The Brave Lady of Haiti

In her first U.S. interview, the HIVer who broke Haiti's silence on AIDS sounds off on voodoo, George Bush--and how activism must put PWAs first.

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In February 2004, anarchy roiled the vital Haitian port of St. Marc. Rebel forces, hoping to unseat then-president Jean-Bertrand Aristide, burned down police stations, as locals erected barricades against government troops with car chassis, tree trunks and flaming tires. Aristide's troops chased out the rebels, then began what one newspaper called a "terrifying lockdown," burning opposition sympathizers alive in their homes and leaving wild dogs to feast on corpses. Thousands of St. Marc residents fled to nearby mountains.

Among those who stayed behind was petite, soft-spoken 48-year-old Esther Boucicault, founder of the AIDS organization Fondation Esther Boucicault Stanislas (FEBS). "I had to stay," she says, alternating between the Haitian tongues of French and Creole. "On Mondays, I distribute antiretrovirals to our clients." She also had prevention work to do, since with soldiers come both rape and promiscuity. When Boucicault (pronounced BOO-*see-koe*), now sitting safely in *POZ*'s offices during a recent New York visit, recounts how she moved freely through St. Marc by bribing rebel and government forces with rubbers, her translator and friend, Elsy Mecklembourg-Guibert, does a double-take. Boucicault, visibly tired from a previous speaking engagement, gives a rare smile.

Heroism has long been part o fBoucicault's job description. Approximately 6 percent of Haiti's 8.4 million people have HIV, the highest rate outside sub-Saharan Africa. In 1999, Boucicault became the first person in Haiti to publicly say she was HIV positive, announcing her status on a series of Haitian radio and TV shows intended to educate the public. In the first television interview, the host nervously asks Boucicault, who is off camera, if she is sure she wants to show her face. After she says yes, she appears on screen, calm and professional in a plaid blazer, lipstick and her trademark hoop earrings. "I'm not afraid," she says.

Haitians greeted her disclosure with astonishment. Here was a healthy-looking middle-class woman talking frankly about a dread, sexually transmitted disease. Haiti is the western world's poorest nation—some 75 percent of its people live in poverty—and its combination of Catholicism and voodoo have contributed to profound AIDS stigma and misconceptions. Many Haitians believe that AIDS is a curse, perhaps bought by an enemy. "Some people thought I was lying," Boucicault says, "or that the government had paid me."

Some time after, in the capital city of Port-au-Prince, she addressed a teen audience—which initially jeered her, then fell into stunned silence as she told her story. Mecklembourg-Guibert has seen the same thing happen with Haitian audiences in the U.S. “When Esther starts to speak, people won’t pay attention, or they’ll mutter about not believing her. By the end, they’re listening.” Since Boucicault’s revelation, she has become famous in Haiti. Strangers stop her on the street to tell her that they have HIV. She shares with them her own health woes: A regimen of Kaletra, Trizivir and Viread controls her HIV, but she suffers from both diabetes and neuropathy.

Boucicault’s work at FEBS started her on the path toward her groundbreaking announcement. She founded the once-tiny organization in 1996, shortly after she was diagnosed. It now provides services to roughly 500 people, including 150 AIDS orphans,250 people living with HIV and 110 people on HIV meds. They come to the cozy two-story home that houses FEBS to get all that they can—meds,condoms, support and nutritional information.

Most important, though, is Boucicault’s emphasis on PWA empowerment—a greater challenge, she says, than access to meds. “I want to see my clients reintegrated into society after having dealt with the fact that they have HIV,” Boucicault says, “I want them to be able to continue working.” One of Boucicault’s many slogans: “AIDS is not an end, but the beginning of a new way of living.” “Now people with HIV can look at Esther and not feel ashamed for themselves,” says Mecklembourg-Guibert, a New York City–based Haitian who founded EMG Health Communications, a health-education organization that does AIDS outreach to Haitians in the U.S. and works with FEBS clients.

As a result of Boucicault’s message, FEBS has forged a widespread network of Haitians who embrace their identity as people living with HIV. “There are only a handful of strong PWA organizations in poor countries, like South Africa’s Treatment Action Coalition or Uganda’s AIDS Support Organization. FEBS is on that level. It’s like a nonreligious ministry,” says Joia Mukherjee, MD, medical director of Partners In Health (PIH), a Boston-based global treatment organization. PIH, which pioneered AIDS treatment in Haiti by creating a community-based systemof regular visits to patients’ homes, chose to work through FEBS to help bring HIV meds to the St. Marc region because Boucicault already had a similar system in place. “Adapting the PIH model of [treatment] delivery was very easy to lay over that,” says Mukherjee. Paul Farmer, MD, world-renowned cofounder of PIH, credits Boucicault not only with helping to pave the way for HIV treatment in Haiti but with galvanizing PIH’s own HIV positive leaders. “She is a beacon of hope and dignity,” he says.

Boucicault doesn’t know where she got the nerve to become the first person to publicly disclose in Haiti. She says she’s simply “a naturally energetic person who likes to take on challenges” and that she is lucky to have a supportive family, including her two daughters, Michelle, 22, and Stephanie, 10. Her modesty belies not only her trailblazing accomplishments but her own painful AIDS history. When asked to tell it, she drops her head wearily and pleads with Mecklembourg-Guibert to do it for her. She eventually agrees to tell it herself, but entirely in Creole, the daily language of most Haitians. She warns she has let herself forget dates and details because “the case is closed.”

In the early ’90s, Boucicault’s husband, Bob Stanislas, a rice-factory director, fell gravely ill. As is common inHaiti, Boucicault visited a *houngan*,or voodoo priest, hoping he could lift whatever curse was causing the illness. “I paid the houngan thousands of dollars,” she says, “and he died anyway.” Suspecting that her husband might have died of AIDS—he had both pneumonia and tuberculosis—Boucicault got tested, but the result was negative. Then in 1995, Boucicault had a son with a new partner. While she was pregnant with their second child, Stephanie, her son died at nine months of age. Suspecting again that the cause was HIV, Boucicault and her partner both got tested; he was negative, but Boucicault was positive. She believes that both her husband and son died of AIDS and that her first HIV test was incorrect. Happily, Stephanie cleared the virus after she was born, but Boucicault’s health suffered. “I had every infection you could have—shingles, herpes, TB,” she says. Friends in France sent her HIV meds, and Boucicault’s health stabilized in six months. She immediately went about founding FEBS.

Three years later Boucicault decided to go public with her status. On a visit to her daughter’s pediatrician, she told him she wanted to speak out about her experience with HIV; he helped orchestrate the 1999 radio and TV interviews. Despite her remarkable history, Boucicault remains relatively unknown outside Haiti. Mecklembourg-Guibert wants to change that: EMG Health brings Boucicault to the U.S. regularly to educate Haitian immigrants about HIV. Boucicault maintains that AIDS stigma canbe worse in the U.S., despite access to excellent care. “When I ask [Haitian] PWAs here to help me and tell their stories, very few are willing,” she says.

Boucicault knows the U.S. is key in the fight against AIDS in Haiti. She’s not too modest to ask whether *POZ* has connections to celebrities who could help her raise AIDS awareness. She refuses to criticize the abstinence strings attached to President Bush’s PEPFAR millions: “Abstinence, fidelity and condoms—we say they are three boats on the water. Just make sure you get in one. If not, then—*pffft!*—you sink.”

While Haiti’s political situation remains dire—United Nations–mandated elections will take place in the fall—world governments recently pledged a billion dollars in aid to the ailing nation; millions are earmarked for AIDS. The UN Global Fund will spend $35.5 million on Haitian projects. PEPFAR poobah Randall Tobias announced last winter,in the presence of Haiti’s interim prime minister Gerard Latortue, that the U.S. was giving Haiti $40 million in 2005, nearly double 2004’scommitment. FEBS, however, is far from swimming in money. Mecklembourg- Guibert says she gave a speech in which she mentioned that Boucicault didn’t even have the use of a car, prompting the U.S.ambassador to donate one.

In the future, Mukherjee would like to see FEBS “spinoffs.” Perhaps Boucicault’s daughters, who have inherited her passion for fighting AIDS, could spearhead them. Michelle studies community medicine in the Dominican Republic and plans to work at FEBS. Stephanie, meanwhile, has been known to hold a FEBS megaphone in one hand and a box of condoms in the other and invite clients to help themselves. “I would like my daughters to someday run FEBS,” says Boucicault, who gives another of her infrequent smiles when the subject of her children arises. “But always with someone who is HIV positive.”

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