meetings

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### ABSTRACT

HPV vaccine uptake remains below national goals in the US, driven in part by parental uncertainty about the vaccine fueled by negative stories on social media and other information platforms. To identify opportunities for mobilizing parents to increase HPV vaccination uptake, the National HPV Vaccination Roundtable and Vaccinate Adolescents Against Cancers program convened two national meetings in 2016 at the American Cancer Society. Stakeholders recommended a focus on positive message to parents; cultivating parent champions to use the power of personal storytelling and to distribute these messages; and defining the role of national organizations in supporting parent champions. Stakeholders supported three message themes: HPV vaccination is the norm, HPV vaccination is cancer prevention, and HPV vaccination supports families across generations. Parents' negative stories about vaccination are especially difficult to counteract with scientific evidence, making the cultivation of pro-vaccine parent champions an especially promising intervention on social media and other information platforms.

### ARTICLE HISTORY

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Human papillomavirus; HPV vaccine; Cancer

Human papillomavirus (HPV) vaccine first became available in the United States (US) over a decade ago, in 2006. Yet HPV vaccine uptake remains below national goals, driven in part by parental uncertainty about the vaccine.<sup>1-3</sup> Parental concerns center around the need for vaccination against a sexually transmitted infection, vaccine safety, and the difficulty of demonstrating effectiveness against cancers that occur decades after infection.<sup>2</sup> Providers often give hesitant and lackluster recommendations for the vaccine, or no recommendation at all.<sup>1,4</sup> In addition, the anti-vaccine community has extensively targeted HPV vaccination with negative posts on social media,<sup>5</sup> increasing parents' confusion over the benefits and risks of vaccination.

Unverified and inaccurate stories of severe side effects and purported harms of vaccination raise concerns among parents.<sup>6</sup> Providers are ill-equipped to engage with vaccine-hesitant parents because no effective best practice exists for easing their concerns. An intriguing new direction is relying on parents' peers to build parents' confidence in HPV vaccine and other vaccines. However, little research has explored how to generate parent-led pro-vaccine efforts as a possible strategy to address HPV vaccine concerns.

### Soliciting expert opinion

In summer of 2016, the American Cancer Society's (ACS) National HPV Vaccination Roundtable (HPV Roundtable) and Vaccinate Adolescents Against Cancers (VACs) program convened two national meetings to identify how to best mobilize parents to increase HPV vaccination uptake in the United States. The first meeting was a one-day think tank with 20 key national stakeholders including parent champions, parent-led pro-vaccine non-profit organizations, the Centers for Disease

Control and Prevention (CDC), vaccine communication experts, academic and industry partners. The second meeting was part of a National HPV Vaccination Roundtable-sponsored event attended by 100 HPV vaccine delivery experts including scientists, clinicians, and other stakeholders. At this meeting, a breakout session addressed strategies to engage parents and allies to increase vaccine confidence in HPV vaccination. The following summary includes combined key recommendations from the two meetings.

### Recommended messages

Stakeholders overwhelmingly agreed with three message themes. First, HPV vaccination is the norm (e.g., "most parents vaccinate their children). Second, HPV vaccination protects the people who receive it (e.g., CDC's message that HPV vaccination is cancer prevention). Third, the vaccine supports families by protecting the ability to have children and helping people stay healthy to see their grandchildren (e.g., help your children become grandparents). Stakeholders thought that personal stories play a role in vaccine hesitancy and are especially difficult to counteract with scientific evidence. Positive and personal stories from pro-vaccine parents can counteract unsubstantiated parent claims about harms of HPV vaccination. Thus, first-person accounts and stories from survivors and parents are important vehicles for these three messages.

### Role of parent vaccine champions

Stakeholders discussed the importance of cultivating local vaccine champions to share their personal vaccination stories. Key attributes of ideal parent vaccine champions included

being enthusiastic and passionate, well-connected, and having a personal and positive connection to vaccination. Identifying parents of both girls and boys was also seen as critical to ensuring gender-neutral messages.

Stakeholders recognized that parents and allies would have different skill sets and capacities to invest in HPV prioritization activities, and therefore envisioned multiple levels and strategies for volunteerism. These strategies included speaking to one's own doctor, posting a pro-vaccine message on a personal Facebook page, hosting a thank you note writing party to thank local pediatricians for protecting their children against HPV-cancers, and speaking at schools or other venues. Activism on social media received substantial discussion, with general agreement on the importance of social media engagement. Participants discussed that having an "army" of parents "flood" social media spaces with positive messages about the vaccine might counter the negative messages that currently exist online. Blogs and forums for parents would be spaces for longer messages that are personal and intimate.

To prepare volunteers for questions and potential online hostility, training and ongoing support would be a crucial component of any initiative, including training to address "false balance" in the media. One method was training parent "peers" to use online platforms to talk to other parents about HPV vaccination, using their experiences and their stories to normalize HPV vaccination. The idea would be to use personal stories about why parents chose to vaccinate their children rather than detailed scientific or medical information. These stories could be shared informally with their peer group, on the sidelines at the sports events, during drop-off for clubs or activities, or more formally as agenda items at meetings of parent-teacher organizations or other groups.

### Role of national public health organizations to engage pro-vaccine parent champions

Established organizations, like the American Cancer Society, Cervivor, Voices for Vaccines, Every Child by Two, and others would be well positioned to take the lead in cultivating parent vaccine champions as they already have experience training volunteers to be cancer prevention advocates. These organizations can take on roles such as training parents, creating social media "shareables" that volunteers can use, organizing and hosting twitter chats, coordinating pro-vaccine mommy bloggers, using Facebook live and other social media outlets, as well as connecting traditional media partners with HPV-attributable cancer survivors and families to create more positive HPV vaccine stories.

With the hyper-accessibility of information on the internet and the proliferation of unverified stories, personal anecdotes presented as medical truths, and other sources of misleading information, the medical profession no longer enjoys its historically privileged position as the preeminent source for credible medical information. Yet few trusted medical

organizations have large presences on social media around HPV vaccination, partially due to the rapidity of information flow and the substantial amount of staff time and expertise required to be effective in this space. Because parents increasingly rely on peers when making vaccine decisions,<sup>7</sup> leveraging existing organizations and creating volunteer networks of pro-vaccine parents may provide the needed voices to represent the majority of parents: those who vaccinate.

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