University of Rhode Island
DigitalCommons@URI

Senior Honors Projects | Honors Program at the University of Rhode Island

5-2012

The End of Nowhere: The History of Tuberculosis in RI

Emma G. Sconyers
University of Rhode Island, e_sconyers@my.uri.edu

Follow this and additional works at: http://digitalcommons.uri.edu/srhonorsprog

Part of the Bacterial Infections and Mycoses Commons, Bioethics and Medical Ethics Commons, Community Health and Preventive Medicine Commons, History of Science, Technology, and Medicine Commons, Nonfiction Commons, Other Public Health Commons, Social History Commons, and the Women's History Commons

Recommended Citation
Sconyers, Emma G., "The End of Nowhere: The History of Tuberculosis in RI" (2012). *Senior Honors Projects*. Paper 294.
http://digitalcommons.uri.edu/srhonorsprog/294

This Article is brought to you for free and open access by the Honors Program at the University of Rhode Island at DigitalCommons@URI. It has been accepted for inclusion in Senior Honors Projects by an authorized administrator of DigitalCommons@URI. For more information, please contact digitalcommons@etal.uri.edu.

The End of Nowhere

By: Emma Sconyers

The knock at the door was sharp, resounding into the small home. Ivy, heavy with her second child, gently shushed the small toddler screaming with laughter, padding back and forth across the kitchen floor. Her husband rose from the kitchen table to answer the door.

"Hello, can I help you?"

"Are you Joseph O'Neill?"

"Yes," he replied bluntly, "what's the matter?"

"Mr. O'Neill you've tested positive for tuberculosis. You'll have to come with us right away."

"This very moment?"

"Yes, right now please."

While others were marching off to face the Second World War, my great-grandfather Joseph marched off into quarantine. It would be two years before he saw his wife or children again. He'd been forcibly taken to Rhode Island's state sanitorium, Wallum Lake. A place his sister in law, Edna, would forever refer to as "the end of nowhere".

Tuberculosis, an infection due to *Mycobacterium tuberculosis,* has been a documented human disease since antiquity. It is now curable with antibiotics; however, prior to the 1940's this disease was considered an incurable, chronic affliction. Before Robert Koch's 1882 discovery of the bacterium that caused tuberculosis, society had a very different understanding of the disease. From antiquity until the very end of the 19th century tuberculosis was referred to as "consumption," a catchall phrase for any wasting disease affecting the lungs. This might include

ailments such as lung cancer, emphysema, severe asthma, or bronchitis. Consumption was referred to as the "Universal Disease"[1] since it seemed to spare no one—rich, poor, black, white, man, woman, or child. In the 18th and 19th centuries, consumption was regarded as a romantic disease. Beyond the status of "ill" calling someone a consumptive could mean they felt sensual and artistic. It was more than a disease of the body; it was a disease of the spirit.[2] However all that changed with the advent of the germ theory.

Look at the language used in the poem "Consumption" by the American poet and longtime editor of the New-York Evening Post William C. Bryant:

Ay, thou art for the grave; thy glances shine
Too brightly to shine long; another Spring
Shall deck her for men's eyes---but not for thine---
Sealed in a sleep which knows no wakening.
The fields for thee have no medicinal leaf,
And the vexed ore no mineral of power;
And they who love thee wait in anxious grief
Till the slow plague shall bring the final hour.
Glide softly to thy rest then; Death should come
Gently, to one of gentle mould like thee,
As light winds wandering through groves of bloom
Detach the delicate blossom from the tree.
Close thy sweet eyes, calmly, and without pain;
And we will trust in God to see thee yet again.

Written in the mid-1800's, this poem romanticized the symptoms and inevitable death of the consumptive. Other poems, such as Keats' "Ode to a Nightingale" were less direct in their soft, consumptive imagery. For example, in "Ode to a Nightingale" Keats writes, "Youth grows pale and spectre thin". It's hardly shocking that Keats himself died of tuberculosis at the age of twenty-six, most assuredly pale and thin as a ghost. Fellow poet and close friend of Keats, Lord Byron, explained the compelling physical symptoms that so many wished to attain, "I look pale…I should like to die of consumption—because the ladies would say 'Look at poor Byron, how interesting he looks in dying." Dumas, best known for his novels *The Three Muskateers* and *The Conte of Monte Cristo*, reflected on this fad from the mid-19th century, "It was the fashion to

suffer from the lungs; everybody was consumptive, poets especially; it was good form to spit blood after each emotion and to die before the Age of thirty."

Compare the soft, poetic imagery of these 19th century writers to the description of a reduced and corrupted tuberculosis patient in a 1911 Hospital Commission:

> *Homeless, friendless, dependant, dissolute, dissipated, and vicious consumptives are those which are likely to be the most dangerous to the community. If not cared for at an institution, they wander from place to place, frequenting saloons, lodging-houses, sleeping in hallways or whatever can be found. Negligent as to the disposal of their expectoration, they disseminate infection in every place which they visit. Such cases must be provided for by the sanitary authorities at any cost, and if necessary they must be forcibly removed to proper institutions and there detained.*[3]

The shift from delicate, swooning victim to incompetent lout, a harbinger of disease and despair, reinforced the necessity of the tuberculosis sanitoria. Although started as "health spas," sanitoria would eventually become medical isolation units, removing consumptives from their friends, families, and the rest of society for months or even years. Many of those who entered never made it out alive.

The physician Hermann Brehmer opened the first tuberculosis sanitorium in 1863 in what was then Prussia, now Sokołowsko, Poland. The high altitude and the clean, crisp, forest air were meant to give patients relief from their ruined lungs when few other treatments were available. In the United States a New York doctor named Edward Trudeau experienced the healing powers of a mountaintop environment when he went on an excursion into the Adirondack Mountains. A consumption sufferer himself, he found that the mountain air improved his breathing, but when he returned to his practice in New York City he almost immediately reverted to a wheezing, consumptive state. Convinced it was the fresh air that had relieved him, Dr. Trudeau made

Saranac Lake his permanent residence in 1876. Taking a cue from Brehmer, whom he researched in 1882, he opened "Adirondack Cottage" on Saranac Lake in 1885.[4] The model for the sanitarium was a hotel-like atmosphere meant as a health spa which allowed for ailing tuberculosis patients to escape the smog-filled cities. The Adirondack Cottage opened just three years after Koch had discovered the tuberculosis bacterium, which was slowly transforming the way Americans viewed disease.

As the understanding of disease shifted to something to be "caught" from bodily excretion and not merely a byproduct of bad air or unlucky inheritance, doctors and public health experts across America clamored for better sanitation. Within just a few decades the human body became a polluter, capable of spewing thousands of "germs" by simple shaking hands, spitting, or sharing a cup. The ill, in the public's view, were now sickly, rotting entities waiting to explode. They were to be feared, quarantined, and demoralized for their effects on public health.[5] Providence, Rhode Island, along with New York City, were the first cities in the country to actively involve city health officials to quell the spread of tuberculosis. Charles V. Chapin of Providence, considered the "Dean of City Health Officials," latched onto Koch's discovery and demanded changes in public health not only in Providence but across Rhode Island. As early as 1890 Chapin rallied for a bill giving the Board of Health the right to inspect and destroy cattle harboring the tuberculosis bacterium. Bovine tuberculosis was transmissible to humans through milk, which was sorely under-regulated at the turn of the century. This was one of the earliest laws in the United States mandating tuberculosis control. [6]

The obvious threat Chapin identified in milk production is intermingled into the story of my great-grandfather. Though my great-grandfather Joseph O'Neill would not be diagnosed with bovine tuberculosis, the Bovine strain affected his life from an early age. When Joseph was quite

young in the 1910's, he lost two siblings to the Bovine TB. His two older sisters, twins, died when they were "quite young" from the zoonotic pathogen. Bovine-tuberculosis, probably ingested from infected milk, had wasted their tiny bodies out of this world and out of the minds of their family. My grandmother explained she didn't find out until later he had even had sisters, much less ones who died from tuberculosis. "When he was growing up his family wouldn't speak of it," she said.

Although Chapin and other public health experts launched campaigns to improve the safety of milk in Rhode Island, other means of transmission remained in place. In the fifth ward, where Joseph grew up and eventually started his little family, the houses were close and crowded. Large, Irish families intermingled and socialized with each other, creating the perfect environment for spreading the deadly bacterium. Unfortunately the same disease that had killed his sisters years before would settle on the young sheet metal worker's lungs, burrowing and blooming into virulent tubercles.

In 1909, coincidentally the same year Joseph was born, the Rhode Island State Board of Health was "required to keep a register of all persons affected with tuberculosis without disclosing personal information. If the information is not provided to the secretary of the State Board of Health within 48 hours the superintendant or other person in charge will be fined no more than $25.^{00}" [7] Chapin had resisted supporting this bill earlier because he recognized the difficulty of carrying out the actual regulation. In years to come, this problem of under-reporting cases would balloon out of control, but for the time being the new state-wide regulations gave the appearance of a state health board hard at work to combat dangerous consumptives.

Cows were not the only thing to pass along the disease. Koch's discovery of the tuberculosis bacterium had created a need for patient control. As the Board of Health soldiered

on establishing anti-TB associations and pushing public-hygiene initiatives, Rhode Island doctors worried it wasn't enough. Dr. Jay Perkins, M.D., of Providence addressed the Rhode Island Medical Society in an 1898 meeting,

> *With intelligent patients it is very easy to carry out the destruction of the sputum. Among the ignorant it is not. Therefore there should be hospitals for such persons, equipped with modern improvements for treating the disease, and, when necessary, isolate them as insane patients are isolated, for they are more dangerous than most insane patients. And not only are they dangerous to others, but also themselves, for one recovering from tuberculosis may again become infected by T.B. inspired in infected air. Most persons once understanding the danger to their friends are ready to carry out almost anything asked.*

The language had shifted in the 16 years since Dr. Trudeau opened his health spa in the Adirondacks. No longer were patients merely sent away on "vacations" to a "health spa" to regain their strength, they were now considered "dangerous to others [and] also themselves." They should be "isolated as insane patients are isolated." Tuberculosis patients, particularly "ignorant" ones, should be locked away and quietly disposed of until the disease went into remission or they passed on. Consumptives were an abomination, a dangerous problem. Dr. Perkins' call for a separate tuberculosis hospital did not go unheard.

Across Rhode Island small scale tuberculosis institutions began to sprout up at the turn of the century. In 1896 the state almshouse in Cranston, RI began treating tuberculosis patients. In North Scituate the Pine Ridge Camp opened in 1904 with a capacity for 30 patients. The St. Joseph's Hospital annex in Hillsgrove opened in 1905 to house mainly the incurable cases. A "seaside hospital" for children with tuberculosis was established in 1907 in East Greenwich as a branch of Rhode Island Hospital.[8] All of these small institutions were set up by local authorities as public health remained primarily in the hands of municipal governments. Notably, the first

state institution for tuberculosis care was the Wallum Lake State Consumptives Sanitorium. This facility admitted its first patient on November 6th, 1905. The patient, George Barrows, would die at the sanitorium a year and a half later on June 4th, 1907. [9]

Following previous sanitorium protocols such as The Adirondack Cottage, the Wallum Lake Sanitorium was constructed at 750 feet above sea level, the highest point in the state. The grounds lay in Burrillville in the extreme northwest corner of Rhode Island—close to the Connecticut state line. Two-hundred and fifty acres of woods surrounded the hospital which overlooked its namesake Wallum Lake (meaning "fox lake" in the native Quinebaug language).[10] It was originally designed to hold 120 patients in separate wards. The ward buildings were purposely arranged so that more could be added in the future. Its estimated cost of construction was $150,000.[11] Once those walls were up, it was only a matter of time before the lives of consumptives came crashing down.

The combination of germ theory and the isolated, "fresh air" regions where sanitoria were built led to a striking shift from an idealized health resort to an institution. Before the hospital was built in 1910, [12] the buildings were labeled as "wards", as if they were running some sort of prison or detention center. Illness had become a label which necessitated social control. When patients were taken there was a loss of identity. No longer were they businessmen, journalists, or mothers, suddenly they were like inmates. In a way, tuberculosis never ceased being a universal disease. Meticulously kept records at Wallum Lake show six blacks in residence in 1913, unsegregated as far as records show. There was a near 50:50 ratio of men to women. There were 98 married couples, 146 singles, 14 widowed and 14 separated or divorced. Patients came from all walks of life. The cost to stay there a week was $15.00; however, there was a fund in place from the trustees for deserving cases. The only stipulation for going there was that you had to be

a Rhode Island resident.[13] By all accounts these were normal, everyday people. Less than fifty years prior, being a consumptive was lovely and artistic. With "modern technologies" society simply developed a proclivity to label the ill as dirtied and diseased, something less than human.

Distance was another factor in stigmatizing patients. Wallum Lake was in a remote, hard to get to area in Rhode Island. Even today anywhere more than a thirty minute drive is labeled a hassle by Rhode Islanders. Without a car, which were not widely available until WWI, it was nearly impossible to schedule visits to see family members or friends living inside the tuberculosis wards. As we learn from the Annual Reports, the sanitorium had two visiting days—Sundays and Thursdays. The trains ran at 8:40am and 4:10 pm Mondays through Saturdays. On Sundays the train left at 9am and 7:20 pm. However, the train stopped a few miles from the sanitorium itself and staff would only drive out to meet visitors at the train station Mondays and Thursdays.[14] That being said, these constraints limited patients' family and friends to Thursdays between 8:40 and 4:10. The timeframe would have severely limited anyone working a fulltime job with normal hours during the week. Essentially, the sanitorium policy made visiting difficult and minimal.

With severely limited contact to the outside world, patients had to make do with those around them. The sanitorium tried to offer patients ways to amuse themselves. In the 1940's a movie theater was installed, as well as a small duckpin bowling alley[15]. As early as the 1920's there was a growing library, lessons for children in "handcrafting", and an outdoor excursion group for young boys called the Tyee Club. Women were encouraged to join the lace making circle that generated revenue for the hospital, gardens were propagated, correspondence courses in automobiles or agriculture taken; one man even learned boat building from one of the hospital staff and created a rowboat for the lake. At first glance, it seems as if the staff's top priority was

making this socially isolated place a fun and stimulating environment. However, one only has to read comments from one of the social workers there to see the patients were somehow less than people. “The greatest problem in the work of this kind is to get the patients to work together, to forget their own little selfish interests and to interest them in the welfare of those with whom they are living not by choice but by necessity.”[16] Being forced to abandon your friends and family, your life as you know it, hardly seems like a “little selfish interest”.

It wasn’t necessary to isolate these individuals. In 1907, coincidently the same year Wallum Lake opened, Dr. Mary Packard, the first woman to graduate from John Hopkins Medical School, and her colleague Dr. Ellen Stone, opened an “open air school” in Providence. With the help of Dr. Perkins, the previously mentioned Dr. Chapin, Judge Ruckert and Dr. Stone’s husband, a large brick horse shed at the Friends’ Meeting house on North Main Street was converted into a series of classrooms. All were equipped with floor to ceiling windows constructed to open completely with a pulley system so that the children would always be in the fresh air. What started as an experiment with ten children soon grew to twenty-five children, the maximum number of students allowed at an “ungraded school”. The school for consumptive children lasted from 9a.m.-2p.m. There was a large outdoor garden, prolonged recess activity, and a great deal of filling, nourishing food to eat such as rice pudding and beef stew. Students weren’t taught advanced arithmetic or grammar, their days consisted of hygiene lessons such as no spitting, don’t put pencils in your mouth, wash hands often and *always* before meals, and never, ever wipe your nose on your sleeve. The focus was to nurture these children back to health close to home. The incredible thing was almost all the students improved, and some went into complete remission. A colleague, Dr. Swarts, wrote to the founders of the school suggesting

that all of Providence schools implement their techniques. He said, "All these things, small and unimportant as they may seem, lead in the right direction."[17]

Dr. Packard's and Dr. Stone's little experiment produced positive, conclusive outcomes for children with tuberculosis. However, none of their work was reproduced on a large scale in Rhode Island. It took two strong willed, creative women thinking outside the box to come up with a new way to treat consumptives. The children in their care weren't carted away; instead they spent five hours of their day in a healthy environment on the hills overlooking downtown Providence. There were precedents for treatment that didn't involve isolation, so why weren't open air buildings and programs implemented for all consumptives, young and old? It may have been because it was simply easier to lock them away. The discourse of "school" was perhaps too positive for the "homeless, friendless, dependant, dissolute, dissipated, and vicious consumptives" wandering the streets of Rhode Island. Better to concentrate them in an institution where they would be removed from society, away from the "normal", healthy folk. It was preferable to send them away out of sight, out of mind.

Wallum Lake was a state run facility, and anyone from Westerly to Woonsocket went there if they couldn't afford higher-end private institutions like Trudeau's on Saranac or the dozens in Colorado or Arizona. However, oddly enough, it wasn't the state that oversaw tuberculosis control. Rhode Island town health departments dealt with it individually. Obviously industrial cities with the highest TB incidence numbers such as Providence or Pawtucket had a much more difficult time dealing with the disease[18] than other small communities such as Wickford which didn't even mention it in their reports. [19] However, it was towns somewhere in between like Newport that struggled with roadblocks and sticky politics concerning tuberculosis

control. Indeed, Newport provides a compelling case study of the evolution of tuberculosis control and illuminates the often insensitive, callous treatment of patients.

The only state mandated law concerning patients was Chapin's 1909 bill to make all cases reportable to the state. In 1917, Newport physicians reported 31 tuberculosis cases, all resulting in death. The Newport Board of Health pointed out in its annual report to the city that this could not possibly be a realistic number of those with tuberculosis. If the only numbers they had were deaths, how many unreported or unknown active-cases were wandering around the city possibly infecting people? "The progress that might reasonably be expected in the control of this disease is not evident; in spite of the good work being done by the Newport Hospital and the Newport Association for the Relief and Prevention of tuberculosis," the board concluded, "an improvement cannot be looked for until some means of segregation is provided in this city." [20] The Board of Health began a decades long plea to the city of Newport for the development of a modern program. According to the report, "cases of tuberculosis are now cared for by a private institution under contract with the City."[21] This is the first time in many years to come that the Newport Board of Health asks the city for control. They ask again nearly a decade later in 1928[22]. Somehow, whether the Newport town officials were too busy or just didn't care, a twenty year stalemate dragged on while the Board of Health repeatedly fought for a better plan of action.

1928 would also be the first time they put in a request for a public health nurse, to screen and prevent cases of tuberculosis from becoming severely debilitating. The fact that the board wanted a designated, trained nurse out in the field focused on finding new cases shows that Newport Board of Health understood the importance of prevention or at least early intervention. The Public Health Nurse wouldn't be hired until 1951[23]—twenty-four years later. The Board of

Health wanted to do something; they just couldn't get the support to go in and change the elementary plan of sending people away or let them wander the streets undiagnosed. There was no program for control; just an extreme solution to a problem the city had no way of preventing.

In 1935, amidst The Great Depression, the Newport Hospital somehow obtained $500 that was allocated to screening juniors and seniors at the local High School with a pulmonary x-ray. [24] 25 % of them were shown to have healed from or were currently affected with tuberculosis lesions. There was no discussion of detention or removal of the 25%, only that the Board was pleased the students had been identified as sufferers of tuberculosis early on. The $500 yearly funds were pulled—unsurprisingly given it was the middle of the Depression. However, the Board of Health continued to laud the early intervention strategy of that 1935 high school screening and begged for the annual $500 screening allowance. They got no response from the city. As they said in 1942, a few years later, again repeating their request for tuberculosis control and a prevention campaign, "up to the present time, there has not even been an acknowledgment of this request". [25]

In 1938, the Newport Board of Health wrote, "Control measures should be strengthened and not relaxed. Definite legal power should be granted to isolate all open cases in approved sanitoriums." Oddly, the report from that year did not contain a request for tuberculosis control to be granted to the Board of Health; they only wanted stricter measures of containment. This seems to be the only request from the Board of Health with which the city followed through. Perhaps it was because it required little commitment and no further official positions to appoint—it was a request that could be carried out by the already standing "private contractors" employed by the city. Because the city documents are so opaque, looking at personal experiences gives us insight into what happened after that request.

In 1939, my great-grandfather, Joseph O'Neill, was only twenty-nine when he was wrenched from his home in Newport. In January when he was dragged away he left behind his little house, a pregnant wife, and a toddler—my grandmother Sheila. As she remembers it, "My mother never said a word about it. It was tough for her. It's hard…because you could ask my mother a question and she'd answer it but she would never sit down and talk about it. From what she said there was never any of that dramatic stuff. She didn't jump up and wail and yell for them not to take him. She just sat there speechless, pregnant, with me running around the house." During this period they lived down on Lee Street, off of lower Thames which at the time was one of the most densely populated areas of Newport. When she was older my great-grandfather would stop at the old house on their Sunday drives after church and point, "That's where you and Mama and little Jimmy lived when I was gone away all that time at Wallum."

The willingness of the City of Newport to comply with the Board of Health's request for "strengthened control measures" might have been attributed to the overall drop in tuberculosis cases across the country. [26] Tuberculosis no longer seemed like such a sweeping plague and the decreasing number of patients who had it could be easily quarantined. And without a major prevention plan as the Board of Health repeatedly requested, the handful of identified patients were taken away from their homes. It seems unlikely a city would send away one hundred or two hundred people, but the removal of a few citizens, especially a working class Irishman surrounded by the stigma of being "a consumptive," probably didn't put a dent in the conscience of the city.

Joseph was taken in the winter of 1939 when his wife Ivy was five months pregnant. Not only was his life put on hold because of his illness, but Ivy's was deeply affected as well. Without any warning her life was ripped out from under her. With no aid provided or help from

the city or the state she relied on her sister and father to help pay the rent and buy groceries. The harrowing bumps in the road didn't end there though: soon after Joseph was taken Ivy found herself begging for the life of her unborn child.

In 1936, just two years before Ivy was subjected to this treatment, an obstetrician-gynecologist by the name of Dr. Frederick J. Taussig published a treatise that would be considered the authority on therapeutic abortions for decades. Abortion was illegal in the United States at that time ; however, with a specific problem and a physician's consent women were able to abort their pregnancies. Some legal reasons included rape victims, the mentally handicapped, girls under sixteen years of age as well as women with "burdensome household responsibilities". Single widowed or divorced women were not allowed abortions simply because they didn't want to bear a bastard child. Married women were also denied abortions for family planning reasons or a desire to hold a job over raising a family.[27] All reasons Taussig outlined for or against abortion were strictly moral judgments which removed a medicalized procedure out of medical discourse. It's odd then, that tubercular women were allowed the right to abort.

Surprisingly, Taussig recommended women with active tuberculosis undergo abortions. From a medical standpoint the baby would put a great deal of strain on an otherwise weak patient, thus exacerbating the tuberculosis. However, there were other factors that merited a therapeutic abortion for a consumptive. Taussig explained an abortion for a consumptive, "is intimately bound up with the socio-economic status of the patient."[28] This judgment relates back to Taussig's reasoning for healthy patients gaining abortion—the "burdensome household responsibilities" argument. For an impoverished woman the stress of another baby would be as detrimental to the rest of her family's health as it would be to herself. Is this rationalization the reason my great-grandmother Ivy was subjected to an abortion panel? Her family, already

considered economic lower-class, had gained the strain of losing its sole bread-winner. Instead of helping this destitute mother to be, physicians forcibly tried to abort her unborn child for her own benefit. When considered, the removal of the fetus parallels the removal of the tuberculosis patient, with more dire consequences.

It also seems heavily steeped in the practice of Eugenics, which was gaining a strong foothold in America during the 1930's. The forced sterilization of so many poor or "low IQ" citizens during the Eugenics movement mirrors the forced abortions and detainments of tubercular patients. The significance of the phrase "ignorant consumptive" becomes all the more harrowing when you consider panels that deemed perfectly average adolescents "mentally retarded"[29]. When all these practices are considered, the disregard of a patient's feelings, thoughts, or opinions, physicians' philosophies start to look less caring and more "doctor knows best". The "patient" is merely an object to be tossed by wayside or disposed of if it seems more practical.

According to my grandmother, the doctors who had screened Joseph were worried about the effects of an active tuberculosis diagnosis on his unborn son. They wanted to abort the child because they didn't know what the bacteria might be doing to the baby, *despite the fact that Ivy was negative for the bacteria*. The fact that she wasn't even a consumptive further demonstrates the Eugenic-like treatment of otherwise healthy patients. Ivy went before a panel of doctors at Newport Hospital and tried to convince the doctors to let her keep the baby. Imagine the fear and distress a young, fiercely Catholic woman must have felt at the thought of a panel of doctors murdering her baby boy. They finally decided she was too far along for them to safely abort the fetus, but Ivy believed the stress caused ripple effects. Ivy, who saw her son grow up to develop

schizophrenia later in life, swore he could hear all that. She accredited his mental problems to the doctors' easy dismissal of his life. Something like that would drive anyone mad.

Joseph, like his wife, didn't speak much to his daughter about his years spent at Wallum Lake. "Except that he got to read a lot," my grandmother explained. "he didn't get to read much at home even though he loved books. It was the Depression after all. But luckily he had a job so he was always working. He was a very hard worker." While at Wallum surgeons removed a part of his lung, a common treatment at the time. My grandmother explained, "I never knew if he was being serious about that or not. He'd tell me they took a chunk of his lung and my mother would just shake his head." It's likely they did remove a piece of the infected lung. Before the advent of antibiotics doctors basically cut out or tried to squash the infection. They'd slice out pieces, entire lobes, or entire lungs to try and rid patients of the bacteria. A popular method called "collapse therapy" flattened the lungs with pressurized air, gobs of cotton, or in some cases a rib cage filled with ping pong balls[30]. Joseph was probably lucky he walked away with only a chunk missing.

My Uncle Jimmy and Grandmother Sheila were tracked all through school to make sure they didn't develop tuberculosis. With the advent of a more rigorous TB control program after WWII, the Newport Board of Health put much of its energy into preventing the disease rather than just seeking out infected individuals. By their own words in the 1940 report, under the heading *Changing Conceptions in Public Health*, "our new philosophy is prevention"[31]. As they had done numerous times before, in 1942 the Newport Board of Health *again* proposed the idea that they be the ones to run tuberculosis prevention. "No progress has been made in the adoption of any program that will coordinate the activities of the organizations interested in tuberculosis. It seems too bad that with the amount of money that is available for a real program to discover

potential and real cases of tuberculosis, there has been no concerted effort to bring about that result." They continue, as I previously quoted, "up to the present time, there has not even been an acknowledgment of this request."[32] This excerpt informs us that contrary to the financial barriers preventing care during the Depression, there were now ample funds for creating a proper anti-tuberculosis team.

Three years later, the City of Newport received a long overdue kick in the pants in the form of federal intervention. The 1945 Board of Health report states, "A federal program in place for tuberculosis prevention and a major of the US Public Health Service was assigned to the area. He made a brief visit in the fall and approved plans of the committee as well as offering the cooperation of his services."[33] The "committee" that had been decades long in the making consisted of the Newport Anti-Tuberculosis volunteers, Newport Hospital, Newport Medical society, and of course the Newport Board of Health. Just a year later, the new Tuberculosis Prevention Committee had secured a portable x-ray machine to use for screenings, as had been done ten years before at the High School. "The thanks of the city should be extended to Newport Hospital for its insight in securing a modern x-ray machine and making this machine available to the public."[34] The use of the machine is better explained in next year's report from 1947, after the machine had been in use,

> *During the past year a great step forward has been taken. The trustees of the Newport Hospital have purchased, at the cost of ten-thousand dollars, a machine for making rapid chest x-ray screening tests of large numbers of people, free of all costs to the public.*
>
> *During the past year, such chest x-rays have been taken of all children in the public and parochial schools from seventh through twelfth grades. All food and alcoholic beverage handlers are now required to be screened as well as all police and fire departments and all city employees.*[35]

The report from 1948 shows a massive increase in screening tests. In just one year between 11,500 and 12,000 citizens out of the 31,025 persons over twelve years of age were given chest

x-rays. That amounts to approximately 38% of Newport's population, not including naval personnel.[36] The wide spread screening fixed the problem of under-reported cases in Newport. In 1944 there were fourteen cases on file with exactly half of those resulting in death. In 1952 there were one hundred and sixty cases on file—a more than eleven fold increase in those being treated for tuberculosis, with only one death on file that year[37]. Prevention seemed to be working.

However, new programs and advances in medicine didn't do much to change the treatment of patients. Tracking patients and families of patients, so nobly proposed by Chapin nearly seventy years before, was now in full swing thanks to the Newport Tuberculosis Prevention Committee. This idea seemed less noble and more sinister to those who had to experience it. "Back in those days they had a doctor in the basement of city hall. Then we'd need an x-ray so we'd walk back up Broadway to the hospital. They had a little room in there for people like us. And we'd always get a notice saying we were fine. And we did that once a year." My grandmother shuddered as she related her experience to me. "I suppose it was good but…it gave me the feeling of being watched. Big Brother, you know? It was so embarrassing."

In explaining the story of my great-grandfather's tuberculosis, my grandmother recalled a girl taken to Wallum Lake their freshman year of high school, 1953. One day she was there, the next she was gone without an explanation. It was only much later that anyone found out Barbara Parkos had been diagnosed with tuberculosis. "It was like she never existed. That word, "T.B.," they covered it up. It almost had a plague-like feeling."[38] Although advances in medicine had come a long way—by that time antibiotics were available to treat tuberculosis—the treatment of the patient stayed relatively similar. There is an overlying disregard for a tuberculosis patient as a person. In their stories they appear somehow less than human.

Barbara endured an experience similar to my great-grandfather. After weeks of putting up with an exhausting cough that just wouldn't go away, Barbara collapsed at a school basketball game. "I'd been soaking my pillow with blood every night from coughing," she said, "but I was so scared I didn't tell anyone." She was brought to Newport Hospital after her collapse at Rogers High School. Barbara waited in agony in complete isolation from anyone but doctors, nurses, and her father. She recalled her time in the isolation unit, "I thought I had leprosy, since that was the only disease I knew of where you had to be in isolation. I kept waiting for my fingers to fall off." After running some tests, he pulled Barbara's father aside in the hallways to tell him his daughter had tested positive for tuberculosis. Barbara heard the conversation down the hall

"She'll need around two to get better."

"Two? Weeks?"

"No, years."

She explained, "After I heard that I burst down the hall into a run. I couldn't believe what I'd just heard. I was terrified. They had to catch me and force me back into my room." She wasn't allowed to go home and get her things, see her room one more time, or even say goodbye to her sisters. Her life as a normal, thirteen year old girl ended in that hospital room.

Barbara spent the next two years at Wallum, making friends, trying to be as normal as possible. She got along well with her roommate, Clara. "They had us sit in bed for hours at a time you see, to 'rest'. We were the youngest ones there at the time, we naturally bonded to protect each other in such a scary place." Clara underwent the extreme collapse therapy while at Wallum—her lungs were filled with ping-pong balls to squish down the infected part of her lung and isolate the bacteria. In a twisted turn, this collapse therapy provided hours of distraction for the girls. "The doctors gave us the leftover ping-pong balls to play with. We made up games to

play with them. We were just little girls after all." Even these tiny shreds of "normalcy", of having a companion, were marred by tragedy. In the middle of the night, Barbara awoke to a flurry of nurses in her room. There was a sheet over her Clara's head. "I asked the nurses what was wrong and they told me she was dead. And then they took her away without another word."[39]

The treatment at Wallum Lake wasn't necessarily cruel, but so many stories are tinged with blunt insensitivity. The image created is not a hopeful, happy place—Wallum Lake had a contrived normalcy. The bowling alley, the lace making circles, and the gardening didn't change the fact that this was a place created for people to be forgotten. Although neither my great-grandfather nor Barbara Parkos died at the lake, for many that faraway place took their last moments of life from them. If my great-grandfather Joseph spent two years without any physical contact from his family, it's probable that other patients wasted away in the same isolated existence. My grandmother commented, "They were nothing but guinea pigs the people they sent there. They weren't treated like people at all."

Curiously, in my interview with my grandmother, she brought up people suffering from tuberculosis now. "I know we've come a long way in this country but these people who just come in and they let them wander around infected with T.B." She was speaking of an immigrant who had recently been found wandering around Providence with an active case of tuberculosis. "I guess I have the ideal that I suffered, you have to suffer too. That's not really proper, I know, but that's how I feel." The discourse of isolation seems to have seeped into the psyche of even those who experienced first-hand the de-humanizing effects of sanitoria. Over the twentieth century antibiotics have made tuberculosis a treatable disease, not a death sentence or a prolonged "wait and see" experience. However, in the past few years and as recently as

February, there have been disturbing reports of more and more powerful antibiotic resistant strains of tuberculosis surfacing around the globe. With the world's extreme interconnectedness it is no longer "another country's problem" if an un-treatable strain of tuberculosis starts to bubble up in populations. It only takes one person flying on an airplane to infect the world. Then where would we be?

Afterwards

So where are we now? What has happened in the hundred or so years since the construction of Wallum Lake? How does this affect us now, in 2012? Are people still being taken away? Despite various "forced detentions" as exemplified by both my great-grandfather and Barbara Parkos, there was no state law in Rhode Island about tubercular quarantine until 1993. The state has the right to detain someone, "when the director determines that the public health or the health of any other person is endangered by a case of tuberculosis, or a suspected case of tuberculosis". He may also, "make application to a court for enforcement of any appropriate orders." However, there are currently other options for treatment such as the DOTs program or self detention in the home. The law is clear that forced quarantine cannot be authorized "until all less restrictive alternatives have been tried and no less-restrictive alternative is available."[40]

Perhaps the most frightening of all, beyond the harm of isolation units, or the unchanged stigma towards patients, is the disease itself. Tuberculosis is rampant in other parts of the globe. In fact, it killed 1.4 million people in 2010 and is the leading cause of death in HIV/AIDS patients[41]. Unfortunately, we can't throw antibiotics at it like we've been doing for the past fifty years. Antibiotics are only making it stronger. People fail to take the full course of antibiotic treatment because after a while they start to feel better. This partial dose of antibiotics kill the

weak bacteria but leave the much stronger ones—the ones that are resistant to antibiotics. Over time, these resistant bacteria breed and multiply until there are large collections of resistant bacteria. In India, where TB antibiotics are free, packets of the drugs litter the ground. "They don't have value anymore," a volunteer at an Indian tuberculosis clinic told me, "they take it, figure they feel a little better and throw it away." [42] Tuberculosis has evolved, in part, because of us.

In the early 90's, doctors began noticing tuberculosis patients that didn't respond to the usual course of treatment[43]. Thus began the emergence of MDR-TB, or "multi-drug-resistant tuberculosis," which is resistant to "first line" antibiotics. XDR-TB, or extensive-drug-resistant tuberculosis, is even stronger. It resists rifampicin and isoniazid, the "first line drugs" MDR-TB evades, as well as to any member of the quinolone family and at least one of the following second-line anti-TB injectable drugs: kanamycin, capreomycin, or amikacin. Treatment requires extensive chemotherapy for up to two years and, of course, complete isolation[44].

The DOTs program, short for Direct Observational Therapy, uses volunteers to watch patients take their medication to make sure they take the entire course of treatment properly. Visits from DOTs volunteers last about nine months to two years.[45] Deemed the best line of care by the World Health Organization[46], it has a tinge of the "Big Brother" feeling my grandmother felt so strongly about. Doctors have decided that patients can't be trusted to treat themselves properly. It's a practical solution to a problem; however, upon further consideration it becomes psychologically demeaning to patients. Patients are deemed incapable of understanding a doctor's explanation of protocol further projecting the idea of the "ignorant consumptive".

Although it seems outdated, and the literature would have you believe it's a rare occurrence, isolation of tuberculosis patients still happens. Dr. Jef Bratberg[47], who currently

works with Rhode Island tuberculosis patients, related a story to me about a woman who had to be placed in an isolation unit after testing positive for tuberculosis. An elderly, immigrant patient, she had been misdiagnosed with pneumonia before doctors ultimately realized she had latent TB. Upon hearing the news, her family promptly abandoned her to the care of the hospital, refusing to give her home care. “It was a really sad case,” he said. The abandonment of this woman serves to prove the stigma against consumptives hasn’t disappeared. They’re still treated with fear and uncertainty, even from their own families.

In 2007, a patient with XDR-TB was forcibly quarantined by the Center for Disease Control after he disregarded their advisory not to fly. It was the first time since 1963 that the CDC has issued an order for a patient to be forcibly quarantined[48]. Tuberculosis is a very dangerous disease, especially a strain that’s as difficult to treat as XDR. However, what was being done to educate this patient about the risks? What was his incentive to fly? It’s easy to side with the CDC, knowing the danger. But take what you now know about how tuberculosis patients were treated—are treated—and consider what his debriefing was like before he decided to fly. Was he treated like just another degenerate, idiot consumptive? If he was an immigrant, was the protocol properly explained to him? This is all speculation, but it is foolish to immediately side with the physicians when the physicians have always fallen short of treating the underprivileged consumptive as anything but less than human.

This stigma not only affects patients on a personal, emotional level; there are studies to prove it’s detrimental to their physical well-being as well. Researchers compiled multiple studies on isolated patients, mostly those suffering from the drug resistant *Staph. aureus* infection more commonly known as MRSA. They found that across the board, isolation resulted in less patient-health care worker contact than regular patients would receive. Stays in isolation wards were also

found to be associated with delays in overall healing as well as an increase in noninfectious adverse events. These included falls, pressure ulcers, and fluid/electrolyte disorders. Not surprisingly, patients in quarantined isolation units were found to have increased symptoms of depression and anxiety. All these problems resulted in decreased patient satisfaction with care[49]. This study shows that isolation, although good for the public, is very harmful to the patient. Healthcare workers must ask themselves if they're willing to sacrifice the health of an individual for public health. There's no pretending isolation is the best option for the patients, they become just a little less human as soon as they're invaded by a tuberculosis bacterium.

If that wasn't horrifying enough, this past Februrary, an entirely new strain of tuberculosis was identified. Doctors are calling it TDR-TB, or totally-drug-resistant tuberculosis. *They cannot treat it*. WHO has objected to that terminology, pointing out that "everything available locally" is not necessarily the same thing as "every drug available anywhere"[50]. Twelve patients were originally reported in a letter to the journal *Clinical Infectious Disease* in December of 2011, which included a cluster of patients from Iran[51]. But now the Indian government is vehemently pushing WHO's suggestion to label the cases as XDR to reduce the press. The compulsion to lock these TDR patients away and shroud the situation in secrecy will only hurt the fight against tuberculosis in the long run. It feels like a sad reiteration to point out—but where are the patients in all this mess? There is no mention of the patients in these reports other than the first five were from Iran, not India. Once again, "the consumptive" is a lonely, shadowy figure marked as untouchable and dangerous. They have no identity other than diseased.

Those patients matter; and it's important to consider them as real people. Even though they are a half a world away, it only takes a plane ride and one infected patient for India's

problem to become our problem. In Rhode Island, according to the 2010 Department of Health report, twenty out of the twenty-six patients with tuberculosis were immigrants. And one of those cases was considered an XDR strain[52]. How will we deal with an outbreak of TDR-TB? Will our sweet neighbors become the "homeless, friendless, dependant, dissolute, dissipated, and vicious consumptives" from the turn of the century? Will the rusted, crumbling walls of Wallum Lake be sanded down and refinished? Will the discarded hospital beds be re-commissioned for open air wards and dying rooms? Will we learn from our mistakes? People's bodies *will* become Petri-dishes, their lungs experimental entities. When antibiotics were discovered it seemed as if there was an end to the nowhere-land. But nowhere will always be a place for tuberculosis patients; for consumptives to fade away poetically from existence. With the emergence of TDR-tuberculosis, the end of nowhere is no more.

---

[1] Bettencourt, David & Miller, G. Wayne. *On The Lake*. Film (Eagle Peak Media, 2009).
[2] Ott, Katherine. *Fevered Lives: Tuberculosis in American Culture since 1870*. (Cambridge, MA, Harvard University Press, 1996) pg1-2.
[3] Barnes, Harry (Secretary). *Commission on Hospitals for Advanced Cases of Tuberculosis*. (Rhode Island, 1911) pg 35 *Rhode Island Historical Society Archives*.
[4] Bettencourt & Wayne. *On The Lake.*
[5] Tomes, Nancy. "Germ Theory, Public Health Education, and the Moralization of Behavior in the Antituberculosis Crusade" *Major Problems in the History of American Medicine and Public Health*. Ed. By Warner, J. and Tighe, (New York, J. Houghton Mifflin, 2001) pg 257-263.
[6] Cassedy, James. *Charles V. Chapin and the Public Health Movement*. (Cambridge, MA, Harvard University Press, 1962) pg 112-125.
[7] Rhode Island Acts and Resolves. January 1909. chpt 386 §10-11, pg 47-48.
[8] Griswold, Peter. "The War On Tuberculosis." *The Rhode Island Historical Society Blog*. Accessed on 1/6/2012. < http://rihs.wordpress.com/tag/sanitorium/>
[9] Bettencourt & Wayne. *On The Lake.*
[10] Barnes, Harry. *The Wallum Lake Estates*. 1992. Pg 10.
[11] "Wallum Lake Sanatorium" pamphlet, (circa 1904/1905). Thorton & Thorton Architects. 152 Weybosset St., Providence, RI. *Rhode Island Historical Society*.
[12] Barnes, Harry. *The Wallum Lake Estates*. (1992), pg 80.
[13] Wallum Lake Annual Report, (1913), pg 29. *Rhode Island Historical Society.*
[14] Wallum Lake Annual Report, (1917), pg 18. *Rhode Island Historical Society.*
[15] Bettencourt & Wayne. *On The Lake.*

[16] "The Growing Role of Social Workers at Wallum Lake" *Providence Journal* D6 7/21/1928 .
[17] Perkins, Joy. *Tuberculosis and the Schools*, (1913). *Rhode Island Historical Society.*
[18] Barnes, Harry (Secretary). *Commission on Hospitals for Advanced Cases of Tuberculosis*, pg 14-15
[19] Wickford Annual Report, 1915. *University of Rhode Island Archives*.
[20] City Documents of City of Newport For the Year 1917, (Newport, RI, The Mercury Publishing Company, 1918). *Newport Historical Society*.
[21] City Documents of City of Newport For the Year 1919, (Newport, RI, The Mercury Publishing Company,1920). *Newport Historical Society*.
[22] Newport Board of Health Annual Report, (1928), pg 7. *Newport City Hall Archives*.
[23] Newport Board of Health Annual Report, (1952), pg 4. *Newport City Hall Archives*.
[24] Newport Board of Health Annual Report, (1936), pg 6. *Newport City Hall Archives.*
[25] Newport Board of Health Annual Report, (1942), pg 6. *Newport City Hall Archives.*
[26] Tomes,Nancy. *Major Problems in the History of American Medicine and Public Health,* pg 263.
[27] Reagan, Leslie. *When Abortion Was a Crime: Women, Medicine, and the Law in the United States,* (Berkeley, California, University of California Press, 1997), pg 142.
[28] Reagan, Leslie. *When Abortion Was a Crime: Women, Medicine, and the Law in the United States* pg 144.
[29] Lombardo, Paul. *Three Generations, No Imbeciles: Eugenics, The Supreme Court, and Buck v. Bell.* (Maryland, The Johns Hopkins University Press, 2008) pg 91-104.
[30] Bettencourt & Wayne. *On The Lake.*
[31] Newport Board of Health Annual Report, (1940), pg 11. *Newport City Hall Archives.*
[32] Newport Board of Health Annual Report, (1942), pg 6. *Newport City Hall Archives.*
[33] Newport Board of Health Annual Report, (1945), pg 5. *Newport City Hall Archives.*
[34] Newport Board of Health Annual Report, (1946), pg 5. *Newport City Hall Archives.*
[35] Newport Board of Health Annual Report, (1947), pg 5-6. *Newport City Hall Archives.*
[36] Newport Board of Health Annual Report, (1948), pg 4-5. *Newport City Hall Archives.*
[37] Newport Board of Health Annual Report, (1952), pg 6. *Newport City Hall Archives.*
[38] Interview with Sheila Sconyers by Emma Sconyers, 3/15/12.
[39]Interview with Barbara Parkos by Emma Sconyers*,* 4/30/12.
[40] Rhode Island Gen. Laws, chpt 253 §5.
Quarantine for treatment of actively or chronically diseased persons. 1993 pg 188-193.
[41] "10 Facts about Tuberculosis" World Health Organization. www.who.int Accessed 4/22/12.
[42] Interview with Mike Persercia by Emma Sconyers, 4/1/12.
[43] Frieden TR, Sterling T, Pablos-Mendez A et al. "The emergence of drug-resistant tuberculosis in New York City". *New England Journal of Medicine.* 1993 vol 328 no 8 p. 521–56.
[44] Center for Disease Control "Emergence of *Mycobacterium tuberculosis* with extensive resistance to second-line drug—Worldwide, 2000–2004". *MMWR Weekly* (2006) vol **55** no 11 pg 301–305.
[45] "Tuberculosis Treatment and Referral Information" State of RI Department of Health.
http://www.health.ri.gov/diseases/tuberculosis/about/treatmentandreferral/ accessed 4/10/12.
[46] "Can you Imagine a world without TB?"(pdf fact sheet) Stop TB Partnership www.stoptb.org.
[47] Dr. Bratberg, Guest Lecture on Tuberculosis for HPR 309: The Global Challenge of Emerging Infectious Disease at The University of Rhode Island 4/3/12.
[48] Wilson, Brenda. "Air Traveler with Drug Resistant TB Quarantined" *NPR*. May 30, 2007.
[49] Morgan M.D., Daniel et al. "Adverse outcomes associated with contact precautions: A review of the literature" *American Journal of Infection Control* March 2009 vol 37 no.2 p85-93.
[50] McKenna, Maryn "Highest Rates Ever Recorded of Multi-Drug-Resistant TB" *Wired Science Blogs*. 2/6/12.
[51] McKenna, Maryn "India Reports Completely Drug-Resistant TB" *Wired Science Blogs*. 1/9/12.
[52] Tuberculosis Demographics 2001-2010. Rhode Island Department of Health. Prepared by the Division of Infectious Disease and Epidemiology, HEALTH, March 24, 2011.