TPWKY - Special Episode - Wendy Chin-Tanner

EW: [00:00:00] Hi, I am Erin Welsh and this is, this podcast Will Kill You. You are listening to the latest episode in our TPWKY Book Club series where I sit down with authors of popular science and medicine books to chat about their latest work. I've gotten to have some incredible conversations so far, and we have even more excellent books lined up for the rest of this season. If you'd like to see the full lineup of books we've covered so far this season and in past seasons, as well as get a sneak peek of the books that we'll be featuring in upcoming episodes, head over to our website. This podcast will kill you.com. There under the extras tab, you'll find a link to our bookshop.org affiliate account. Clicking that link will take you to a page where you can find all sorts of T-P-W-K-Y related book lists, including one that has all of the book club books. I'll be updating this list throughout the season, so check in regularly to see what new ones I've added and I say it. Every time, but I mean it every time. We love hearing from you all. So if you have any thoughts on these books, any suggestions for future ones to cover or topic suggestions for our regular episodes, please reach out. The best way to get in touch with us is through the contact us form on our website and a couple more pieces of business before we can get into the book of the week, and that is to please rate, review, and subscribe. It really does help us. And finally, you can now find full video versions of most of our newer episodes on YouTube. Make sure you're subscribed to the exactly right media YouTube channel, so you never miss an episode drop.

EW: So far in this series, we've covered a huge variety of topics, plant and animal derived poisons, the global history of tuberculosis, how memory works, disease themed movies, and so many more. But all of these topics, or at least all of the books that have reported on them have been nonfiction. Until today. This special episode of the TPWKY Book Club features our very first novel, king of the Armadillos, critically acclaimed winner of the 2025 Louisiana Literary Award. In King of the Armadillos, author, Wendy Chin-Tanner draws on her father's experience to tell the story of a young man diagnosed with Hansen's Disease, then known as Leprosy, who is sent to a federal treatment facility in Carville, Louisiana, ripped away from his family and life in New York City. Victor finds himself adrift in Carville until he finds an outlet in music and a supportive community in the other residents at the leprosarium. Through her lyrical prose and exquisite attention to historical detail, Chin-Tanner transports readers to the lively grounds of Carville in the mid 20th century with its rich tapestry of characters. At Carville, readers experience the world through

Victor's eyes, a world that is not always kind and welcoming. Victor struggles with othering, not only due to his diagnosis, but also his status as a Chinese immigrant, which complicates his relationship with his family as well as his own self-worth by following Victor. During his time at Carville, readers get an insight not only into a disease heavy with meaning throughout its history but also a young boy's coming of age journey with all its heartbreak, wonder lessons, and Love. King of the Armadillos is a beautifully written, heartfelt journey through a long forgotten, but vitally important part of public health history, and it serves as a powerful reminder of the significant stigma that diseases can carry. I am super excited to share this interview with you all. So let's just take a quick break and get started.[00:05:00]

EW: Wendy, thank you so much for joining me today.

WCT: Oh, thank you so much for having me here, and it's such a pleasure.

EW: I wanna start just by getting a little bit about the inspiration of your book. So your book, king of the Armadillos. It takes us through the incredible story of a young man named Victor who was diagnosed with Hansen's Disease, historically known as leprosy at the age of 15, and which leads to him then leaving New York for a treatment facility in Louisiana. And I understand that this is a deeply personal story for you. Can you tell me a bit about the inspiration for your book?

WCT: Absolutely King of the Armadillos is a fictionalized coming of age story that was inspired by my own family. So, um, when my father was 16 years old in 1954, he was living in the Bronx with my grandfather at the back of the laundry he owned in the Bronx. And like Victor, he had come over as a young child leaving my grandmother behind in China, and as a teenager he was, uh, diagnosed with Hansen's disease, otherwise known as leprosy, and sent to the federal institution for the treatment of leprosy in Carville, Louisiana, where he stayed for nine years until 1963. So that was significantly longer than our character Victor.

EW: Nine years. I mean, I, that is, that is an incredibly long time. And how much did you know about your father's story before writing this book? Was this something that like, was sort of discussed regularly? How familiar was it to you?

WCT: Extremely familiar. So it's interesting, um. Even though I knew from a very young age that we shouldn't talk about it outside of our home, I'm an only child, a very sort of enmeshed immigrant only child or uh, or only child of an immigrant family. And as a result, you know, I'm very, very close to my dad. I was a chatty, inquisitive child and my dad is a chatty guy. So, um, you know, within our home and between us. It was very openly discussed because those nine years were so formative to my dad and his best stories were about carville. So to me, growing up, it was this magical place like Narnia or Oz. It was part of our family mythology. And the fact is, you know, my father made it sound this way, and it actually in reality is incredibly beautiful and haunting. And, um, you know, it's on the banks of the Mississippi River in a disused sugar plantation. And, uh, you know, it's. Got live oaks dripping with Spanish moss, 400 acres of rolling green fields, and in reality, it looks more like a small liberal arts college than it does an institution.

EW: It's also this very important institution in the history of public health here in the US, and yet,

WCT: absolutely.

EW: Most people have no idea that it once existed. That what it, where you know today that you can go and there's a museum and what, what do you think accounts for that forgetfulness?

WCT: Well, I think that leprosy is and was I. The most stigmatized and misunderstood illness on earth. I think I can, I can validly say that, um, so much so that leper is a metaphor for stigma. Mm-hmm. Um, so I think that that accounts for it to a degree. I think also people who had been patients there had so much of a taboo around speaking about it after they were discharged. Even today, I don't think that they want to recognize what is in fact a really significant place, significant time and significant role that they played in American history and um, not only in public health history, but in the history of collective and grassroots organization. Because there was this powerful patient's federation that advocated for their own quality of life in a really interesting way. That was in many ways a precursor to the HIV/AIDS movement actually.

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 Wendy Chin Tanner about her book, king of the Armadillos. Let's get back into things. Patient advocacy Yes. Groups and standing up and, and [00:10:00] also just raising awareness. Yes. I think is such an important aspect of that, of that movement utilizing pr. Yeah. Yeah, exactly.

EW: And I, I heard that you, uh, initially were toying with the idea of nonfiction versus fiction. When did you make that decision and what sort of led you to to land on fiction as the way to tell this story?

WCT: I resisted, uh, landing on fiction for a very long time. Time, yes, because before writing this book, I had never written fiction before in any form. I had never even written a short story. Um, I was a poet. I had published a couple of poetry collections before starting to write this book, and, uh, before that my academic training, my graduate training was in sociology. So I knew how to write a social science paper and I knew how to write a poem, but I had no idea how to write, um, fiction, much less a novel.

WCT: So when my dad told me that I kind of had carte blanche to write about his experience. And that wasn't something that happened until, uh, about 2012, 2013, that he had this sort of, um, revelation, I suppose, after having a bout with cancer, which thankfully he is. Completely clean and, and cured his second sort of miraculous recovery in his life. Um, he had this realization, a revelation that, um, his experience was significant and it was something that people should know about and that, you know, we're only as sick as our secrets and that, um, it should be celebrated and acknowledged. So he. Told me that I could write about it. And he also helped me get sort of a backstage pass. Um, he helped me get hundreds and hundreds of pages of archival material from the museum, from the curator who Elizabeth Schneider, who has since become a close family friend, and it was. Really an overwhelming overabundance of material. Yeah. And not only was it just, you know, all of his medical records and all of this history, I couldn't find my way into telling the story the way I wanted to tell it there. There got to a point where the idea of writing a book that was. Absolutely true to my dad's experience of nine years. There became less important than the story that I could tell with the creative freedom that I could tell it with via fiction.

WCT: I mean, as someone who writes in multiple genres, I feel like the writing process is pretty mysterious to me, and there's a point at which a project will announce itself. As whatever it needs to be. And that happened for this book probably after I wrote the first chapter. So I wrote the first chapter. The first chapter that I wrote is actually the first chapter in the book. Amazingly, it was the train journey because wow, you know, I wanted to top and tail it with train journeys like the Magic Mountain, which I wanted to kind of tip my hat, my hat to. But after writing that first chapter. What really started to grasp my imagination were scenes and characters and side stories that I couldn't possibly substantiate with data and with the information that that I had at hand. And I wanted to tell this kind of broader story of the family system of Victor's family system and not just his experience at Carville per se. Um, that, and also, you know, I was writing this book largely during the pandemic, and I had my parents staying with me. I live in upstate New York. My parents live in Greenwich Village in New York City, which you probably recall was like ground zero of COVID.

EW: Mm-hmm.

WCT: And so I brought them up. To upstate New York to our house and they lived there during the pandemic. And you know, my dad was reading over my shoulder as it were, a lot of what I was producing. And while it was really useful to have him there as, um, you know, a fact checker, there came a point where it made me self-conscious. I, I think we all idealize our parents, right? Yes. And um, it's very difficult when you idealize someone to write them as fully human. As they need to be. So, you know, I needed a way to kind of mess Victor up, you know, and make him, as, you know, difficult and contradictory as I know myself to be. But, you know, with my dad there in my home, and [00:15:00] not just, not just with him in my home, but knowing that I was writing. His past, I couldn't do that. I couldn't make him as fully human as I needed to in order to serve the story. Mm-hmm. So that's when I kind of realized that I had to take the plunge into fiction. That, and also when I started to write the music piece, because I'm not a musician. Okay. When,

EW: that's so funny because music plays such a huge role. It's, I feel like he, you know, Victor uses it as an escape at the beginning and then also a tether later on to keep him grounded to the world when things are really overwhelming. And I just assumed that you were musical. Um, but you say that you're not. So what does music represent? To you in this story?

WCT: Well, I'm musical in the sense that I have a deep appreciation for music and have always loved it. And my dad is a musician,

EW: okay, like

WCT: Victor. And he did also like Victor, discover that he had a gift for music when he was in Carville. So there has been music in my home. From day one, and I did have piano lessons as a child, although I, um, didn't progress really um, you know, into being a fully fledged musician, I can carry a tune. And my dad actually, um, taught me to play the piano like he was my first teacher, which was really amazing with. By the way, some of the books that he brought back from Carville, some of his music books, so we still have them. Amazing. And, um, my dad actually a few weeks ago showed me something that I'm somewhat embarrassed about because, um, I, I graffitied one of these books as like a 6-year-old in my sort sprawling. 6-year-old handwriting and it's like, oh my God, this is archival material. This is horrible. I've defaced it, but it was, it was just very alive in my house. And so music for Victor is, um, his, his dis, his self-discovery as an artist and his growth as an artist and is. Part and parcel of his healing, not just in terms of his illness, but in terms of his trauma. Mm-hmm. So, um, getting Hansen's disease wasn't his first trauma. You know, Victor lived through war, lived through famine, lived through family separation and immigration and racism and poverty. So, you know, he had already learned to roll with life's punches by the time. Mm-hmm. He got to carville, so there's a certain kind of numbing or self numbing that. Often occurs, I think particularly in those of us who are socialized male and those of us who are of that generation, which was, uh, technically the silent generation actually. Oh, okay. Because my dad was born in 1937, so, you know, there was, uh, no emotional labor whatsoever anywhere. So, you know, my dad, like many of the other patients at Carville, learned to heavily compartmentalize.

EW: Hmm.

WCT: And, uh, I wanted to portray that in Victor's character, that he, as he explores himself as a musician, that's a way for him to reintegrate the parts that had been separated in, in order to survive. You know, as we all know, coping mechanisms become maladaptive over time. So Victor is discovering that his. Coping mechanisms up until that point had stopped working, and then he found a way into his art in order to heal and grow from that.

EW: I, I love seeing the growth through that musicality, through discovering more about himself. And also I'm, I'm curious whether the process of writing this book, you know, you say that you were familiar with your dad's story since, as for as long as you can remember. Yes. Did the process of writing this book kind of give you any more insight or understanding into his experiences, or was there more that you learned that you were surprised to learn while, while putting this book together?

WCT: So much of both. I think in order to perform that hat trick around music, that was my way into the character and to mm-hmm. Like very fully empathizing with him because in order to portray what it is to discover oneself as a musician and to start to play and start to compose, I had to find a way to bridge my own experience. Discovering myself as a young poet and discovering poetry and writing it, I had to transpose that into Victor's discovery of music and writing music. So within that process, I think there was a kind of deep identification, um, that happened, a kind of transference, if you will, and there was a kind of, uh intense empathy that was created [00:20:00] between me and my understanding of my father at that age. That, and also my dad and I took a trip to Carville in 2016 to do research together, and that was his first time back in 53 years, which was really remarkable. After he was discharged, he went back to New York, which many of his peers did not do because unlike my dad, most of his peers did not have a home to go back to. They were so fully estranged from their families that they chose to stay in. The only home that they had that, and also there was a possibility of federal funding for education. Some of his peers went to LSU, for example, which Victor is grappling with towards the end of the book.

WCT: But my dad went to New York and in his exit interview, as in most exit interviews at that time in the 1960s, he was told to not look behind and to look ahead and to forget about his experience and to not tell anyone that he had been in Carville, to not tell anyone that he had had Hansons. Because if he wanted to reintegrate into society, if he wanted to get a job, get married, move forward in life, like a quote unquote regular person, he would have to leave that behind and re compartmentalize as it were. So this was you know, a sort of official advice, which is somewhat contradictory, self-contradictory, because at the same time, there were services outside of Carville to help patients reintegrate. You know, for example, my dad's first job when he got back to New York was through the American Leprosy mission, I believe. Mm. So there, there were still ties. It wasn't a complete severing, but there was this code of silence that was institutionalized.

EW: Having that be sort of the official guidance?

WCT: Precisely.

EW: It's, uh, surprising but also not surprising, but just sad I think in a way. Mm-hmm. That like this is something, 'cause it, what it does is just further the shame and stigma surrounding Hansen's.

WCT: And I think that also circles back to partially answering one of your previous questions about why this place and this incredible achievement of federally funded medicine is so unsung, right? Yeah. I think it contributes to the, to that, and, you know, for what it's worth, it was realistic, right? Mm-hmm. It was, I, I don't think that 500 patients, only a handful of whom were going to leave the institution were they to reintegrate into their original home environments. I, I don't think it's realistic to assume that they could just be loud and proud that they just didn't have the numbers to do so, and to face. The intensity of the taboo and stigma around leprosy that still exists today. It actually still exists today and stops people from coming forward to seek treatment. I think it's somewhat realistic, sad, but realistic.

EW: Let's take a quick break here. We'll be back before you know it.

EW: Welcome back everyone. I'm here chatting with the wonderful Wendy Chin Tanner about her book, king of the Armadillos. Let's get into some more questions. That kind of gets me to another question that I had about sort of the, the state of Hansen's disease in the 1950s, 1960s. Yes. And just sort of a, if we could go through a general overview first, you know, what causes Hansen's disease, what are the, some of the symptoms, and then what treatments were available to someone at that time?

WCT: Yes. So Hansen's disease is a bacterial infection that left untreated will attack the nervous system. Initially, symptoms arise around lesions, skin lesions, but it can also attack the nerves, which it did in my dad. So my dad had bilateral ulnar nerve surgery in his, uh, arms and hands, which was fairly common. But in terms of the nerve disorder part of it. It will attack the extremities. So hands, feet, fingers, toes, the areas of the body that are colder. It can also cause blindness, which it did in, um, Stanley Stein who, uh, was the inspiration, the real life inspiration for the character Herb Klein. So it can cause a range of symptoms, particularly if left untreated for a very long time. Leprosy is very interesting in that, uh, 95% of the population is naturally immune. And it has a very low communicability. So even the 5% who are susceptible require prolonged contact, close, prolonged contact in order [00:25:00] to contract it. Mm-hmm. So it is not a public health issue at all, actually. Right. And we've known that even before the cure. But then in 1941 carville discovered the cure, the miracle of Carville, which is, um, sulfur drugs, proman. Mm-hmm. That enabled people to be fully cured. So from 1941 on there was absolutely no need for quarantine. There was no need for quarantine before that. But from 1941 on, they knew scientifically that there was no need for quarantine and yet quarantine persisted until the 1960s. So what does that tell us? That tells us that this is politically based. And not scientifically based. Mm-hmm. Nothing makes people panic quite like leprosy.

EW: It's true. And I was wondering also about carville and so if, if someone was diagnosed, let's say, you know, when, when your dad was diagnosed with Hansen's disease, what options were available? Someone clearly, you know, there was this fear-based quarantine aspect of it, but depending on age, on socioeconomic status, on your race, on where you lived, what sort of options were available?

WCT: I mean, everyone was sent. To Carville actually, with the diagnosis, everyone was sent to Carville, which is okay. Which is amazing because then in Carville, having Hansen's disease was the great leveler. Yeah. So Carville became this incredible microcosm of the United States. It was racially diverse. Mm-hmm. And it was also socioeconomically diverse. And it was diverse in terms of class. So you had people there who were literally socialites. Yeah, before entering Carville and you had people who were illiterate. That's incredible. Yes, it's absolutely incredible. And that also speaks to Carville as a social experiment.

EW: Going back to this discussions that we've been having surrounding shame and stigma. You know, at Carville, I. Because everyone that you are around also has Hansen's disease, understands maybe some of the aspects of stigma and shame, which then might alleviate some of that, but at the same time, you're on the grounds that are surrounded by a barbed wire fence. Yes. How did that sort of dynamic influence daily life at Carville and the interaction with the surrounding town?

WCT: I think there was very little interaction with the surrounding town, except in these sort of IV forays out. Mm-hmm. So there was, um, there was a bar that was down the river road, a kind of dive bar called the Red Rooster that patients would sneak out of a hole in the fence. To get to, and they would also sneak out of a hole in the fence to go fishing on the Mississippi River or to go have picnics on the banks of the Mississippi River and also to abscond. So some people did run off for various reasons, either to get married and then come back in or to, to just, you know, book it, either home or elsewhere. And if they were caught and returned, then they would have to stay in the Carville jail. For, uh, 30 days car jail. Oh gosh. The car jail. Yes. But so within the confines of the institution you had, during its heyday, which were the 1950s, the period that I'm writing about, about 500 patients, and it functioned like a small town in and of itself, so it was completely self-contained. Mm-hmm. It had its own working dairy. It had its own post office. It had two churches. It had a school where my dad finished high school, and it had all of the amenities of a small liberal arts college or of a country club. You know, it had a golf course, it had a lake, it had a pool, it had a theater, it had a movie theater. It had a volleyball court. It had a softball diamond, I mean. Everything you can think of a golf course, you know all the things, and it had a press. Where they published an internationally circulated magazine. So it was a world unto itself. It was completely self-contained. So for the most part, day-to-day life was very normal. You know, and human beings have this incredible capacity to normalize almost anything. But in reality, in the 1950s, the quality of life was very high, and it was really just like small town America.

EW: It sounds like a very progressive place. Yes. Relative to the time and the location. The, the surrounding location.

WCT: Yes. It was integrated at a time when the south was segregated, so right outside that fence. There was segregation and Jim Crow and you know, the high school was a Benetton ad. I'm showing my age by saying that the high [00:30:00] school was very multi,

EW: I'm showing my age by knowing what you mean. That's amazing. Um, everyone who was diagnosed with Hansen's disease was sent to Carville and then had to spend a certain amount of time there. Despite, you know, as you mentioned, uh, there being sulfa drugs that would essentially eliminate the need for any sort of quarantine. At what point did they leave? What was that process like for being released from Carville? I.

WCT: Well, until the 1960s it was, it was a very arduous process that was, once again, scientifically speaking, not necessary. So patients had to have monthly skin smear tests to see how much of the Hansen's bacilli they still had in their system, and they required 12 consecutive negative tests in order to be considered for discharge

EW: and negative meaning no bacteria whatsoever. Correct?

WCT: Correct. So you could, in essence, get 11 negatives and then suddenly test positive and then you were right back to square one. But you know, even after the 12th. Negative test, you had to go before the board and you had to, you know, have the, the go ahead of the physicians and the medical officer in charge in order to then be officially discharged.

EW: That does sound like a hugely frustrating process. As you beautifully described in your book, this anxious awaiting of each month, what's going to happen? What's it going to show? What does that mean for my future, this unknowing about what will happen? Um, and just sort of being beholden to that.

WCT: So in some ways it made sense that some people just kind of gave up and decided, I'm just gonna stay here forever because this is kind of the good life anyway. Yeah. And there's also this, um, actually a psychological phenomenon around institutionalization of becoming so accustomed to incarceration, essentially, that you become indoctrinated or, uh, interpolated into that system and you are fearful of returning to society even if you can. You know, Carville is a federally funded institution that amazingly, uh, had both the funds and the wish to allow patients to choose. Whether they would, uh, be discharged or stay even after they were technically able to be discharged. So a lot of people did choose to stay, including Stanley Stein,

EW: which I, I would love to talk more about Stanley Stein because yeah, Herb is one of my favorite characters in your book. I loved him and I was very curious to know more about the real life person that this character is based on. So what can you tell me about Stanley?

WCT: Yes. So Herb Klein is based on a real live, uh, disabled gay Jewish American hero, um, whose name was Stanley Stein. And, uh, you know, he was a closeted gay man at the time, but it was, you know, it, it was, uh, an unspoken truth. Um, and interestingly too. Even though he was living with a man, and it was generally known that, you know, he was a gay man. He was the head of the patients federation. He was the founding editor and editor in chief of the Star Magazine. And you know, he was the defacto mayor of Carville, basically. Mm-hmm. He was a pharmacist. From, uh, a small town in Texas and in the 1930s he was diagnosed with Hansen's disease and he was sent to Carville, and this was 10 years before the cure, so he lived with a disease for so long that he became permanently disabled. So by the time my dad got there in the 1950s and met him in the infirmary, Stanley was unable to walk without a cane. Eventually, he would be unable to walk at all, and he was blind and he couldn't even read Braille. Because his fingertips had become so desensitized from the disease that, um, he had to have everything read out loud to him. So my dad and Victor in the book volunteered to be one of his readers. So he would read everything from his correspondence to newspapers, to proofs of, of the articles, which he would then edit, you know, and yeah, it was really

EW: extraordinary. That is. That is amazing. And I also just love that your dad, like Victor in your book, actually had this like very close relationship.

WCT: Yes. And in real life too. Stanley became, somehow he was incredibly charismatic and charming, just this [00:35:00] uncommonly, charismatic and charm, charming man. And he became pen pals initially with Hollywood Star Tallah Bankhead. Yes. That's amazing. And then they became besties in real life. I have archival photos of Stanley and Tallulah. There was a point at which Stanley went on leave and he and Tallulah were. Uh, in New York, going to parties, going to Broadway shows, there are pictures of Tallulah sitting on his lap. I mean, it's, it's really incredible. And so Tallulah became his sort of Hollywood spokesperson for the Star Magazine, and she strong armed all of her friends to subscribe. And it grew from being a sort of, as Stanley called it, a gossip brag, uh, within Carville itself to having 90,000 subscribers all around the world.

EW: First of all, I really wanna see those pictures. They sound amazing. Yeah. And secondly, I, I love that spread of the Star magazine, how, how huge that got. And so what was in this magazine, what sort of articles were there? What information was presented?

WCT: So it was founded just a couple of years after Stanley got to Carville. And uh, what was really interesting about that was this kind of stumbling into, you know, what I like to think of as SS in the sense of life force, not just libido. Mm-hmm. Right? So, and ERO stands in contradiction, Totos, which is the death drive, right. So. Carville was all about Eros. It was all about imagination, creative endeavor. You know, not only was Stanley really interested in musical theater and you know, he was involved in plays and stuff like that, but he founded within a couple of years of getting to Carville, the Star Magazine, he had been interested in journalism.

WCT: Before getting to Carville, he had dabbled in it, but his father was a pharmacist, so he became a pharmacist. And so he was a bit of a frustrated creative who then was able to blossom as a fully fledged creative when he got to Carville, which was really interesting. So it started really small. Just a, a locally circulated, you know, within Carville sort of magazine. And over time it had a bigger mission and the mission was to shine a light on the truth of Hansen's disease and restore dignity to its sufferers. So I think Stanley basically took the star as an opportunity to show the outside world. What was happening within Carville Show, the outside world, what patient life really was like to reduce the stigma around Hanson's, to talk about the newest discoveries and things like that.

WCT: But he also, I think, used it very brilliantly to put the screws to the administration. When he and the patient's federation were advocating for higher quality of life because, you know, while it was mostly a progressive place, it wasn't always so, and the quality of life for patients was almost entirely dictated by the medical officer in charge. So it was either a benevolent dictatorship. Or it was not. So there were some times in which, you know, you had this kind of golden age or you know, Carville-ian, renaissance of, of culture. If you had a medical officer in charge who like Dr. Johansen, after which the lake is named because he built it for the patients. Uh, there was a kind of blossoming of normalcy and culture and arts, and he was, you know, very slack about people going out of the hole in the fence. And he allowed for, uh, leaves and vacations and things like that because, you know, he was science-based and he was also very empathy based.

EW: Right

WCT: after he retired, another guy came in, Dr. Gordon, who was, you know, a real stickler for the rules and he reinstituted all of these really draconian rules and he cracked down on everything from dancing to dating and, uh, the married co cottages where, you know, married people lived. And Stanley and his quote unquote friend, um, oh my God, I. Yeah, so he, yes, he was the only bachelor living in the married cottages. But, so Dr. Gordon tried to crack down on all of this, and, and the patient's federation organized, they, um, utilized a lot of the same tactics that the civil rights movement was using. They had. Sit-ins, they had [00:40:00] strikes. Imagine my dad being a 17-year-old, 18-year-old, very excited about making signs and having sit-ins and strikes. And Stanley also utilized the star to publicize what was happening, the conditions. That, um, they were dealing with within Carville and so there was external pressure and the patient's federation was able to use connections that he cultivated to hire a lawyer. Who went to the hill to speak on their behalf and also a local politician to go to the hill and speak on their behalf. And within only four years they managed to kick this guy out. Oh my. The most marginalized of marginalized people

EW: Yes. To it's a and to, to think what one, and I know that it was, it was many people involved, but to have that sort of, to have Stanley spearheading this what one person can do. Yeah. And achieve is amazing to think about

WCT: and also what solidarity and cism can achieve. Yes. 'cause within the patient's federation, there were a lot of differing opinions, a lot of differing. Political opinions and ideologies and, uh, religions and whatnot. I mean, you could have very much had factions and schisms and you know, what we're seeing now, for example, in our country at large. Mm-hmm. You could have had, you could have had that, but. They had the opposite. They had solidarity. They had a cause, a common cause, a common enemy, I guess a common cause that they coalesced around and, uh, they made things happen. And so I think that this experience at such a formative time for my dad really made him the man that he.

WCT: You know, like my dad likes to call himself a radical and he is, um, you know, after he was discharged, he protested the Vietnam War. He marched with Dr. King. He protested multiple wars with me, and he was down at Occupy Wall Street. Much to my mother's chagrin. Because, you know, there were a lot of arrests that were happening and, you know, he was already somewhat elderly by that point, but he didn't care. He was down there with his, uh, with his camera. So I think that is the legacy of Carville. You know, he became a very politically engaged citizen. Mm-hmm.

EW: And, and just the power too of the people that you surround yourself with at a formative time of your life. Yeah, and that kind of brings me to this, this idea that I love that comes through in your book so much, these themes of family and the complexities of family and found family. And Victor in your book, one of his, uh, found family members is Herb, but he also has these. These other individuals that make this up, and I wanted to ask you more about that, whether that is, you know, from how you chose that for Victor, or how Victor told you that's what he needed and what that reflected about, you know, life at Carville, the population at Carville, and also your dad's experience.

WCT: Yeah, I mean, those questions are somewhat entwined. You know, my dad left my grandmother behind when he was eight years old, like Victor and his father was in reality, even more sort of distant emotionally from him than Sam in the book. So my dad and Victor were both very, very hungry for connection and very, very hungry for mentorship and I wanted to portray that in Victor. I wanted to show him as this, um, you know, very sensitive kid who was looking everywhere he could for found family, not just mentorship, but looking for father figures, looking for mother figures, and he found them. I think in reality in Carville there was also that sort of mentorship, particularly of young patients who were separated from their families. So they were sort of adopted and taken under the wing of older patients. So these sorts of informal found families and informal adoptions would happen in real life there. Um, another one of the found family members that Victor. Has in the book is Sister Helen, who is based also on a real person sister Hillary Ross, who was a very accomplished research scientist who was also the head of the lab and did all of the medical photography and she was instrumental in, uh, helping to find a cure in 1941. So I wanted to kind of fold her into this story as well.

EW: I wanted to kind of talk a little bit about victor's how [00:45:00] his life is just sort of punctuated by trauma after trauma and you know, with his diagnosis of Hansen's disease being one of them. And you do such an incredible job of letting the reader experience. This, this physical pain through Victor's eyes, through his, his body, his discomfort, his isolation, that he feels this loneliness who like, I don't know any of these people. What is this place? What do I do here? And then also just not knowing what's happening to him. Yeah. His body. Because the doctors are at the time very paternalistic and not really feeling It's important to let the patient know what is happening, right? How all of these feelings are also. Wrapped up in his experience as a Chinese immigrant. Yes. So I wonder if you could just talk a little bit about all of these different, the swirls of emotion with this, with this aspect of his identity.

WCT: Yes. I mean, it's also bound up in his experience as an adolescent. Yes. Because he's becoming a man. So I, I wanted to think about Carville as a sort of liminal space, you know, as the in-between place that everyone goes through during rites of passage. So it is a liminal space between Victor's boyhood and manhood. It's a liminal space between Victor's illness and wellness. So that's one aspect of it. Another aspect, the racial aspect is very interesting. So there was a very large Asian population at Carville and when I was researching oral histories in particular, because, you know, that was actually one of the, uh, pieces of research material that was the most rich for me in terms of helping me understand aspects that I couldn't find otherwise for the book, I couldn't find a single firsthand narrative by an Asian patient, even though there was such a significantly large population of them. I don't know if that was because of, uh, self-selected abstinence, if that was institutional neglect or something, you know, more nefarious around, you know, just blatant racism. I don't know. I can't say, but I know that there was a hole in the record, and so, mm-hmm. You know, not only did I feel compelled to fill it, but I felt compelled to dive even deeper into it.

WCT: So, another thing that I didn't know until I started researching around the history of the book, not just around the history of Carville, was that there is a long relationship in America, in anti-Asian hate, um, between stigmatization of illness, specifically leprosy. And anti-Asian hate. So, um, I discovered, for example, that in the 19th century there was a labor leader named Dennis Kearney in San Francisco. Dennis Kearney was an Irish immigrant, which is perhaps ironic that he was also an immigrant. But, you know, he was the head of, uh, a labor movement that was pushing for the exclusion act to happen because, you know. Uh, Chinese laborers were strike breaking and they were taking white jobs, et cetera, et cetera. Mm-hmm. So, you know, part of the racial pecking order of that time, because Irish immigrants were also not considered fully white.

WCT: Mm-hmm. So, um, you know, that's, that's another sort of nuanced, intersectional aspect of this. So, at one point. Dennis Kearney couldn't get enough traction with just your usual narratives of taking white jobs and selling opium and you know, running brothels. So he found a Chinese man who had lesions on his face. Mm-hmm. And he marched him through the streets of San Francisco and said, if we don't kick out the Chinese, they're going to give us all leprosy. So disease stigma globally. Throughout history has been a tool, a propaganda tool for exclusion of particular groups. But so this leprosy story and the relationship between leprosy and the Chinese population has persisted from that point on. So following on the heels of Dennis Kearney and the exclusion Act that was passed in 1882, the Joseph Jones, who was the former head of Louisiana State's, uh, department of Public Health, went on the record to spread misinformation. Um, and he, he said on the public record that, um, Chinese laundries in New York City, how he would know that, I don't know. But in New York City and in New Orleans had a habit of spitting water [00:50:00] on the clothes that they were ironing and thus spreading leprosy to all of their customers. So, um, you know, as you can probably imagine, the media ate this up. Of course, this is very, of course, sensationalist, clickbait, if you will. Mm-hmm. And this story was recycled over and over again. I found incidents of it in the 1940s and even in the 1950s. So, uh, yeah, it was regurgitated again and again because, you know, it's very, it's spicy, it's, yeah, it

EW: is. God, it is amazing how history. I mean, maybe it doesn't repeat, but it rhymes. Mm. And it's just,

WCT: I love that

EW: just, it's something that I feel like we're saying a lot on the podcast, like misinformation has been around forever and it is a tool or disinformation. Mm-hmm. Yes. Specifically a tool, and there is an agenda behind it.

WCT: I will say too, that as a result of the Exclusion Act, family separation for Asian families. Asian American families, I should say, persisted for generations. Mm-hmm. So in my dad's case, for example, the first immigrant in my family to come to the United States was in 1849, the Gold Rush. But as a result of exclusion laws, Chinese men would stay in the States. And then go back to China Periodically, they would get married, they might have children, and they would bring their male children to the States. So you would have generations, 3, 4, 5 generations of families that were separated. And what do you think this does to the psychology of people? What do you think this does to their capacity to, you know, not only parent themselves, but to form healthy relationships? It's, it's a psychological wound that we see within the community that mm-hmm. Is persistent for, you know, decades and decades and decades.

EW: Generational harm. Yes. From this and I, there are so many different things that I feel like people can take away from your book. So many important lessons, so much that we can learn from. Carville and, uh, I, we could probably spend another hour talking about all of those, but I, I wanted to ask you what, what your big hope is, if you have one for what people take away from this book.

WCT: Wow. That's a big question. I mean, I think, um, it's twofold. You know, on, on the one hand, on a more sort of, um, philosophical level, perhaps I would want people to take away the idea or the, the truth that people are people wherever we are. Whether that's in an 18th century castle in France, or it's in a federal institution for the treatment of leprosy in the 1950s, or if it's in 2025 in New York City, we all have the same hopes and desires and dreams, and we all have the same capacity to love and to do harm and to make mistakes and live with the consequences of them. That this sort of thread of persistent humanity, that the patients at Carville, that the people that I portrayed in the book are more than their circumstances. Hmm. Um, so that's. On a philosophical level, on a more concrete level, I think a takeaway, um, that I would love for people to have certainly now is that Carville is an example of the government doing it right. Government medicine and federally funded science and medicine, achieving something that really did a lot of good and that not only found the cure. Quite quickly, but also took care of thousands and thousands and thousands of patients in a way that was empathy based and communitarian and positive. As you said, we don't have to repeat history, but as Maya Angelou says, you know when you know better. Do better.

EW: Beautiful words. Very apt. Such an important message. I, I really just really appreciate you taking the time to chat with me today. Thank you so much. This was such a great conversation.

WCT: Oh, it's my absolute pleasure and thank you so much for having me. I truly appreciate the opportunity. I.

EW: A big thank you again to Wendy for taking the time to chat with me. I so enjoyed this conversation and book. If you like today's episode and would like to learn more, check out our website. This podcast will kill you.com, where I'll post a link to where you can find King of the Armadillos, as [00:55:00] well as a link to Wendy's website where you can find her other incredible work. And 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, our Good reads list of firsthand account form and music by blood mobile. Speaking of which, thank you to Blood Mobile for providing the music for this episode and. All of our episodes, thank you to Liana Sci and Tom Bry Fogel for our audio mixing. And thanks to you listeners for listening. I hope you liked this episode and are loving being part of the T-P-W-K-Y 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.