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# The Elusive Tuberculosis Case: The CDC and Andrew Speaker<sup>1</sup>

The US Centers for Disease Control and Prevention (CDC) was the nation's chief public health office. Among other duties, the Atlanta-based government agency developed health policy, implemented prevention strategies and investigated health problems. It took a special interest in infectious diseases, monitoring for outbreaks that might pose a wider risk to public health. On occasion, this meant intervening when an individual might pose a risk to other people.

In May 2007, a tuberculosis case came to CDC's attention. Fulton County, Georgia, public health officials notified the CDC's Division on Global Migration and Quarantine (DGMQ) that Andrew Speaker, a young lawyer in Atlanta, had multidrug-resistant TB (MDR TB)—an infectious disease. Typically, doctors would explain to a suspected TB patient that s/he posed danger to others, and ask him to limit the potential spread of the disease by restricting travel and other activities. Speaker had wedding plans for late May—in Greece.

On May 10, doctors from the Fulton County Department of Health and Wellness had met with Speaker to discuss treatment, and recommended that he cancel travel plans. The next day, the health officials mailed Speaker a letter restating their views on travel. The letter never reached him: Speaker had moved up his departure date and flown to Europe. As Fulton County and CDC officials scrambled to track him down, lab results returned an even bleaker diagnosis: Speaker's TB was actually an extremely drug-resistant strain (XDR TB)--even harder to treat, and more lethal than MDR TB both for Speaker and others.

Only on May 22 did the CDC locate Speaker, by now on honeymoon in Rome. CDC quarantine officer Dr. David Kim called Speaker to explain the new diagnosis and treatment options in the US. But how to get Speaker back? He could not take a commercial flight because of the health risk to others. Telephone conversations with an increasingly anxious Speaker were confusing and inconclusive, so on the morning of May 24, the CDC sent a Rome-based former employee to his hotel to discuss options in person. Speaker and his bride were gone.

CDC officials were confounded. How could they inform the public about the potential health threat Speaker posed if they didn't know where he was? Assuming he would try to re-enter

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NOTE: This case was written from secondary sources.

the US, what then—detain him? Speaker had exposed both an alarming number of people to a dangerous disease, and an alarming number of flaws in public health procedures. On May 25, officers from DGMQ held a conference call with the CDC media relations office to decide on a public communications strategy, as well as what to do with Speaker himself. That evening they received an alert: Andrew Speaker had crossed the border from Canada into the US. They had to act now.

# **Investigation begins**

The treatment and control of TB in the US was a multi-tiered system. It involved medical providers, who often detected a case; state and local health departments, whose TB clinics were responsible for much of the treatment and counseling of TB patients; and multiple divisions at the CDC. The Division of Tuberculosis Elimination was tasked with overseeing nationwide TB prevention and control programs in the US, and with providing programmatic and technical assistance, including advanced lab testing, to state and local TB management efforts throughout the country. Meanwhile, the Division on Global Migration and Quarantine was responsible for monitoring and controlling infectious disease among mobile populations such as immigrants and international travelers.

Quarantine officers based at the 20 DGMQ quarantine stations at airports and other points of entry around the county played a key role in ensuring that infectious illness did not cross US borders. Part of their role was to provide information and support to local medical workers dealing with infectious disease patients. It was in this capacity that, on the evening of May 10, 2007, Dr. David Kim, a quarantine officer based at the CDC's Atlanta quarantine station, responded to an email from the State of Georgia Health Department's tuberculosis program. Fulton County medical officials were writing to notify him of a patient, not identified by name, who had multidrugresistant tuberculosis. They feared the patient might travel overseas against their advice. What, they asked, were their options for discouraging his travel?

Dr. Kim and the Fulton County officials exchanged emails discussing options, including sending a letter to the patient officially restating their advice that he not travel. A week went by with no word; the case appeared to be under control. But on May 18, Dr. Kim heard from the same officials again. They had sent the letter, but it apparently had never arrived. They suspected the patient, whom they now identified as Andrew Speaker, had moved up his departure date and was now in Greece—but they could not be sure.

The CDC could not act on presumption of a problem. Before it could take any kind of legal action, or request intervention by the Department of Homeland Security, the CDC would have to

piece together who the patient was; if he did, in fact, have MDR TB; and where in the world he might be.<sup>2</sup> Dr. Kim and his team opened an investigation.

Andrew Speaker. As they learned, Andrew Speaker was a 31-year-old graduate of the University of Georgia School of Law. Clean-cut, athletic, and ambitious, he had spent three years at his father's small Atlanta firm specializing in personal injury law and was considering opening his own practice.<sup>3</sup> In December 2006, he had become engaged to third-year Emory University law student Sarah Cooksey.<sup>4</sup>

Speaker was a fan of international travel. He had backpacked through Europe, and more recent trips included a 2001 visit to Peru and a five-week stint volunteering in 2006 with the Rotary Club in hospitals and orphanages in Vietnam.<sup>5</sup> Speaker and Cooksey were planning a May 2007 wedding in Greece, followed by a two-week European honeymoon.

In late January 2007, Speaker took a hard fall. An x-ray ruled out a broken left rib, but turned up an unexpected abnormality on the opposite side of his chest: a tennis ball-sized lesion on the upper lobe of his right lung. Doctors suspected tuberculosis, but needed to do further tests to be sure. They scheduled a bronchoscopy for early March.

### TB: shrouded in misconceptions

An airborne infectious disease, TB had been shrouded in misconception for centuries. Known historically as consumption, wasting disease, and the white plague, it was long thought to be hereditary—and, prior to the discovery of effective antibiotics, a death sentence. Signaled by a racking cough, chest pains, fever and, in its advanced stages, coughing up blood, the pulmonary form of the disease was the most common and well known. But TB could actually infect other parts of the body as well, including the kidneys, brain, or bone, or multiple sites at once. Although it could infect people of all ages, TB was famous for striking down young adults in their prime.

In the late 19<sup>th</sup> century, TB was discovered to be not hereditary, but contagious, caused by the bacteria *Mycobacteria tuberculosis*. It remained a leading cause of death in the US until the discovery of effective antibiotics in the mid-20<sup>th</sup> century dramatically reduced mortality rates. The sanatoriums where TB patients had long been sent to ride out the disease were gradually closed,

Dr. Julie Gerberding, Director of the Centers for Disease Control and Prevention, testimony, "Cracks in the System: An Examination of One Tuberculosis Patient's International Public Health Threat," A Special Hearing before a Subcommittee of the Committee on Appropriations, United States Senate, Washington, D.C, June 6, 2007, p. 29.

A picture of Andrew Speaker: https://casestudies.jrn.columbia.edu/casestudy/files/photos/769/tb-travelerx.jpg

Cooksey at the time was a 25-year-old single mother. The two of them met in a bar.

Nina Burleigh, "Medical Fugitive," *People Magazine*, June 18, 2007. See: http://www.people.com/people/article/0,,20061197,00.html. Also Eve Conant, "His Side of the Story," *Newsweek Magazine*, June 1, 2007. See: http://www.thedailybeast.com/newsweek/2007/05/31/his-side-of-the-story.html

and eradication of the illness in the US seemed within reach. <sup>6</sup> In the 1980s a combination of factors, including the rise of multidrug-resistant TB, led to an unexpected resurgence in reported cases in the US, but renewed TB control efforts and increased funding once more brought overall declines by the early 1990s. <sup>7</sup>

By the first decade of the 21st century, those declines had continued in the US and worldwide, but popular first-world perceptions that TB was no longer a public health threat were misplaced. It remained one of the world's most common and deadly infections, second only to HIV/AIDS in deaths due to a single infectious agent; among the top three causes of death for young women; and an especially lethal disease for people living with HIV, the estimated cause of 25 percent of their deaths. TB was especially common and deadly in resource-poor countries, where providing effective treatment was difficult. In 2011, nearly 9 million people around the world got the disease, and around 1.4 million died of TB-related causes—over 95 percent of these in low- to middle- income countries.

### Controlling TB: public health challenge

Controlling the spread of TB remained difficult for a number of reasons. It was not commonly understood that TB could occur in both latent and active forms. Transmission could take place when tiny particles (droplet nuclei) containing *M. tuberculosis* were expelled by someone with TB disease (usually by coughing, sneezing, spitting, speaking, or singing), then inhaled by others. But transmission depended on a number of factors, including how infectious the TB carrier was, how virulent his TB bacteria, and where and for how long the exposure had occurred. Close contacts were the most likely to become infected, but even then, on average only 20-30 percent of them would become infected.<sup>11</sup>

<sup>&</sup>lt;sup>6</sup> US Centers for Disease Control and Prevention, "Tuberculosis Fact Sheet." See:

http://www.cdc.gov/tb/publications/factsheets/statistics/TBTrends.htm

Self-Study Modules on Tuberculosis, Module 2: "Epidemiology of Tuberculosis," US Centers for Disease Control and Prevention, 2008, p. 5. http://www.cdc.gov/tb/education/ssmodules/

According to the World Health Organization, "the estimated number of people falling ill with tuberculosis each year is declining, although very slowly, which means that the world is on track to achieve the Millennium Development Goal to reverse the spread of TB by 2015. The TB death rate dropped 41% between 1990 and 2011." World Health Organization, Fact Sheet No. 104, "Tuberculosis." See: http://www.who.int/mediacentre/factsheets/fs104/en/.

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US Centers for Disease Control and Prevention, "Tuberculosis: Data and Statistics." See: http://www.cdc.gov/tb/statistics/default.htm.

Studies had found that about 20 percent of close contacts of smear negative patients contracted LTBI. (Jereb J, Etkind SC, Joglar OT, Moore M, Taylor Z. "Tuberculosis contact investigations: outcomes in selected areas of the United States, 1999." Int J Tuberc Lung Dis 2003;7:S384—90). But rates were significantly higher—30-40 percent—for close contacts of smear positive pulmonary TB patients (Reichler MR, Reves R, Bur S, et al. "Evaluation of investigations conducted to detect and prevent transmission of tuberculosis." JAMA 2002;287:991—5).

When a healthy person was infected—meaning the *M. tuberculosis* reached the lungs, multiplied, and began to spread through the body via the bloodstream—the immune system usually intervened within two to eight weeks to stop the process and prevent the development of TB disease, although it did not eliminate the organism from the body altogether. These people were then classified as having Latent Tuberculosis Infection (LTBI).

LTBI itself was not contagious, and only about 10 percent of people with healthy immune systems who had it would ever go on to develop the active form of the disease. <sup>12</sup> But for people with compromised immune systems, the odds that LTBI would progress to active TB increased significantly. For patients with diabetes, for example, the risk of developing active TB rose to 30 percent over a lifetime—three times higher than for a healthy person—and HIV patients' risk was up to 100 times greater than for a non-immunocompromised person. <sup>13</sup>

The preferred treatment for LTBI was a nine-month regimen of the drug isoniazid, which had proven very effective at preventing the development of TB disease, even in people with weakened immune systems. <sup>14</sup> Since LTBI was like a ticking time bomb—albeit one that would go off only 10 percent of the time—detecting and treating it was considered an important public health initiative by the CDC. <sup>15</sup> But as carriers manifested no symptoms, this was difficult. LTBI's prevalence worldwide made testing all potential carriers impossible: estimates suggested that one-third of the world's population—about 2 billion people—were infected with LTBI. <sup>16</sup> Once an LTBI patient did develop TB disease, he could potentially infect others, but since symptoms could remain mild or even nonexistent for months, diagnosis and treatment were often delayed, which meant the patient could potentially spread the infection without ever knowing he was sick.

Skin or blood tests were often the first step in the diagnostic process, but these could determine only if the bacteria was in the body, not whether the patient's infection had progressed to active TB, and for some people with TB disease the results still came out negative. A medical history to determine risk factors, such as exposure to infected persons, and a physical exam, including chest x-rays like the one Andrew Speaker got by chance, were also standard steps in the

The chances were greatest within the first year or two of infection, when about 5 percent developed the disease; another 5 percent would develop it over the rest of their lives.

Other factors that increased risk include substance abuse, organ transplant, silicosis, kidney disease, certain types of cancer or intestinal conditions, previous treatment with corticosteroids or other immunosuppressive drugs, and low body weight. Source: Self-Study Modules on Tuberculosis, "Module 1: Transmission and Pathogenesis of Tuberculosis," US Centers for Disease Control and Prevention, 2008, p. 20-21. See: <a href="http://www.cdc.gov/tb/education/ssmodules/">http://www.cdc.gov/tb/education/ssmodules/</a>

Self-Study Modules on Tuberculosis, "Module 4: Treatment of Latent Tuberculosis Infection and Disease," US Centers for Disease Control and Prevention, 2008, p. 8. See: http://www.cdc.gov/tb/education/ssmodules/

Self-Study Modules on Tuberculosis, "Module 3: Targeted Testing and the Diagnosis of Latent Tuberculosis Infection and Tuberculosis Disease," US Centers for Disease Control and Prevention, 2008, p. 6. See: <a href="http://www.cdc.gov/tb/education/ssmodules/">http://www.cdc.gov/tb/education/ssmodules/</a>

US Centers for Disease Control and Prevention, "Tuberculosis: Data and Statistics." See: http://www.cdc.gov/tb/statistics/default.htm.

diagnostic process. But a confirmed diagnosis of TB disease, and an analysis to determine whether it was drug-resistant, required bacteriological testing in a lab. In 2007, this process could take anywhere from six to 16 weeks.<sup>17</sup> This was the stage at which Speaker found himself following his initial abnormal x-ray results.

#### **Diagnosis Confirmed**

On March 8 at an Atlanta hospital, a still asymptomatic Speaker underwent a bronchoscopy, a procedure in which a doctor inserted an instrument through his mouth to retrieve a sample of sputum (phlegm from deep in the lungs) or tissue from the diseased part of the lung. As per standard procedure, the sample was immediately "smear tested," or examined under a microscope to determine the presence of visible TB bacteria. Patients were deemed "smear positive" if their sample contained sufficient bacteria to be seen and counted under a microscope. Until further tests could be done, smear positive patients were considered contagious, because they could potentially expel the bacteria into the air; the more strongly positive the result, the more contagious the patient was generally believed to be.<sup>18</sup>

This test usually took under 24 hours, and Speaker quickly received good news: he was smear negative, which meant he might still have TB, but if he did he was not yet very sick, nor very contagious. With the diagnosis still unconfirmed, he was not prescribed any medicine, nor told to take any specific precautions. But to definitively rule out TB, the sample had to be cultured in a lab: since bacteria could still be present, just not immediately visible, this process gave the slow-growing bacteria time to develop.

On April 23, 2007, culture tests confirmed that Speaker's sputum contained a small number of TB bacteria: he was culture-positive for active tuberculosis, so technically he could spread the disease to others. As CDC Director Julie Gerberding explained:

If the patient is smear-negative, culture-positive, he could transmit [TB] to people under certain circumstances, and overall about 17 percent of the tuberculosis that we see in the United States comes from people who are culture-positive and smear-negative. So it's not a zero risk.<sup>19</sup>

Since the Speaker incident in 2007, diagnosis has accelerated. In 2010, the WHO endorsed a rapid molecular test that could diagnose TB and resistance to the drug rifampin in under two hours, and uptake has been promising, including in resource-poor countries. The WHO reports that by June 2012, low- to middle-income countries had purchased 1.1 million tests. Source: "2012 Global Tuberculosis Report," The World Health Organization, Executive Summary, p. 1. See: http://www.who.int/tb/publications/global\_report/gtbr12\_executivesummary.pdf.

Even if the patient was strongly smear positive, further testing still had to be done to definitively diagnose TB, because the bacteria seen under microscope could potentially be not TB but another kind of mycobacteria. Source: Self-Study Modules on Tuberculosis, "Module 3: Targeted Testing and the Diagnosis of Latent Tuberculosis Infection and Tuberculosis Disease," US Centers for Disease Control and Prevention, 2008, p. 53-54. See: http://www.cdc.gov/tb/education/ssmodules/

Gerberding, Senate hearing testimony, p. 30-31.

Speaker's physician prescribed Speaker the standard four drugs usually given to non-drug-resistant TB patients for an eight-week initial phase of treatment. This was usually followed by a continuation phase, lasting several more months, of at least two drugs.<sup>20</sup> Even if the patient never felt sick at all, following the regimen exactly as prescribed was essential for preventing relapse or the development of drug resistance.

For his part, Speaker appeared to take the diagnosis in stride, and he started the medications. <sup>21</sup> He still felt fine, and the cure rate for healthy people treated for tuberculosis was extremely high—95 percent; after just two weeks of treatment most patients were no longer considered contagious. Speaker and his family proceeded with wedding plans.

#### Fulton County takes the case

As required by US law, Speaker's physician immediately reported his diagnosis to the Fulton County Department of Health and Wellness, and health officials quickly got in touch with the patient. Fully cooperative, Speaker canceled his appointments and reported to the Fulton County TB clinic on April 25. There he was examined by TB specialist Dr. Andrew Vernon.

Dr. Vernon held a CDC title—Chief of the Clinical and Health Systems Research Branch in the CDC's Division of Tuberculosis Elimination (DTBE). But when he examined Speaker, he was on loan to Fulton County's TB clinic, not acting as a CDC representative. During that appointment, or shortly after, Speaker told Dr. Vernon he planned to travel to Europe the following month to get married.

Dr. Vernon took another sputum sample, which showed that Speaker remained smear-negative. But to determine definitively if Speaker's TB had progressed, potentially making him more contagious, not to mention sicker, Dr. Vernon sent the new sample to a lab to be cultured again, a process that would take another several weeks.

MDR TB tests. The new round of tests would determine not only whether Speaker's TB had advanced, but also whether and to what degree it was resistant to specific drugs, including the four he was already taking. Worldwide, reported cases of drug-resistant TB had increased alarmingly since the 1980s, largely due to the mismanagement of TB treatment: incomplete treatment, treatment using too few drugs, or use of poor quality drugs could all cause strains of TB

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The initial four drugs were isoniazid, rifampin, pyrazinamide, and ethambutol. For more on treatment of LTBI and TB disease see Self-Study Modules on Tuberculosis, "Module 4: Treatment of Latent Tuberculosis Infection and Disease," US Centers for Disease Control and Prevention, 2008, p. 23. See: <a href="http://www.cdc.gov/tb/education/ssmodules/">http://www.cdc.gov/tb/education/ssmodules/</a>

Burleigh, "Medical Fugitive."

Dr. Steven Katkowsky, director of Department of Health and Wellness, Fulton County, Georgia, testimony, "Cracks in the System: An Examination of One Tuberculosis Patient's International Public Health Threat," A Special Hearing before a Subcommittee of the Committee on Appropriations, United States Senate, Washington, D.C, June 6, 2007, p. 46.

to become resistant. Patients could either contract a strain of TB that was already drug resistant (known as primary resistance), or they could be infected with regular TB that only later became resistant due to mishandling of their treatment (called secondary, or acquired, resistance).

TB that was resistant to at least the two most powerful first-line drugs, isoniazid and rifampin, was labeled multidrug-resistant tuberculosis (MDR TB), and had to be treated for 18-24 months with less-effective, more expensive "second-line" drugs.<sup>23</sup> These drugs frequently had harsh side effects and resource-poor countries often found the cost of delivering them prohibitive. The cure rate for MDR TB patients receiving treatment in ideal conditions was 70-80 percent—but in practice it was often closer to 50 percent.<sup>24</sup>

### A new diagnosis

By May 1, Dr. Vernon had the results of the initial drug-resistance tests: Speaker's TB was multidrug-resistant. As he explained to Speaker by phone, the degree of resistance would not be determined by the lab for another few weeks. Georgia's public health labs had conducted the initial tests for resistance to the first-line drugs, but the more advanced tests for resistance to second-line drugs would have to be outsourced to a CDC lab.<sup>25</sup> But for now, Speaker should stop taking the drugs he had been prescribed; they would have no effect.

Treatment would now be longer—up to two years, more expensive, and more complicated. Yes, Speaker was still smear negative, so it was unlikely that he was highly contagious, but since he had been receiving no effective treatment at all, there was a chance he could transmit the disease. Should that happen, this new prognosis meant the results could be far graver than before for those he infected. Therefore, Dr. Vernon explained, Speaker should not travel—he would need to postpone or relocate his Greek destination wedding, scheduled for three weeks later.

Recently updated World Health Organization guidelines on tuberculosis and air travel were very clear on this issue. Studies indicated that, contrary to popular belief, the risk of contagion on an airplane was no greater than in other enclosed public places, and no evidence had been found of passengers developing TB *disease* as a result of flying with an infectious patient. However, there was some evidence that latent TB infection could be transmitted to those seated

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In 2009, a CDC task force estimated in-patient costs for an MDR-TB patient at \$200-250,000. Source: Philip LoBue, Christine Sizemore, and Kenneth G. Castro, *Plan to Combat Extensively Drug-Resistant Tuberculosis Recommendations of the Federal Tuberculosis Task Force*, MMWR Recommendations and Reports, Centers for Disease Control and Prevention, February 13, 2009. See: <a href="http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5803a1.htm?scid=rr5803a1">http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5803a1.htm?scid=rr5803a1</a> e

Gerberding, Senate hearing testimony, p. 12.

Ibid., p. 46.

very near a TB patient on flights exceeding eight hours.<sup>26</sup> The WHO advised physicians that travelers with non-drug-resistant TB could fly as long as they had been responsive to at least two weeks of treatment—such patients could reasonably be assumed to be non-contagious—but that "physicians should inform all MDR-TB patients that they must not travel by air—under any circumstances or on a flight of any duration—until they are proven to be culture-negative."<sup>27</sup>

Concerned that Speaker was not fully digesting this advice, Dr. Vernon scheduled a meeting with Speaker and his family to "explain why the travel should be delayed in order to move promptly to limitation [sic] of contact and initiation of therapy in some appropriate way." The meeting was scheduled for May 10, four days before Speaker's scheduled flight to Europe.

*Existing law.* Preparing for that meeting, Dr. Vernon and his colleague Eric Benning, director of communicable diseases for the Fulton County Health Department, knew they could do little more than try to persuade Speaker not to leave the country. State and local health departments were usually responsible for restricting the movement of infectious disease patients within state borders, but in the vast majority of cases forcibly imposing isolation or quarantine was not necessary because patients complied voluntarily. <sup>29</sup> Relying on a so-called "covenant of trust" with their patients, health officials explained the risks they posed to others, and patients usually adopted the measures to reduce those risks, such as avoiding public places or travel abroad.<sup>30</sup>

Cases in which infectious patients were, or seemed likely to be, noncompliant, were more complicated, and laws varied by state. In some states, including Georgia, isolation could be enforced only with a court order—which could only be obtained if the patient had already been demonstrably noncompliant. Doctors Vernon and Benning had consulted the Fulton County Attorney's Office and determined that a hunch that Speaker might be noncompliant in the future was not enough to justify issuing such an order. As Director of the Fulton County Department of Health and Wellness Steven Katkowsky later explained:

The way a lot of the laws are written is, action can't be taken until a violation has occurred. In other words, we can't be proactive. I can't look at somebody and say they might rob a bank. I have to wait until they rob a bank to then be able to take the necessary legal action... [Andrew Speaker] did not refuse treatment. He did not refuse to be tested. He had also not

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<sup>&</sup>quot;Tuberculosis and Air Travel: Guidelines for Prevention and Control," The World Health Organization, Second Edition, 2006, p. 6.

Ibid, p. 28.

US District Court For the Northern District of Georgia, "Andrew Harley Speaker V. United States Department of Health and Human Services Centers for Disease Control and Prevention," March 14, 2012, p. 3.

Although the terms were often used interchangeably, isolation technically referred to the separation of an infectious patient from the healthy population, and quarantine to the separation of someone known to have been exposed to an infectious agent but not yet sick.

Gerberding, Senate hearing testimony, p. 6.

violated the medical directive to not travel. So we found ourselves in a Catch-22 where the law provides for action to be taken after there's a violation, but not before in a preemptive way.<sup>31</sup>

Technically, the doctors had another option: contact the CDC to request that it issue a federal isolation order. But in practice these orders were extremely rare—the last one had been issued in a 1963 smallpox case. Federal isolation orders had not been used during the 2003 SARS outbreak, nor to restrict the movements of the over 100 MDR TB patients documented in the US in 2006. At this stage, such a request would have seemed like an overreaction. Better to follow the usual procedure and attempt to persuade the patient that voluntary compliance was in his own—and others'—best interest.

# The May 10 Meeting

As planned, on May 10 Dr. Benning and Speaker's personal doctor met with Speaker and his family to discuss treatment options and travel plans.<sup>33</sup> This time Speaker was joined by his father Ted, a personal injury lawyer and Vietnam vet, his fiancée Sarah Cooksey, and her father Robert Cooksey. The doctors explained Speaker's new prognosis.

It would take two to three weeks to get the lab results giving more details about his degree of drug resistance and which drugs could work for him. That should be enough time to secure a spot at National Jewish Medical Center in Denver, where they recommended he seek treatment. National Jewish was one of a handful of hospitals that performed surgery to remove portions of MDR TB patients' lungs, which might be a good approach in Speaker's case. So it looked like he could begin his new treatment in about three weeks. In the meantime, the doctors told Speaker, they would prefer he not travel.<sup>34</sup>

Speaker and his family pressed doctors on the question of his level of contagiousness: he had not been advised to take any precautions around family or coworkers. No one at the meeting was wearing a mask, which seemed to indicate that the doctors themselves were not concerned about contracting the illness. If Speaker was no threat to anyone, and his treatment—which promised to be long-term and grueling—would not begin for several weeks, what was the harm in following through with his long-planned weedding in the meantime?<sup>35</sup>

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Katkowsky, Senate hearing testimony, p. 46.

<sup>&</sup>quot;Public Health and Border Security," United States Government Accountability Office, Report to Congressional Requesters, October, 2008, p. 2.

Dr. Vernon did not attend the May 10 meeting.

US District Court For the Northern District of Georgia, "Andrew Harley Speaker V. United States Department of Health and Human Services Centers for Disease Control and Prevention," p. 3-4.

Andrew Speaker, testimony, "Cracks in the System: An Examination of One Tuberculosis Patient's International Public Health Threat," A Special Hearing before a Subcommittee of the Committee on Appropriations, United States Senate, Washington, D.C, June 6, 2007, p. 42.

The doctors emphasized that although Speaker was not *highly* contagious at the moment, there was a chance he could become more so, or that he could develop symptoms in the coming weeks—he had as yet received no effective treatment to prevent the illness from progressing. Moreover, should he become seriously ill while he was abroad, they could not guarantee the quality of his care.<sup>36</sup>

The meeting did not fully assuage the doctors' concern that Speaker might disregard their recommendation against overseas travel. Although Speaker had not stated his intentions outright, he had done little to mask his skepticism at their advice, and he had compelling personal reasons to ignore it. It was at that point that the doctors had decided to turn to the CDC for advice and sent their initial email to CDC Atlanta quarantine officer Dr. Kim.

Dead letter. As per Dr. Kim's suggestion, on May 11 the Fulton County health department mailed a letter to Speaker's home stating that

The Fulton County Department of Health and Wellness has been notified that you are planning to travel to Greece on May 14, 2007. As a precaution, it is strongly recommended that you postpone your travel and see a specialist in Denver, Colorado. In the event you do not comply with this recommendation, the Fulton County Department of Health and Wellness cannot be responsible for the exposure of this to the public. It is imperative that you are aware that you are traveling against medical advice.<sup>37</sup>

With their advice now in writing, they would have had grounds to ask a judge to sign off on an isolation order should Speaker take steps against it. But when they tried to follow up, it turned out that Speaker had not been present to receive that letter. Efforts to locate him over the next few days by contacting his home, his office, and his family all failed. Fulton County officials suspected he had moved up his departure date and left for Europe. Once again, they contacted Dr. Kim.

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Ibid. Speaker later disputed his doctors' version of events. He argued that what was actually communicated to him in the meeting, both verbally and nonverbally (meaning his doctors' apparent lack of concern that he might infect them), was that he was not contagious, period. Speaker's father had, in fact, tape recorded the meeting—a habit he attributed to mild hearing loss—and the tape corroborated, at least in part, Speaker's version: at least twice, Benning could be heard saying "you are not contagious." Source: "T.B. Traveler Tells His Side of Story," *Larry King Live*, CNN, June 6, 2007. See: <a href="http://transcripts.cnn.com/TRANSCRIPTS/0706/06/lkl.01.html">http://transcripts.cnn.com/TRANSCRIPTS/0706/06/lkl.01.html</a>.

Ted Speaker, Andrew Speaker's father, would later contend that Fulton County's efforts to locate Andrew's family around May 11-12 could not have been as exhaustive as they claimed because he was listed in the phone book and did not receive a call. He also argued that he was working in his office all day both days and although county officials knew where it was located—they had come there to test him for TB previously—they apparently made no effort to track him down there. Ibid.

# **Tracking Speaker**

On May 18, upon learning that Speaker had apparently left the country against medical advice, Dr. Kim and his CDC team joined forces with Fulton County to try to track him down. Delta Airline flight records showed he had not boarded his originally scheduled flight to Paris on May 14, nor any other Delta flight for three days before or three days after. The health officials knew he was probably in Greece, but beyond that they had little to go on. They had some contact information for Speaker's family, but this was also a dead end: like Speaker, they appeared to be out of the country, perhaps attending the wedding.

On May 19, Dr. Kim learned that Speaker's intended father-in-law was actually a CDC employee. By coincidence, Robert Cooksey, who had been present at the May 10 meeting between Fulton County doctors and Speaker's family, was a microbiologist specializing in tuberculosis. He had been dismissed early on as the source of his son-in-law's illness because he was routinely tested for TB but had never returned a positive result. On May 21, after other efforts to find Speaker had failed, Dr. Kim left Dr. Cooksey a message expressing the CDC's concerns about Speaker's health and overseas travel, and urging Speaker to be in touch. <sup>39</sup>

With as yet no word from Speaker or his family, on May 22 Dr. Kim learned that Speaker's diagnosis had changed yet again. Earlier that day, the CDC's Dr. Beverley Metchock, who had overseen analysis of the sample from Speaker's April 25 bronchoscophy at a CDC lab, had issued a preliminary report stating that Speaker's TB was not just multidrug-resistant as previously thought, but extensively drug-resistant (XDR TB).

Another diagnosis. XDR TB was an extreme form of MDR TB in which the bacteria was resistant to the most effective first- and second-line drugs. Although transmitted in the same way as other forms of TB and not necessarily more contagious—as with less drug resistant TB, contagiousness varied greatly by patient—since XDR TB was so challenging and expensive to treat it was considered an even greater public health threat. In 2006, reported mortality rates among non-immunocompromised patients with XDR-TB were 70 percent—roughly the same as for regular TB before antibiotics were developed to treat it—with most dying within the first five years. Those rates were even higher and death quicker for patients with compromised immune systems.

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Ibid.

US District Court For the Northern District of Georgia, "Andrew Harley Speaker V. United States Department of Health and Human Services Centers for Disease Control and Prevention," p. 6.

In 2009, a CDC task force estimated average hospitalization costs for an XDR-TB patient at \$483,000, approximately twice what it cost to treat an MDR-TB patient. Source: Philip LoBue, Christine Sizemore, and Kenneth G. Castro, *Plan to Combat Extensively Drug-Resistant Tuberculosis Recommendations of the Federal Tuberculosis Task Force*, MMWR Recommendations and Reports, Centers for Disease Control and Prevention, February 13, 2009. See: <a href="http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5803a1.htm?s\_cid=rr5803a1\_e">http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5803a1.htm?s\_cid=rr5803a1\_e</a>.

By executive order of the President, US citizens believed to have one of several communicable diseases, including infectious TB, could be isolated when attempting to re-enter the country, and infectious non-citizens denied entry altogether. In light of Speaker's new diagnosis, Dr. Kim asked officials at the Atlanta Field Office of the Department of Homeland Security's Customs and Border Protection (CBP) agency to flag Speaker in their TECS database, a computerized inspection system used to identify individuals for detention at the border. If Speaker tried to re-enter the US at any point of entry, upon scanning his passport CBP officers would see a notification that Speaker had XDR TB, was a public health risk, and should be detained in a well-ventilated room until public health officials could be contacted.

#### What next?

Later that same day, May 22, Robert Cooksey returned Dr. Kim's phone call. It turned out that Speaker had, in fact, moved up his departure date from May 14 to 12. He had also switched airlines and taken an Air France flight to Paris, where his wife, following their original Delta itinerary, had met him two days later. The couple had traveled together to Greece and gotten married in a small family ceremony in Santorini<sup>44</sup>. They were now on the first stop of their honeymoon, Rome, and planning to take a train to Florence the following day.

Dr. Kim explained to Cooksey it was imperative that Speaker be in touch with him: his TB was more serious than previously thought, he had been put on a CPB watch list, and they needed to discuss his treatment and travel options. Cooksey agreed to relay this information in an email to his new son-in-law. Speaker quickly contacted the CDC. He and Dr. Kim had the first of two phone conversations on what was the afternoon of May 22 in the eastern US—and 12:30 a.m. May 23 in Rome.

Dr. Kim explained what the new diagnosis meant for Speaker's treatment and prospects for recovery. Again the two discussed his level of contagiousness. As Dr. Kim explained, the new diagnosis did not necessarily indicate that Speaker was more contagious than before, but since the lab sample used to make the diagnosis was from a month earlier and Speaker had received no treatment, the disease *might* have progressed in the meantime, meaning Speaker might be both more infectious and sicker. Only new tests could determine that. For now, he should cancel his

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The list of communicable diseases authorized in 2007 by Executive Order of the President for federal isolation and quarantine included cholera, diphtheria, infectious tuberculosis, plague, smallpox, yellow fever, viral hemorrhagic fevers, SARS (severe acute respiratory syndrome), and influenza that could potentially cause a pandemic. For further details see the National Conference of State Legislatures website, see <a href="http://www.ncsl.org/issues-research/health/state-quarantine-and-isolation-statutes.aspx">http://www.ncsl.org/issues-research/health/state-quarantine-and-isolation-statutes.aspx</a>, or the website for the CDC's Division on Global Migration and Quarantine: <a href="http://www.cdc.gov/ncezid/dgmq/">http://www.cdc.gov/ncezid/dgmq/</a>.

Deborah J. Spero, Deputy Commissioner, United States Customs and Border Protection, Department of Homeland Security, testimony, "Cracks in the System: An Examination of One Tuberculosis Patient's International Public Health Threat," A Special Hearing before a Subcommittee of the Committee on Appropriations, United States Senate, Washington, D.C, June 6, 2007, p. 26.

See: http://www.nytimes.com/imagepages/2007/06/02/us/02tick CA1.ready.html

travel plans and remain in Rome until the CDC could figure out how to proceed; under no circumstances should he take a commercial flight.

It was Dr. Kim's impression that Speaker was alarmed at this new diagnosis and eager to cooperate. The conversation ended with Dr. Kim instructing Speaker to call again the following day for further instructions. In the meantime, the CDC would research chest hospitals in Rome and short- and long-term options for bringing Speaker home on a non-commercial flight. <sup>45</sup> Speaker agreed to cancel his travel plans and reserve another night in the hotel.

Speaker's account was a bit different: he would later contend that in that first phone call, he was told that while the new diagnosis changed his treatment options, his level of contagion had not altered, and that he was no greater threat to his wife or anyone else than before. It was his understanding that the CDC was making arrangements to fly him home, which they would communicate to him by phone the following day.<sup>46</sup>

# What to do with Speaker

There was no official CDC procedure for what to do with a patient under these circumstances. According to State Department policy, citizens were responsible for their own transportation home if they had a medical emergency abroad, including an infectious disease. But as CDC Director Julie Gerberding recalled, "we felt in this situation, since he was not only a risk to himself but a risk to other people, that we really should try to see if we could do something to facilitate and help him get home." With a second phone call scheduled for the following day, Dr. Kim and CDC staff researched their options.

One by one, the alternatives proved impracticable. Speaker's insurer would not cover the cost of an air ambulance. The CDC did have two leased airplanes, but these were not equipped to isolate patients with respiratory illnesses, essential on such a long flight, and there was no way to quickly reconfigure them to do so. The US military was another option: it had an isolator it could roll on and off its planes, but a military transport could not be arranged in a timely way. Moreover, this would be expensive, it had not been budgeted for, and how the CDC would reimburse the Department of Defense for it was not immediately clear.

It seemed increasingly likely that Speaker's best option would be to seek treatment in Rome—or to arrange and pay for his own private transport. Dr. Kim's team contacted Dr. Nancy Binkin, a former CDC employee now working at the Italian Ministry of Health. Dr. Binkin was a

Dr. Julie Gerberding, Senate hearing testimony, p. 7.

<sup>46</sup> US District Court For the Northern District of Georgia, "Andrew Harley Speaker V. United States Department of Health and Human Services Centers for Disease Control and Prevention," p. 7–8.

Gerberding, Senate hearing testimony, p. 7–8.

<sup>48</sup> Ibid., 8.

TB expert, familiar with the chest hospitals in Rome. If necessary, she was on standby to go to Speaker's hotel to speak to him in person.

On May 23, late in the afternoon in Rome and mid-day in the eastern US, Speaker called Dr. Kim again, as previously arranged. Dr. Kim explained that the CDC had exhausted all its options: they simply did not have the resources to bring Speaker home. He would need to either finance a charter flight himself, which they estimated would cost \$140,000, or voluntarily check into a hospital in Italy to receive treatment there. Dr. Binkin would come to his hotel room the next morning to discuss his options.

Speaker was alarmed and upset. He would later contend that the seriousness of the illness, and the possibility that he was now contagious, was not communicated to him in the second phone call—that Dr. Kim even told him he should feel free to leave his hotel and have dinner in a restaurant as he contemplated his options. <sup>49</sup> Speaker also later said that it was his understanding that not a former CDC official, but Italian authorities, would be coming to his hotel room the next morning to take him into quarantine. <sup>50</sup>

Gone, again. At 4 a.m. EST the next morning, May 24, Dr. Kim heard from Dr. Binkin. She had gone to Speaker's hotel that morning as arranged, but Speaker and Cooksey had checked out and were gone. Dr. Kim immediately notified his superiors.

The CDC activated its Director's Emergency Operations Center (DEOC), a centralized office that responded to serious public health threats, to coordinate efforts to track, isolate, and deliver Speaker back to the US. Among first steps, they contacted the director of communicable disease control in Italy, as well as the Transportation Security Administration (TSA), an agency within the Department of Homeland Security, to request that Speaker be put on a no-fly list to prevent him from boarding a US-bound commercial flight.

#### Action plan

On May 25, 2007, the Friday before Memorial Day weekend, with Speaker's whereabouts still unknown, CDC officials from media relations and the Division on Global Migration and Quarantine held a conference call to discuss next steps. Speaker had been informed that his best chance for successful treatment was in Denver, and he had seemed understandably worried for his health on the phone. Most likely, he would try to re-enter the country soon.

When he did, what, exactly should be done with him? Did the case warrant the first issuance of a federal isolation order since 1963? Or would a covenant of trust—voluntary

US District Court For the Northern District of Georgia, "Andrew Harley Speaker V. United States Department of Health and Human Services Centers for Disease Control and Prevention," p. 8.

Conant, "His Side of the Story."

cooperation—now be the best approach, given that Speaker would likely be eager to receive treatment? In any case, once he did reappear, how should he be isolated and transported?

Officials also had to quickly develop a communications strategy. They anticipated intense media interest in this case, especially if a federal isolation order was issued. Moreover, the airline had not yet been able to provide a passenger manifest, and talking to the press could help the CDC locate those who had been exposed to Speaker and who should now be tested for TB.<sup>51</sup> At the same time, that was a very small number of people and it was entirely possible that Speaker had infected no one; inducing unnecessary panic would be irresponsible. CDC policy when communicating with the media was to protect patients' names and to provide only as much information as was essential for public health purposes.<sup>52</sup> But what exactly constituted essential information in this case?

Going public would also mean tough questions from citizens and their representatives. Speaker's experience had exposed weaknesses at various stages in the public health system; these would have to be identified and addressed. Could CDC and Fulton County officials have communicated more effectively with Speaker to better protect his own and the public's health? Once he had gone missing, could agencies and officials have responded more productively?

They would not have long to reflect before putting their plans into action. That evening, Dr. Martin Cetron, director of DGMQ, heard from the Department of Homeland Security: Speaker and his new wife had boarded a commercial Czech Airlines flight in Prague the day before, and eluded the TSA no-fly list by flying into Canada. There they had apparently rented a car and driven to the border.

The TECS system showed that their passports had been scanned at the US point of entry at Champlain, New York at 6:18 p.m. on May 24. But to Dr. Cetron's dismay, the CBP officer at the border had apparently disregarded instructions to detain and isolate Speaker, and instead allowed him simply to pass into the country. The CDC would have to take immediate action, before Speaker further endangered himself or others.

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US District Court For the Northern District of Georgia, "Andrew Harley Speaker V. United States Department of Health and Human Services Centers for Disease Control and Prevention," p. 12.

Ibid.