TPWKY - Special Episode - John Green

EW: [00:00:00] Hi, I'm Erin Welsh and this is, This Podcast Will Kill You. Welcome to our very first T-P-W-K-Y book Club episode of the season. In these episodes, I get to chat with authors of popular science and medicine books about their latest work. And I get a behind the scenes look at what goes into putting these books together. I am so excited to be bringing you more of these episodes over this next year, and we have got such an incredible lineup so far for a sneak peek of some of the books that will be featured on upcoming episodes or to check out the ones that we've covered in past seasons. Head on over to our website. This podcast will kill you.com, where you can find a link to our bookshop.org affiliate account, which has all sorts of T-P-W-K-Y related lists, including a book club list. I'll be updating that list throughout this season as I add more books to the episode lineup, and so check in regularly. As always. We love getting your feedback on the work that we do, so please reach out via the contact us form on our website to share your thoughts. I especially appreciate each and every one of you who has written in about these episodes or suggested books to cover. I've definitely followed up on a few of these recommendations, so stay tuned. Two final things to mention before moving on to the book of the week. Number one, please rate, review and subscribe. It really does help us out. Number two, we are now on YouTube. You can find full video versions of most of our newest episodes by going to the exactly right media YouTube channel. Make sure you subscribe so you never miss an episode.

EW: Alright, let's get to the real reason we're here, John Green's Everything Is Tuberculosis. I know that many of you out there like me have been eagerly awaiting this book's publication, and let me tell you that it is well worth the wait. Its arrival could not have come at a better time as tuberculosis cases surge across the globe. Amidst massive funding cuts to global health programs such as USAID in everything is Tuberculosis Green Award-winning, internationally Bestselling author, famous YouTuber, and excellent science communicator. Takes a panoramic view of this fascinating and deadly disease linking its biology and history with the perception and prevalence of tuberculosis today. For many of us, tuberculosis may conjure up Charles Dickens or long abandoned sanatoriums in upstate New York. But as green describes tuberculosis is far from a disease relegated to the past, despite the fact that curative treatments for this disease have existed for decades, hence, those sanatoriums being abandoned. Tuberculosis remains a significant contributor. To morbidity and mortality around the world. This is a disease caused by a microorganism, mycobacterium, tuberculosis, but it's also so much more than

that. Over the centuries, people have ascribed various meanings to tuberculosis, each of which carries the significant burden of othering. It has been used to romanticize and stigmatize. It has changed the course of history in untold ways, and it stands today as a deadly consequence of how the global healthcare decisions that are driven by profit, lead to unnecessary death and suffering for millions of people around the world. Through his heartfelt and incisive writing, green demonstrates the human cost of tuberculosis and how intervention is not only possible, but necessary. It was an absolutely surreal delight to get to chat with John, and I am very excited to share our conversation with you all. So let's get right to it after this short break.[00:05:00]

EW: John, thank you so much for joining me today. I really can't tell you what a thrill it is to get to chat with you.

JG: Oh, well thank you Erin. It's great to be here. I'm a fan of the pod.

EW: That is, that is so thrilling. That absolutely made my day. So usually I start off these book club episodes by asking someone, how did you get the idea for this book? Or, how did this book come to be? But today with you, I'd love to begin by asking about Henry. Can you tell me how meeting Henry started you on this journey that led to this book?

JG: Sure. In 2019, I had no idea that tuberculosis is the world's deadliest infectious disease. I would've been stunned to hear that I was visiting Sierra Leone with my wife, where we work with partners in health on maternal mortality and infant mortality in the KNO region. And on the last day of the trip, some of the doctors we were traveling with asked if we could go to a tuberculosis hospital, and I was like. Tuberculosis hospital, that's still a thing,

EW: right? I hadn't

JG: listened to enough of the pod, so when we got to the hospital, I was immediately grabbed, like physically grabbed by the shirt, by a boy whose name was Henry, which is also my son's name, and this boy appeared to be about the same age as my son, who was nine at the time. And this boy started walking me around the hospital. Most Sierra Leonians are multilingual, but Henry spoke particularly good English for a, a, a young child. And so I was able to kind of talk with him and, and, and en enjoy the conversation with him. And he took me to the lab where he showed me a microscope and told me to look for TB bacteria in the microscope. He took me, uh, around the wards. He took me to the kitchen where the food was being made, and then eventually we made our way back to the entrance of the hospital. Where the doctors were meeting and

one of the nurses sort of lovingly shooed him away. And I was like, who? Whose kid is that? Is that like a doctor's kid? And they were like, no, that's one of the patients we're really worried about. And it turned out he wasn't nine years old, he was 17. Uh, he'd just been so, uh, emaciated, uh, stunted by Mount Malnourishment and then emaciated, further emaciated by tuberculosis. And it was really through meeting Henry and knowing Henry that I came to be interested in tuberculosis. I, I came home after that trip and, and just started reading voraciously about, about the disease, trying to understand how there'd been this massive hole in my understanding of the world around me. I.

EW: Yeah, it is. You know, there's, there's this, um, statistic that you say early on in your book, about 150 million people having died since we've had a cure for tuberculosis. And that's just been like circulating and echoing in my head over and over again. And I pull people aside and I'm like, did you know this? And I feel like it is, so, it's such a stark statistic because it really cuts to this core question of like, how did we. Allow this to happen and later in our conversation, I do wanna touch on more of like the details of that, but like broadly speaking, can you kind of take me through what are some of the major drivers in allowing that number to grow every single year?

JG: Yeah. I think the biggest driver is choice. Human choice. We have chosen to live in a world with tuberculosis. We've chosen to live in a world where in countries like Germany or the US or Australia, TB is very rare. And in countries like Sierra Leone or even middle income countries like India and the Philippines, TB is very common and. Some of that is because TB is difficult to cure. You know, it takes four to six months of daily antibiotics with the newest regimens it used to take even longer. And so it's, it's a hard disease to cure. But my brother had Hodgkin lymphoma a couple years ago, which is also a hard disease to cure, but curable, and there was no question as to whether or not he would receive treatment or whether or not we would do a, a good job of getting him treatment. Dr. Peter Mgeni, this great Ugandan physician, said in 2000 of of HIV drugs, which we're still not getting to where, uh, they were most needed at the time. He said, where are the drugs? The drugs are where the disease is not, and where is the disease? The disease is where the drugs are not. Mm-hmm. And that's very much still the case with tuberculosis.

EW: Yeah, absolutely. And I, you know, I, I wanna kind of circle back to the, to the current present and then the, you know, potential future, uh, in a bit. But let's take a step back and look at the deep history of tuberculosis. Yeah. I mean, this is a disease that has been with humans for millennia, and yet, as with many other infectious diseases. It is rarely acknowledged outside of, you know, specific disease history books, you know, on influenza or on cholera as like this

major force that is shaping historical events. I've wondered this [00:10:00] so much, like why is that? Why do we not consider the role of infectious disease in shaping history?

JG: Well, I think it's a great mystery, but in the book, I argue that one of the reasons we do is that we're so biased toward human agency. Hmm. We love a story where humans are in control, and we love a story where humans make choices rather than have those choices made, made for them by microorganisms or. Or viruses, like that's a, that's an uncomfortable thing to live with.

EW: Hmm.

JG: So I, I, I speculate in the book that maybe the reason we, we, we continue to spread, the rumor that Alexander the Great died by poisoning when he almost certainly died of malaria or typhoid, is that we just don't want to reckon with a world where the, where the most powerful person on earth can be killed by a tiny bacteria or virus.

EW: Let's take a quick break, and when we get back, there's still so much to discuss.

EW: Welcome back everyone. I've been chatting with John Green about his latest book. Everything is Tuberculosis. Let's get back into things.

EW: I mean, especially when you're, when examining wars and the history of wars, like right. Generals aren't acting in isolation and neither are the diseases that are spreading throughout the entire military or through war torn regions. You can't look at these diseases or these factors leading to disease individually, which is a point that you bring up in your book like that. We can't look even at tuberculosis through these narrow lenses. That being said, I'd love to ask you about a few specific influences that Tuberculosis has had throughout history, especially on the granting of statehood and early 20th century global politics.

JG: Sure. I mean, there's, it's very unlikely New Mexico would've become a state, or at least become a state when it did without tuberculosis, because New Mexico had all the institutions needed for statehood, and it wanted statehood, but Congress repeatedly rejected it because it had such a large Spanish speaking population for just reasons of, of outright racism and. And, and also because it had a large population of indigenous people. And so New Mexico realized that in order to become a state, it needed to attract more white residents. And the way that it did that was making itself sort of a, uh, advertising itself as a great place for people with consumption to come and recover. Had the dry air. It had

the sunshine. And at the time we believed that sunshine and, and dry air would sort of heal the, the wet lungs of consumption. And so by, I think by 1900, about 10% of all people living in New Mexico were tuberculosis patients. And there were enough of them, uh, that Congress eventually, uh, acknowledged that New Mexico should become a state in accordance with its desires. And that's how, or one of the reasons why New Mexico became a state in the first place.

JG: Then you have something like World War I. Uh, you know, I, I think you're so right that every war is shaped by disease. The Franco Prussian war was shaped in part by the fact that one side had access to antiseptics and the other side didn't. And so in, you know, injuries that were utterly unsurvivable five years earlier were suddenly survivable.

EW: Mm-hmm.

JG: But with TB in particular, I'm fascinated by the role that TB played in in World War I because all three of the assassins who sort of semi succeeded in killing the Archduke, Fran Ferdinand, knew that they were dying of consumption. They were all quite sick, and they knew that they were dying and they wanted to die for a great cause, as young people often do. And they thought this great cause was the the nationalism of their community. Then. Being able to be a nation independent of the Austro-Hungarian Empire, and that's why they assassinated the Archduke. Fran Ferdinand, all three of those boys, they were 19 and I think all three of them were 19, died within a couple years of tuberculosis after, after assassinating the Archduke.

EW: That is wild to think about that this disease could have such far reaching consequences and, and I'd love to hear more about one of these consequences. Slightly less extreme than a world war maybe, and that is why we may have tuberculosis to thank or blame, depending on who you ask for the cowboy hat.

JG: Oh yeah, no, that's an interesting one. So this young Hatmaker was living in New Jersey. His name was John, and he got TB and was told that his only chance of survival was to head west, which young people were often told, especially young men. I. Who got consumption. And so he headed west. He only made it as far as St. Joseph's, Missouri, which might be the most humid, least, uh, dry air place I've ever [00:15:00] been personally. But nonetheless, that's where he ended up. And, uh, while he was there, he, he recovered. So about 25% of people for reasons we still don't really understand, recover spontaneously from, from tuberculosis. Uh, one of the things that made it such a difficult disease to deal with societally. Was, it's unpredictable. Mm-hmm. And it is, it's unpredictable course. And so John recovered and as he recovered this

hat, this young hat maker noticed that the hats in the west weren't very good. There were the kind of coonskin caps that were bug infested and, and gross. And then there were straw hats that folk from, uh, Mexico and Texas had, had, had brought up to Missouri. Uh, but those didn't hold up particularly well in the rain. And so, uh, eventually John b Stetson invented what we now know as the Stetson or the cowboy hat.

EW: It's amazing that that final reveal of like, and then Stetson was his last name. Yeah. Yeah. It's, it's really good. Also, it's just, it's so funny that like it. It was just all of these different factors combining. I mean, it's, it's what I love about, you know, history and how we can make these different connections, but

JG: Yeah.

EW: Yeah. So humans have long given different meanings to disease in part to, you know, make sense of the world to answer why me or why them. And that meaning seems like it varies a lot depending on how the disease is transmitted, uh, who's affected or what the disease looks like, like on the outside. Um, something like. Plague compared to, uh, tuberculosis, for instance. Sure. And for a long period of time, tuberculosis, as you discussed, was romanticized. Why was such a devastating disease seen this way?

JG: Well, I think you make a really good point that part of it is the outward appearance of the disease, right? Like mycobacterium tuberculosis is very closely related to the bacteria that causes leprosy. And leprosy of course, is perceived very differently because it's seen as a disfiguring disease rather than as an ennobling one uhhuh. Um, although. At times leprosy has also been seen as ennobling because of its connection to, to Jesus, at least in the Christian world.

EW: Mm-hmm.

JG: But with tv, everybody started to get it in the late 18th century in England. About a third of all people who died, died of tuberculosis. About a third of all death was caused by tb.

EW: It's a staggering statistic.

JG: Staggering. I mean, it's it, it was completely overwhelming. One writer referred to it as the frightful tuberculation of humanity, and it was terrifying.

EW: Yeah.

JG: And so how do you make sense of a disease that, as Charles Dickens put it, wealth never ward it off a disease that you can't easily stigmatize a disease that doesn't just affect poor people or marginalized people. I mean, the richest guy of the 19th century died of tuberculosis. Mm-hmm. How do you make sense of that disease? And I think one of the ways we made sense of it was, was through stigma. And another way we made sense of it was through romanticization. And it's easy to think of those things as opposites. One dehumanizes someone, one argues that someone is sort of like more than human, more beautiful than is possible if you're a regular human, but they're really alternate ways of othering the sick. Mm. You know, just, just kind of creating a, a world where the sick exists that isn't the, the, the so-called normal world or the healthy world or whatever. And the, the romanticization of tuberculosis was so intense in Northern Europe and the United States that it's really hard to overstate it. It was really, really weird looking back on it.

JG: Um, it feels weird to us, you know, men were said to become geniuses because they had tuberculosis. I, I, I, I think I write in the book about when. Shelly found out that Keatts had tuberculosis. He was like, well, you know, this is a disease that affects people who write good verses as you have done, which I think is especially funny or sad or whatever it is, because Shelly also had tuberculosis and so he was kind of like patting himself on the back, even as he was complimenting John Keatts. Yeah. But um, but also like for women, it was seen as this disease that made you really beautiful. You know, it made you very pale and, and whiteness of the skin was really. Kind of worshiped at the time. It gave you rosy cheeks. And, and so people would use rouge to try to affect the same, uh, outcome as, as tuberculosis. It gave you a big sunken eyes. Uh, and so people would apply Bella, Donna to their eyelids to make their, uh, their, their pupils look appropriately tober. And I think all of this was an attempt to make sense of the crisis. Yeah. An attempt to just deal in some way with the fact that. An overwhelming number of people were dying young.

EW: The words like tuber and tuberculous. Tuber, what is it? Tuberculation? Yeah. It's what other infectious diseases have so many like derivative words developed from them. It's, it's remarkable. And you know, I think this, this again, these statistics that you bring up one third of everyone, you know, dying of tuberculosis or who died, died of tuberculosis. Um, [00:20:00] this is so, it's so fascinating because in contrast with other. Infectious diseases during that time, you know, in the pre antibiotic, pre antiseptic mm-hmm. Pre vaccine era. They, the spread was so different too. You know, plagued, tore through a community, cholera, tore through a community, typhus all these things. And, and to some degree or another maybe they weren't quite as, um, what does Dickens say? They weren't quite as wealth, never ward it off. Right. But at the

same time, like, how do you think that that played a role, the way that tuberculosis spread? So. Insidiously in a way.

JG: Yeah. And this is a really, I think that's a really important point. Tuberculosis was almost universally in Northern Europe, believed to be inherited. Mm-hmm. And so it was seen as a hereditary disease that ran in families. And that as such also came with certain other personality traits, the way that those are also passed down in families. And one of those personality traits, this was called spez. Tika, I think the, the, the, the tuber spirit and, and one of one of these personality traits was that you were very sensitive. Uh, if you're a very deep thinker, you were attuned to the suffering in the world. Um, and you were also quite, quite beautiful. And wispy. This idea that as, as the body shrank, the spirit grew.

EW: Mm.

JG: Was very powerful at the time, but because it was seen as hereditary, as opposed to a disease like cholera or typhus or plague, that would just tear through a community. And even if it wasn't quite understood to be infectious, it was certainly understood to be something weird. Mm. Um, and not inherited that changed the way that consumption was imagined. In the 18th and 19th centuries, which is why it was such a big deal when Robert Koch discovered that tuberculosis was in fact caused by a bacteria like cholera, like anthrax, like the other diseases that were coming to be understood as infectious.

EW: I wanna kind of get into that switch of, of what that medicalization of tuberculosis meant. But before I wanna ask how we can. See the effects of tuberculosis in the art and literature of the day. I know we've mentioned Dickens a couple of times, but it's everywhere else. And Shelly and, yeah.

JG: It's everywhere. It's everywhere. Um, it's everywhere. And not just in Western art. It's also, I, I, I write a lot about the Japanese and Indian artists and poets who lived with tuberculosis, but in, in Northern Europe, in the 19th century, because there was this romanticization of tuberculosis, there was also. Um, a romanticization that, that affected art and poetry. You see, well, you know, paintings by to lose lare, for instance of, of, of a woman applying rice powder to her, her face and she's very pale. The great actor Eliza Poe, who was Ed Brown, Poe's mother, um, looked stereotypically tuber and was sort of worshiped for her. Beauty, uh, and you see it a lot in poetry. I mean, in, in Keats writes about youth growing specter thin and dying. Uh, which is of course precisely what happened to him when he was just 25 years old. And so I think from poetry to visual art to theater, uh, to tuberculosis, played a huge role in

shaping the both what we sort of thought of as, as beautiful. But also what we thought of as, as, as very fragile. Mm-hmm. You know, we, at the time, we, we really associated beauty with a kind of fragility of fleetingness. You know, that the idea that maybe you won't be in the world for very long, but you'll be very beautiful while you're here. Victor, Hugo, I remember, uh, his friends would joke with him that he would become a great novelist if only he got tuberculosis. That's how much it was believed that this disease made you a great artist.

EW: The name consumption comes from the fact that like, it, it is a consuming disease. So how, it's just, it's fascinating to think about how that connection was made. How can you produce novels or plays or pieces of art while you are being consumed from the inside?

JG: I think that's exactly right. I mean, look, this, this romanticization of consumption, like the romanticization of mental illness today, or the romanticization of whatever diseases we romanticize or stigmatize, like it's all hooey. Yeah. It's really important to note that like dying of tuberculosis is, is, is horrible. Mm-hmm. Um, and, and. Really painful and, and it's not nearly as, uh, romantic as, as it was made out to be.

EW: Yeah. This ever present threat of death from tuberculosis and, and everything else that was happening during, in many industrialized regions of the world during the 17 hundreds, 18 hundreds. I, I, I was thinking about this in the context of how people related to their own mortality at any stage or the mortality of their friends and family. Uh, what did that. I know that tuberculosis is one part of this, but what did that look like and how did that sort of lead to people creating these concepts or perceptions of what an ideal death should be?

JG: Yeah. I think TB was and remains really hard because it, it [00:25:00] was called the robber of youth. It killed people in the one time of life when you were supposed to be relatively insulated from, from death and dying. Right. Like half of all people at the time were, were dying before the age of five. Mm-hmm. And then, of course, lots of people were dying over the age of 55, but between the ages of, say. 10 and, and 45. You, you, you were supposed to be relatively healthy. You were supposed to be in the prime of life and consumption often killed people in that prime of life, which made it really hard to make sense of, and, and I think especially devastating for, for families. And so I'm convinced that when we do not have an answer, we find one.

EW: Yeah,

JG: we make one up. And I remember my dad had cancer twice when I was a little kid in the 1980s. I. And people would tell my dad that he I, that it was commonly believed at the time that cancer came from bottling up your feelings. I mean, people told my dad that, right? You know, that he got cancer because he hadn't been expressive enough about his own emotions. And that's us trying to find an explanation for the unexplainable. Mm-hmm. And I think that happened a lot with consumption in the 18th and 19th century.

EW: Let's take a quick break here. We'll be back before you know it. Welcome back everyone. I'm here chatting with the incredible John Green about his book. Everything is Tuberculosis. Let's get into some more questions. People have never dealt with uncertainty or been able to sit with uncertainty. Even if we know the mechanism of disease and how the path, you know, the pathophysiology, it's still, there's still plenty of room for blame and Absolutely. And stigma and shame. And so you, you touched on this a bit with the conflation of tuberculosis and whiteness. How was the prevailing assumption of tuberculosis as like a white man's disease shaped by colonialism and white supremacy?

JG: Profoundly profoundly. Yeah. Um, it was really believed by, by white doctors that consumption was impossible among people of color. And this was partly because consumption was so romanticized that it was believed to be a disease of, of the great intellects and a disease of the very beautiful and a disease of paleness and all of this stuff and all these ideas that, that we had in Europe and, and the United States around whiteness. Penetrated our understanding of disease as well. And so, you know, Frank Ryan writes very movingly about how tuberculosis in black and brown people was considered to be a different disease, a disease that was not even given a name, which speaks, I think, both to healthcare access and to the, you know, total racism of the medical establishment at the time. Mm-hmm. So until TB became understood as an infectious disease, it was generally believed to be rare or impossible among people of color.

EW: Then how did the discovery of Mycobacterium tuberculosis sort of change that? Both, um, that aspect, but also overall what tuberculosis, you know, the romanticization and sort of now this, this new othering of this disease.

JG: Yeah, it changed everything. Once we understood the TB was infectious, suddenly, um, it became a disease that was no longer romanticized and was heavily stigmatized associated with. Poverty associated with poor working conditions, uh, crowded living conditions, and especially associated with people of color. So whereas before white supremacy had had held that o only white

people could get this disease of civilization, now white supremacy held that disproportionately this disease would affect, uh, quote unquote less civilized people. And that had. Devastating consequences for the way that the medical establishment, uh, treated people with TB for the way the medical establishment understood TB in people of color. And even today, there's still a huge disproportionate, uh, bias toward people of color when it comes to the burden of tuberculosis, even in rich countries. Uh, but all throughout the world.

EW: Yeah, I, I was thinking about this, this transitional period and, and tuberculosis had such an impact as we've talked about on art and literature and all these different aspects of, of life. When that medicalization happened, how did that, like, how quickly did that disappear from that like culture of tuberculosis?

JG: It, it disappeared pretty quickly, but the, it disappeared as quickly as people started to really agree that the disease was infectious, that it wasn't hereditary. So it took a couple decades. A, a number of people kind of held onto the idea that the disease was hereditary and therefore that this idea of the tuber personality. Still should hold sway. [00:30:00] But as, as it became clearer and clearer and the evidence mounted that this is actually an infectious disease that started to melt away, and you can almost see it in the language, like before 1882, consumption is almost always referred to as consumption. And after 1882, it's almost always referred to as tuberculosis. So you see the medicalization of it, even in, in the language that we use to describe the illness almost as if they're two different illnesses because they're imagined so differently.

EW: Yeah, it is. Um, it is sort of like, yeah, this, this romantic disease to this horror that is tuberculosis.

JG: Yeah. And, and there is something inherently horrific about infectious disease, right? Like, there's something terrifying about the idea that, that like, we can survive lions and bears and tigers and, and make all of them, uh, irrelevant to, to our safety, but we can't survive these tiny microorganisms that spread through the air. I mean, that is the stuff of a literal horror movie.

EW: Yep. Absolutely no. It's, um, that that period of seeing finally these things and making a connection is, is fascinating to think about how we perceived a cause of disease. But so this medicalization, this discovery of the fact that tuberculosis was caused by bacterium, this led to a lot of stigma and that stigma is in large part still present today. Yeah, very much. And so can you talk a little bit about that, you know, what happens when someone is diagnosed? How

might friends or family or the community broadly respond to someone's diagnosis with tuberculosis? I.

JG: Yeah. So in a different age and a different time, someone like Henry would've been really lifted up for having tb, right? I mean, he's a very, he writes poetry, he's a very, uh, engaged, sensitive kid, and he embodied that idea of the tuber personality and, and if we'd had an inherited genetic model for tb, he would've very much fit into that romanticization of the disease. But because he got TB in a different time and place, he was instead hugely stigmatized. Mm-hmm. Um, it's very common for people who have TB to be dropped off at the hospital and completely abandoned by their families in some cases, to never see their families again. One of the most heartbreaking things I've heard from nurses working in TB hospitals is how they often have to be the only person at the funeral for someone who dies of tb. Uh, where they're, they're, that person is buried alone and the nurse and or the nurses are the only people who are there. And you know, that's because TB is seen as a disease of poverty. It's sometimes seen as a disease of demon possession, even

EW: Hmm.

JG: A disease that's associated with all kinds of wrongly, uh, I think it's safe to say, associated with all kinds of moral failings. Mm-hmm. And, and so it's really a hugely stigmatizing experience, Henry. Talks about the, in, in a memoir that he wrote. He talks about the experience of, um, being abandoned by his cousins, being abandoned by his friends. He was very fortunate not to be abandoned by his mother. So his mother I saw to stayed incredibly close to him, visited him almost every day for, for three years while he was hospitalized. Um, and, and that made a huge difference in his life. But for many people, that's not, that's not the norm. I think it's safe to say.

EW: Which is just utterly heartbreaking. I mean, especially given that the stigmatizing, isolating disease is one that we've had effective treatments for since the 1950s, how did the development of those treatments change the perception of tuberculosis?

JG: Yeah, so it went from being a death sentence to suddenly being a curable disease. Um, I read a number of memoirs from people who lived in Santoria at the height of the TB crisis in the United States in, in the early 19 hundreds. I. There were almost as many hospital beds for TB patients as there were for all other causes combined, and there were hundreds of these sanatoria around the country. There were cities like Asheville, North Carolina, Pasadena, California, that were essentially founded as tuberculosis colonies, and. All of a sudden,

these places just emptied out. I mean, you read about these people who'd lived in Sanatoria. I, I read one memoir by a, a woman who lived in a sanitorium from the age of three until she was 17, and suddenly streptomycin made it so that she could go home. And she didn't even remember what it was like to be lovingly. Touched, she didn't remember what it was like to be, be with friends and family, be in that kind of like loud, boisterous environment of a home. But for many millions of people, that was the case. I mean, the, the antibiotic era, I. Really dramatically reduced the burden of tb, but it also made it so that we imagined TB differently. Instead of being an incurable, chronic, terrifying condition, it became something that we [00:35:00] know how to cure. The problem is that in many communities, it remained an incurable chronic condition.

EW: And simply due to lack of access. And I think that we have a tendency, or at least here in the us, we have a tendency to think of like, oh, we solved that. We figured that out. Going back to that Charles Dickens quote of tuberculosis as the great leveler. But we see these patterns of disease and tuberculosis on a global scale that really show that it's, it's not. The disease that wealth never warded off anymore. Yeah. What are these patterns that we see and how do they kind of reveal global priorities in public health?

JG: I mean, the pattern that we see is the pattern that you identified at the beginning of the this conversation, which is that since TB became curable, we let 150 million people die of it.

EW: Yeah. I

JG: mean, probably more than that. That's a conservative estimate and. We have done that because of systems of resource distribution. And where we allocate our shared resources. Uh, I have to tell you as we're recording this, I just received a message from my friend, Atul Gawande, who was the head of Global health at U-S-A-I-D and saying that there are boxes of TB medication right now rotting in, in warehouses, waiting to be distributed, and there's no way to distribute them. That's the kind of thing that we have seen really for, for decades on various levels. You know, we've, we've, we've seen sometimes there are systematic attempts to get tuberculosis treatment to lots of people. A lot of times those attempts are very haphazard, inconsistent. Um, they, they are, you know, funded by small nonprofits or by, um, individuals and, you know, not in, not in a way that's long term sustainable or, or can. Can deal with the size of the crisis that we face. And TB anywhere is a threat to people everywhere. I mean, I think it's really important to acknowledge that. Mm-hmm. Like, yes, we have dealt with TB in the United States, but we have had a TB outbreak in, in Kansas

earlier this year. We have, we have over 10,000 cases of active tuberculosis every year in the United States, and probably over a hundred thousand cases of latent TB that, that we don't always identify.

JG: And so. It's a truly global problem. Mm. Now it's very rare to die of tuberculosis in the United States because people can generally access healthcare, but it does happen. Mm-hmm. And, um, as if we, if we continue to let this disease. Spread among millions of people every year, uh, and, and we're inconsistent with, uh, treatment regimens. We are allowing the disease to have millions and millions of opportunities to evolve further resistance to the tools that we have to fight it. And because we haven't done a good job of inventing new tools over the last 60 years,

EW: yeah,

JG: that's a real issue.

EW: Yeah, I mean truly, and I appreciate that, the global perspective of sort of how all of these things are playing together. And I wanna kind of narrow in on Sierra Leone specifically to connect the dots between all of these different factors that contribute to people, you know, developing tuberculosis and then not. Receiving the care that they should be receiving. And there's, you know, there's healthcare infrastructure, there's funding inconsistencies, there's an overall lack of access. Can you sort of help me connect to the dots for how all of these things lead to tuberculosis as the end result?

JG: I think that's exactly right. You have to understand this in historical context. We have to understand that, uh, tuberculosis did not just arrive in Sierra Leone. It did not just like show up in Henry one day. This happened because of a series of historical events and historical forces that go back for centuries that go back to the transatlantic slave trade in colonialism and, uh, the extraction of resources from Sierra Leone's economy and, uh, so many other factors. But you know, Henry in the end got sick because TB has been allowed to thrive in Sierra Leone, uh, for the last several hundred years and has been allowed to thrive since we developed tools to fight it. Henry developed drug resistant tuberculosis, and so for someone like him. Treatment is very difficult. Not because it's impossible or because it's, you know, the treatment is made of gold or we have to go to the moon to get it or something. But because the global health system thinks of tuberculosis as being very expensive to treat, and especially as of drug resistant tuberculosis as being very expensive to treat, now that's starting to change. But when Henry got sick in 2018, uh, when he first was really diagnosed with drug resistant tuberculosis and became very, very ill, I.

JG: There were very few options available to people like him in a country like Sierra Leone. If I'd gotten the exact same strain of drug resistant tuberculosis at the exact same time, I would've received an immediate, uh, molecular test to identify not just whether I had tb, but which [00:40:00] antibiotics my TB would respond to. I would've been put on appropriate treatment immediately. I would've been isolated. I, and, and within a few months I would've been able to go home and within a year I would've been. Healthy and cured. But that wasn't the case for Henry. Henry, um, had to go to Laka to this tuberculosis hospital and, um, and he had to be put on second line antibiotics, which it turned out didn't work, but, and we would've known that they, they wouldn't work if he could have afforded that molecular test, but they weren't available in Sierra Leone at the time.

EW: Mm-hmm. Yeah. And um, so you mentioned that Henry had a, uh, drug resistant form of tuberculosis and one of the primary reasons cited for the rise and spread of drug resistant tuberculosis is patient noncompliance. But there is so much more nuance to that term patient noncompliance that I really, uh, appreciate that you went into in your book. And this how this term. Unfairly places blame and burden entirely on the patient without examining the reasons for patient noncompliance. So can you sort of, you know, talk a little bit more about that and this, this nuance with noncompliance?

JG: Sure. Well, first off, if you receive a seven day treatment of antibiotics to cure strep throat and you take it for six days, you're technically a, a non-compliant patient. So, mm-hmm. Just bear that in mind. I mean, how many of us have, you know, not taken that last day of antibiotics because we felt better? Well, imagine having to take. Dozens of pills every day for four months or six months or a year that make you very sick, that have side effects that you don't like. Um, that's, that's one thing to consider. But then also, I remember once I was in Sierra Leone and I was, uh, making a home visit with a, a doctor and a community health worker. And the community health worker asked the. The young patient, have you been able to take your TB meds today? And she said, no, I don't have any food. And if I take them without food, I just throw up. I just throw them up immediately. And so the doctor said, well, you know, sometimes if you pour a little bit of sugar into your water, it can settle your stomach a little and allow you to take the medication. And that was the only thing that he was able to say to her because, um, there were no resources to to, to buy her food in that moment. And. So is that a non-compliant patient? I mean, I've, I've, uh, you know, if you throw up immediately after taking your medication because you don't have access to food, are you a non-compliant patient? Are you a non-compliant patient If you can't afford the transportation to get to the clinic every single day, because still often patients have to be physically observed. It's called

directly observed therapy. They have to be physically observed taking their medication every single day to make sure that they're quote unquote compliant.

EW: Right.

JG: But that the burden of having to get to a, he a healthcare facility every day, affording transportation, affording childcare, what, what, whatever the complexities are in your particular life, that burden is often overwhelming for people. Mm-hmm. So there are a number of reasons why people might be deemed noncompliant or, or deemed lost to follow up, which is another phrase I find horrifying.

EW: Mm-hmm.

JG: And. We have to make space for the healthcare system to meet the needs of patients rather than requiring patients to meet the needs of the healthcare system. We, we do a bad job of that everywhere. I mean, I don't think we do a particularly good job of it in the United States. I know that, like I struggle sometimes to get access to mental health care that I need, even though I have lots of resources available to me. Uh, but, but I, I think we need to do a much better job of it, especially in impoverished communities.

EW: The way that so many people with tuberculosis are treated just shows this lack of trust in them as individuals who also want to, they don't want to be sick with this. Like, it just sort of is a, is that non-compliance term really kind of has these connotations of like, well, they just don't care enough. And it's like, of course they do. Mm-hmm. How could that be the conclusion? Yeah.

JG: Right. Right, or that they're somehow like not dedicated, they're not adequately, you know, they're not adequately hardworking or, or committed to their own health or whatever. But like, you know, first off, lots of people struggle to take their medication. I struggle to take my medication. I don't know exactly why. I think some of it has to do with stigma, with this idea that, you know, somehow I'm less, I take medication to treat OCD and major depression. And, and some of it has to do with this idea that somehow, like I'm, I'm. Less whole or self-sufficient or complete or whatever. If I, if I need medication in order to be myself or in order to be, well, some of it has to do with the burden of getting the medication, you know? Mm-hmm. And my, my burden of getting the medication is, is just calling up the pharmacy and getting a refill. It's, it couldn't be easier for me. And yet still, like that barrier sometimes feels overwhelming to me.

EW: Mm-hmm.

JG: And then you have to remember that a lot of people living with tuberculosis are also living with other. Health problems, including severe mental health problems. I remember meeting with a, a young man who'd been completely abandoned by his family, who struggled to take his [00:45:00] medication, who'd been abandoned by his friends, who was utterly alone in the world, who felt absolutely hopeless, who was, you know, consumed by depression. And, you know, were, we're asking this person to. Make his way to a clinic every day so that he can take his medication. Like that's, that's asking a lot.

EW: Yeah. I think these are, these are aspects that aren't, don't always come out in, in medical literature unless it's about this specific, you know? Right. The, the context of, uh, non-compliance and what that, what that actually reveals. Given that some of this awful side effects of these tuberculosis medications, it seems like one way to overcome this would be to develop new drugs for the disease yet. As, as you discuss, uh, very few tuberculosis drugs have been developed in, in recent years, and these newer drugs even are prohibitively expensive despite mostly being funded with, you know, with public funds. So what are some of the ways that people are working on this problem?

JG: Yeah, so this is a place of encouragement for me, and I'm sorry if this has been a largely discouraging conversation, but this really is a place of encouragement for me. Between 1944 and 1965, we developed something like eight classes of drugs to treat tuberculosis, and then between 1966 and 2012, we developed none. Hmm. And all those years we, we could have been developing great tools to treat tb, but we didn't because the profit motive wasn't there.

EW: Yeah.

JG: Now, um, and, and some of this has become complicated of late, but now there are more mechanisms in place to try to incentivize the creation of anti-TB drugs and drugs in general, that I consider diseases of injustice, diseases that are caused not primarily by. Whatever the pathogen is, but really by human choice, by human built systems like tuberculosis, like, uh, cholera, I think is another, another great example.

EW: Mm-hmm.

JG: Typhoid iss a good example. Malaria is one of the, the big examples in the, in the 21st century.

EW: Yeah.

JG: All those diseases, I think they still don't receive nearly the amount of attention that they should, nearly the funding that they should, but they receive more funding. And so in the last 10 or 12 years, we've developed some powerful new medications to treat tb, including bedaquiline and delaminate, which are, which are really good drugs. Now, as you point out. They have historically been too expensive and, and so we're using a lot of times second line antibiotics that are from the sixties that we know aren't very good and that are highly toxic. That can cause total hearing loss and up to 20% of people who take them. Lots of other adverse effects. But we're starting to see the better regimens roll out and more encouraging. Still. The amount of time that people need to be treated for tuberculosis is, is going down. So we're starting to see the NTB trials, which were funded by partners in Health and, and uh, doctors Without Borders. Those saw. That we can cure TB in less time than we thought we could. And, and, and that's encouraging. So I think we have better tools than ever. We have better diagnostic tools than ever. We're on the cusp of maybe having a tongue swab test for tb that would be game changing. Mm-hmm. And very inexpensive. Uh, we have better drugs than ever. We have shorter regimens than ever. And, and on all those fronts, we are starting to see real progress in the last 10 years.

EW: Yeah, that is, that is really encouraging. And I think that, yeah, it's, it's, it's, it's easy to get wrapped up in all of the, um, the challenges ahead of us. But it is so important to remember that there are people who are doing really excellent work and really trying to, uh, change things when it comes to the way that we. Treat and deal with tuberculosis and these sustained improvements that we would be able to make when it comes to tuberculosis. You know, requires investment in healthcare infrastructure, in treatment, and early detection and active case finding. And. If we did a better job with tuberculosis, that would be money saving in the long run, like tremendously. So, yes, and I hate to always bring it to money, but that is such a crucial part of every single like public health decision. Why does that calculation not seem to matter? I. Yeah.

JG: Every dollar we invest in TB brings $40 in future health benefits.

JG: Yeah. And every time we end a chain of transmission of tb, it means less TB in the world. You know, TB is a curable disease, which means that we could eliminate it. We could, we could live in a world without tb. If you think about how much we used to spend on tuberculosis in the United States when we had 700,000 hospital beds devoted to the disease and how much we spend on it now, you see that impact, right? Like you can just see it intuitively that we used to spend a ton of money on tb. In the US and now we have to spend much less,

although we're having to start to spend more because we're seeing more TB in the us.

EW: Mm-hmm.

JG: I, I think the reason we don't make those investments is because we're quite shortsighted when it comes to public health, and so we think. I mean, Paul Farmer used to rail against this. He used to talk about the, everybody talks about [00:50:00] the cost of treating tb and nobody talks about the cost of not treating tb. Yeah. And the cost of not treating TB is so high, but we're accustomed to paying that cost. We've been paying that cost in an ongoing way for generations. It's time to start paying the cost to treat TB and find out the benefits of not having to pay the cost of not treating tb.

EW: Not to mention that so many of the structural improvements that would help to reduce the burden of tuberculosis would make a major impact in so many other aspects of infectious disease. It's not totally, especially when there's interactions between tuberculosis and your immune system and, and if you're infected with this disease and, and tuberculosis, then that maybe that makes active tuberculosis more likely. It's. It all is interconnected and we are able to make large scale changes that would impact tuberculosis and many, many other things.

JG: Yeah, and I think you're right that when we invest in a disease like tuberculosis, we also invest in a stronger healthcare system when we're doing active case finding for tb. We're also checking people's blood pressure. We're also checking for diabetes. We're also checking, you know, for other non-communicable diseases, and that's a really important thing to understand that stronger healthcare systems overall beget stronger healthcare systems overall and investment in in healthcare that really strengthens the system is not just good for tuberculosis, it's also good for malaria. It's also good for HIV. It's also good for diabetes and any other disease that people get.

EW: Yeah, it's, um, it's all, it's all, it's, it's like they're all connected, you know?

JG: It's, it's almost like they're all connected. How

EW: about that? Uh, yeah. So I, I, I wanna wrap up on a, on a hopeful note and, um, and with two, with two final questions for you. The first is, Henry, what is, what is Henry up to these days?

JG: So Henry was sick for a really long time and it took a long time to cure Henry. But thanks to the Sierra Leone Ministry of Health and the organization Partners in Health, uh, the medicine that Henry needed was finally made available to him and he survived tb. He was cured. He is, um, a healthy. Happy young man now, um, he's 24 years old and he's a student at the University of Sierra Leone. He's studying, uh, business and, and human resources. I'm immensely proud of him. We're, we're very close, and, um, he's just doing awesome.

EW: That's, it's amazing. And I, he has a TikTok channel, is that right?

JG: Oh, yeah, he definitely has a TikTok. Okay. And he also has a YouTube channel and he wants you to subscribe. So Google Henry Writer YouTube.

EW: Good, good. So. We have this roadmap for how to make things better with tuberculosis. We, we know what we can do. We have people working on it. What are you most hopeful for in the next, in, in the near future, in the, you know, maybe distant future? What, what do you most hope to see happen?

JG: Well, we have a really good roadmap for how to eliminate TB globally as a public health threat, and it goes by an acronym like Everything in the World of Global Health. Like everything in the world of tuberculosis. The acronym is STP, search, treat, prevent. So first large scale active case finding like we did in the US in the 1940s and fifties, where we had mobile vans with chest x-rays inside of them, fan out across the country, offer people free chest x-rays and then, and, and then find cases that way. So you're not only finding cases when people are so sick that they come into the hospital, you're identifying the disease earlier, uh, when it's easier to treat and there's less risk of long-term disability. And then there's the second letter T for treat. Treat every single person. With tuberculosis, offer them, um, the, the kind of care that they need in order to get well.

JG: And then the last letter P stands for prevent preventative Therapy. So we have, uh, a way of making sure that somebody who's exposed to TB never gets sick. Um, it's one month of preventative antibiotics. And so if we offer preventative therapy to all the close contacts of the people we identify with tb, we can end that chain of transmission completely. This is an a bold, ambitious plan. You know, some of the estimates say that it would cost $25 billion a year, but as you pointed out, each of those dollars would result in $40 of, uh, future benefit to our, our species. And more importantly, it would, it would result in 6.6, uh, by some estimates, million, fewer deaths over the next seven years. And there is hardly a better bet in global health than that.

EW: Yeah, I, I completely agree. John, it has been so fantastic to chat with you and an honor to meet you. Truly thrilling. Thank you so much for a great conversation.

JG: Thank you so much, Erin. It's so cool to be able to meet you and to be on on the pod. I really appreciate it.[00:55:00]

EW: A huge thanks again to John Green for taking the time to chat with me. That was such a great conversation. For more tuberculosis talk, check out our website. This podcast will kill you.com, where I'll post a link to where you can find everything is tuberculosis, as well as a link to John's site. Don't forget, you can check out our website for all sorts of other cool things, including but not limited to transcripts, quarantining and placebo reader recipes. Show notes and references for all of our episodes. Links to merch. Our bookshop.org affiliate account are Goodreads List, a firsthand account form and music by blood Mobile. Speaking of which, thank you to Blood Mobile for preventing the music for this episode and all of our episodes. Thank you to Liana Kuchi and Tom Bry Fogel for our excellent audio mixing. And thank you to you listeners for listening. I hope you liked this episode and our loving being part of the TP WKY book Club. A special thank you as always to our fantastic patrons. We appreciate your support so very much. Well, until next time, keep washing those hands.