In 1997, Lucy Chesire became the first female health professional in Kenya to publicly acknowledge that she was living with HIV. A fearless woman, she continued working as a clinical dietician and stayed active in her community. Lucy battled HIV for a decade, but it was not until she contracted tuberculosis (TB) that she came close to dying. "I was able to live with HIV very well and manage it in a very good way," she says. "It was TB that almost brought me to my deathbed."

Lucy's story isn't unique among women. TB is the third leading cause of death for women worldwide, killing over half a million women each year. The disease primarily affects women of child-bearing age and is a leading cause of infertility. Health care providers and women living with HIV/AIDS have an even higher risk. Traditionally, more men than women are diagnosed with TB each year. But not for much longer, according to Dr. Max O'Donnell, Assistant Professor of Pulmonary Medicine at Albert Einstein College of Medicine. "HIV really has changed the game and has put women at increased risk in recent years," said O'Donnell. "In Africa, if you count the sputum smear negative cases [instances of disease where health workers initially were unable to spot the TB germ under a microscope], it's becoming predominately a female disease."

With the rise in TB cases has also come a rise in stigma. In many countries, women avoid seeking care for fear of divorce, abandonment and social exclusion. Lucy recounts the story of a woman in her community who sold tomatoes on the side of the road. "When people found out she was on TB treatment, they stopped buying tomatoes from her. It cut her source of income," she explained. "People don't have the information that once you begin treatment you are quickly no longer infectious."

Despite its status as a leading killer of women, virtually no public or political attention is paid to TB as a women's health issue. "HIV has gotten so much attention, as have other conditions that impact women," explains Dr. Amita Gupta, Assistant Professor of Medicine and International Health at Johns Hopkins University, "and yet clearly there's a huge burden." Lucy believes this must change—and that NGOs have a key role to play. Here are five ways civil society can better work to eliminate TB as a leading cause of death and disability among women:

1. Educate yourself and your community about TB.
   - Lack of knowledge about TB contributes...
to delays in treatment, stigma and spread of the disease. Educating yourself about the signs, symptoms and social determinants of TB—and sharing what you learn with others—is the first line of defense against the disease. Improving TB literacy is critical to both individuals and communities. “There is a tremendous benefit to just educating women on the basics of TB,” says Gupta. “Education has been shown to improve detection and treatment seeking behaviors.”

2. Integrate TB services into HIV, reproductive health and family planning programs.
In many communities in sub-Saharan Africa, up to 80 percent of TB patients are co-infected with HIV. Experts agree integrating TB and HIV programs is an effective way to address co-infection. “When you don’t properly address TB, investment in HIV/AIDS goes down the drain,” voices Chesire. “These are two diseases in one person, so they need one response,” she often says. Integration must also happen in reproductive health and family planning programs. Pregnant women with TB are twice as likely to give birth to a premature baby and four times more likely to die during childbirth. Because of this, all pregnant women living in high burden settings should be screened for symptoms of TB when they go for antenatal check-ups. “This simple screen is not very time consuming,” says Gupta. “But it needs to be done in a consistent fashion.” The World Health Organization recommends screening for four symptoms: current cough, night sweats, unexplained weight loss and fever.

3. Evaluate programs and share best practices.
Local NGOs are well positioned to research and assess what models of care work best in their communities. Evaluate programs to see what strategies work best and then compare approaches. Which interventions are most effective? Which ones are not? Which programs are most successful at improving health outcomes by integrating services? These are issues “NGOs are well positioned to study,” says Gupta. “Particularly if they can add a cost-benefit analysis to their practices in the field.”

Educating policy-makers about TB and its huge impact on women can affect important changes in policy. After surviving a long battle with the disease, Lucy emerged determined to help others with TB receive better care. She helped start a grassroots advocacy NGO in Kenya and became a global advocate championing TB and TB-HIV.
“We need to engage with policy-makers at the national level because these are the very people who fund the programs,” explains Chesire. When she was first diagnosed with TB, there were no policies in place advising people with HIV to be screened for TB, despite high rates of co-infection. Since then, she and other advocates made recommendations for TB-HIV program integration that policy-makers later adapted.

5. Advocate to raise the visibility of TB as a women’s health issue.
“First and foremost, we need more visibility in disseminating the concept that TB is a women’s health issue,” says Gupta. Building a grassroots network of peers and patient advocates, organizing a community dialogue and speaking at local events are great ways to draw attention to TB as a women’s health issue. “When I came to South Africa ten years ago, nothing was going on for HIV,” recalls O’Donnell. “It was 100 percent the activists and advocates who drove the process.” Chesire believes civil society must demand better testing and treatment for women with TB—just as they demanded better testing and treatment for HIV. “We need to renew political commitment to fight the disease,” she says. “To make TB a disease of the past we need to turn declarations into deeds and promises into programs.”

For more information on tuberculosis and women please visit www.action.org.