

SHE - The Untold Story of HIV

TogoRun and Bristol-Myers Squibb, Jan 1, 2013

Summary: 2013 Silver Anvil Award Winner — Public Affairs — Business

HIV is the leading cause of death/disease worldwide among women of reproductive age. In Europe, women represent one-third of the new HIV diagnoses. Despite this, information/resources in Europe tend to target men and generally lack relevant information on women-only HIV issues, leaving many women feeling isolated.

Bristol-Myers Squibb (BMS) sought to overcome this by providing helpful resources, and changing the European HIV landscape to consider the specific needs of women. SHE (Strong, HIV positive, Empowered women) is the first peer-support program to help European women with HIV feel empowered and supported; its success ultimately led to a change in policy.

Public affairs includes programs specifically designed to influence public policy and/or affect legislation, regulations, political activities or candidacies — at the local, state or federal government levels — so that the entity funding the program benefits.

Full Text: SITUATION ANALYSIS

HIV is the leading cause of death and disease worldwide among women of reproductive age.¹ Although the number of new HIV infections is declining², the untold story is that the percentage of women living with HIV is increasing.³ Worldwide, 70% of women have been forced to have unprotected sex¹, and women are twice as likely as men to contract HIV due to biology, sexual coercion and cultural issues.⁴ In Europe, women represent one-third⁵ of the 21,000+ new HIV diagnoses.⁶ Despite these alarming statistics, information/resources in Europe tend to target men and generally lack relevant information on women-only HIV issues, leaving many women feeling isolated and without hope. HIV advocates highlighted the lack of resources and policies in the EU to answer the specific needs of HIV-positive women. In partnership with physicians and HIV advocates, Bristol-Myers Squibb (BMS) sought to address those challenges, empower women by providing resources, and change the European HIV landscape to consider the specific needs of women.

RESEARCH

Research was conducted to examine the void EU women living with HIV were experiencing.

Primary Research

- Discussions with women living with HIV found women often felt alone and unsupported after an HIV diagnosis, not even able to turn to their health care providers (HCPs) for information:
 - *“After my HIV diagnosis I felt very alone and just wanted to hide.”* Silvia
 - *“HIV is like living with this terrible secret...that makes you feel really bad about yourself.”* Adrienne
- Direct correspondence with EU health officials confirmed EU HIV policies did not

prioritize women: “It is therefore my hope that your work...shall help raise awareness of the inequalities faced by women living with HIV, while also developing constructive ideas to better translate their specific needs into national policies and programs in terms of improved prevention, diagnosis, treatment and care.” Member of European Parliament (MEP)

- A survey of European women conducted by a well-regarded research firm, Synovate-Ipsos, established that available services and resources did not focus on the specific needs of women living with HIV.

Secondary Research:

- An audit of media coverage and analyses from public health organizations supported the need for additional resources in the EU to empower women living with HIV and overcome the disparity faced between diagnosis and informed health care:
 - “Many national HIV/AIDS programs fail to address underlying gender inequalities. In 2008, only 52% of countries who reported to the UN General Assembly included specific, budgeted support for women-focused HIV/AIDS programs.” - *World Health Organization*
 - 2010 UNAids conference: “70 percent of women worldwide have been forced to have unprotected sex...experiencing violence hampers women’s ability to negotiate safe sex.” - *BBC News*

The research established the need for HIV resources, materials and support systems in the EU that specifically target women and empower them to live healthy lives.

PLANNING

After evaluating research results, an advisory board comprised of HIV community advocates, women living with HIV, and HCPs, funded and organized by BMS, developed SHE (**S**trong, **H**IV positive, **E**mpowered women) to support European women living with HIV and provide educational resources to their HCPs.

Objectives:

1. Address the unmet needs of women living with HIV;
2. Foster better dialogue between women living with HIV and HCPs;
3. Improve the quality of care of women living with HIV and apply a gender-sensitive approach to prevention and treatment.

Strategy:

The strategy focused on telling the untold story of HIV through the creative lens of women living with it, to spark change and answer unmet needs:

1. Establish an advisory board to develop resources and serve as the voice for women in Europe living with HIV; collaborate with advisory board to gain endorsement of additional stakeholders;
2. Develop comprehensive and creative educational resources and a patient peer support program that can be implemented in clinical or community settings;
3. Raise awareness of unmet needs for women living with HIV by unveiling SHE to target European audiences – media, policy makers, HCPs, advocacy groups.

Overall Plan:

Offering a robust online resource with digestible information written by women impacted by HIV, SHE emphasizes the proven powers of peer support to help improve the care and quality of life of women living with HIV. SHE is the first peer-support program designed to help European women with HIV feel empowered. A complementary SHE scientific program identifies best practices and knowledge gaps for women’s medical care.

Criteria for success:

1. 50 articles, 20 million media impressions, 12,000 website visits in six months;
2. SHE clinical support pilot programs in three hospitals;
3. Support from one EU policymaker.

Budget: Specific budget numbers are confidential.

EXECUTION

Online Resource: Written by women living with HIV, the resource provides *detailed information on critical topics and issues* such as: disclosure, human rights, sex and relationships, general and reproductive health, pregnancy and feeding babies, contraception, and peer support. The resource was distributed at European clinics, hospitals and community groups, and is also used by women living with HIV to empower them to form community peer support groups and act as peer support facilitators.

SHE Online: www.SHEtoSHE.org offers *practical information and videos*. The women featured on the website are all living with HIV and are champions of SHE. The videos offer testimonials from these women that speak to the major concerns newly diagnosed European women may have. The website also houses the online resource as a downloadable PDF that can be customized for each visitor.

Global Launch: The SHE peer support program and resource launched during the International AIDS Society (IAS) 2011 annual meeting, where *SHE was selected as an official IAS-affiliated event*. SHE advisory board members *trained 60 women* living with and/or affected by HIV, and HCPs, from 10 countries, to implement the program in clinical and community settings. 23 members of the media were also introduced to SHE at a launch press conference.

Post-Launch and Local Implementation: SHE was a *featured program at AIDS 2012, the premier international HIV congress*. Advisory board members *introduced SHE to 1,000+ booth visitors*, including media. SHE was then adapted and rolled-out locally.

Additional local tactics and highlights:

- Program endorsed in Poland by the National Institute of Hygiene, one of the most important national health institutions.
- A dossier was developed in Spain to present SHE to Spanish Health Authorities (National AIDS Plan) and key AIDS organizations.
 - *"It is much more useful for an individual who has HIV to discuss issues relating to treatment, diagnosis or quality of life with another woman living with HIV because it is perceived as more credible and trustworthy."* SHE advisory board member quoted in Spanish newswire *EFE*

EVALUATION

Success Criteria

50 articles; 20 million media impressions; 12K site visits (6 months)

Outcome

- More than **270 articles and 75 million media impressions**, approximately 4 times the target, from outlets such as: UK's *Daily Mirror*, Italy's *Corriere della Sera*, Spain's *Europa Press* newswire, France's *Marie Claire*, *LeMonde* and TV5.
- 15K web visits in 6 months and **80K+ visits to the SHE websites from 100+ countries to date; 1,300 downloads to**

SHE clinical support pilot programs in three hospitals

date of the online resource.

- Now **available in 13 European countries** in more than 10 languages.
- Endorsed by 14 HIV patient advocacy/professional/support organizations.
- **32 hospital support programs** (multidisciplinary team that includes HIV specialists, HCPs and peer support facilitators) are established in 7 countries with additional units in progress; community groups operating locally and thriving in Europe.
- A British Member of the European Parliament has met with SHE representatives and has supported SHE
- The FEEM Committee on Women's Rights and Gender Equality at European Parliament invited a SHE advisory board member to speak at the Public Hearing on Sexual and Reproductive Health and Rights (1/13)

Support from one EU Parliament member

An Impact on Political Landscape: In 2011, prior to the launch of SHE, the European Commission stated there were no plans to “promote specific action targeted to women” living with HIV. One of the most significant results following the implementation of SHE is that members of European Parliament endorsed the program. All these results show how the passion of a small group of women, and peer to peer power, can create a tremendous change.

Public Relations Society of America © 2013

Product #: 6BW-1306A04