Tuberculosis (TB), an ancient and highly contagious airborne disease caused by the Mycobacterium tuberculosis bacterium, has infected over 15,000 people in the state of Massachusetts. A proposal generated by the Medical Advisory Committee for the Elimination of TB (MACET) for the fiscal year 2012 would work toward relieving the costs of TB not only for victims of the life threatening illness, but also the entirety of the Commonwealth by eliminating patient co-pays and deductibles for TB care.

Access to TB Services

Robert Mesika '12
Bayleigh Ruhm '12

■ The Line Items
4512-0103 HIV/AIDS Prevention, Treatment and Services
4516-1000 Hinton State Laboratory Institute and Communicable Disease Control Services
4510-0100 Department of Public Health Critical Operations

■ Elevator Speech
Hello, Representative [Name]! I’m glad I bumped into you because I know you care about preserving public security and health by preventing possible epidemics across our community and state. Many of your neighbors and constituents are fearful of seeking TB services due to insurance restrictions and lack of affordability. Our inside section to the amended House budget will eliminate patient co-payments and deductibles for life-saving TB services, thereby encouraging victims within our state to seek prompt treatment and stopping the spread of this highly contagious, fatal, and increasingly drug-resistant disease. You, Representative [Name], can protect our great state from this future epidemic by voting “Yes!” on our outside section in the amended and final House budget, and by encouraging the Chair of the Ways and Means Committee and your fellow legislators to support this measure, as well.

Robert Mesika ’12 and Bayleigh Ruhm ’12
Advocacy for Policy Change: Brandeis students work to reform Massachusetts law

■ Excerpt from Storybook

Myrna Leiper is an RN and the Public Nurse Coordinator for TB Service Area (TSA) 1, consisting of Central and Western Massachusetts. Myrna had the following story to share regarding one of her patients, “Jane.”

Jane is a 43-year-old Haitian woman, wife, and mother of two. Although her husband emigrated to the U.S. approximately 20 years ago, and her daughters two years ago, Jane was unable to do so until little over one year ago. She and her family currently live in a small, confined two-bedroom apartment in a tightly-knit community in Western Massachusetts. Jane does not speak English, and at the time this story was shared, no translators had been available during her medical situation.

When Jane first arrived in Massachusetts, she was sent to a local emergency care facility for treatment of third-degree burns. At this time she was determined to be HIV+ and to suffer from multiple mental health disorders. Jane was brought to another facility when her burns did not heal; she was hospitalized and suspected to be a victim of domestic violence. With this second visit and the appearance of coughing and weight-loss symptoms, Jane was finally diagnosed with Active Pulmonary and Disseminated TB.

It would later be determined that Jane’s original burns and those after her initial health care visit were inflicted due to cultural stigma. Haitians believe that TB is a sinner’s curse and that the only way to rid the body of it is through burning. Haitians will generally not treat TB medically.

While Jane is currently on her husband’s insurance, it has high patient costs including approximately an $80 co-payment. Jane does not qualify for the government health programs due to her short residency in the U.S. Her husband’s insurance will force her discharge from the hospital, where she is in a ward specifically reserved for the care and prevention of TB, as soon as she is considered no longer contagious. However Jane will be unable to continue treatment without the aid of the hospital, as the nearest TB clinic to her home is 40 driving minutes away and her community is without public transit. If Jane does make it to the clinic, even without a translator, the clinic will be able to treat her HIV, but not her mental illnesses. Jane will also be confined to a small apartment where she will come in contact with family and with helpful friends and neighbors, potentially spreading the airborne illness quickly if she is unable to continue treatment.

One of Jane’s daughters now tests positive for a latent TB infection, but is not being treated.

Jane is now experiencing nearly all the barriers to care for TB in the Massachusetts public health system, including lack of structural support, language barriers, additional and compounded illnesses, and increased medical costs. To improve Jane’s situation and that of so many others, as well as prevent the spread of TB, support for TB services must improve and the patient costs to care must be decreased. This may be done by eliminating co-payments and deductibles currently required of patients.

■ Excerpts from Campaign Journals

Robert

We made a clear connection to Representative Canavan’s past nursing career. Yet, we found out that while the story from Dr. Garvey was effective, some of the statistics presented, such as there being 222 TB cases in MA last year, downplayed the threat of the disease to Canavan. She even said, “Wow, I expected those numbers to be higher” in response to the number of cases. We fixed this in later meetings by making sure to adjust statistics that seemed subtle to highlight their relevance to our cause.

Bayleigh

The simplest example of the need for flexibility in the arranged plan arrived in the first meeting, with Representative Toomey’s aide, Tim Snyder. Although the MACET group seemed to be stating the issues straightforwardly, Mr. Snyder repeatedly asked how the line items would actually affect TB services. He also became sidetracked with the idea that Massachusetts had already achieved great strides in this area, despite being astounded at the case statistics mentioned at the beginning of the meeting. It seemed as though the group was able to regain his attention to what needed to be done, but he could or would not commit his own support – he gave the impression he would inform Toomey of the issues surrounding TB, but not fight for it. This meeting cemented the idea “it is not just what you say, but how you say it.”

■ Update (May 2011)

Line Item 4512-0103 HIV/AIDS Prevention, Treatment and Services passed, but the other two amendments (4516-1000 and 4510-0100) were cut.

For more information

Massachusetts Medical Advisory Committee for the Elimination of Tuberculosis: www.mamacet.org