

## Transcript: John Green vs. Johnson & Johnson (part 1)

**Dan:** Hey there. A little while ago, I got to talk with this widely-beloved dude.

**John Green:** My name is John Green, and I'm a writer and youtuber

**Dan:** John Green, writer, may be the most likely to ring a bell. His best-known book, "The Fault in Our Stars," sold millions of copies and became a movie.

But before he was such a big deal as a writer, he and his brother Hank were a big deal on YouTube. They still are. We'll get into the details a little bit later.

But for now the thing to know is: Pretty recently, John Green got on the main YouTube channel he and his brother share, and started talking to hundreds of thousands of people about how the drug-maker Johnson and Johnson was using legalistic drug patent games to deny access to life saving tuberculosis medicine to millions of people in poor countries. And John Green wanted anybody listening to stand up and do something about it.

**John Green:** Tell your friends about this injustice, tell your family, tell the internet, because the only reason Johnson Johnson executives think they can get away with this is that they think we aren't paying attention in the part of the world where they sell most of their products, their Band Aids, their Tylenol, their Listerine.

**Dan:** And a lot of the people who watch John Green's videos-- the community calls themselves "nerdfighters" -- made a fair amount of noise.

And a few days later, Johnson and Johnson seemed to blink. The company issued a statement saying it would allow a cheaper generic version of that TB drug to be more widely distributed. Here's John's brother Hank from their next YouTube video.

**Hank Green:** and this happened in a week, John, you made a video on Tuesday, it's Friday right now! I'm really proud to be a part of this community I'm really proud to be your brother...

**Dan:** I mean, that's a super-fun story that we're gonna get into: How a self-proclaimed nerd raised an internet posse to influence a global pharma giant to do something pretty decent-sounding.

We are definitely going to tell that story.

... But that story is just a first impression, because the whole thing is bigger and way more complicated.

As John Green would tell you-- as he told me-- he was adding his bit to a global movement -- to advocates and lawyers in places like India, for instance, that have been doing the heavy, heavy lifting, for years.

And of course to understand any of this, we are going to have to get into how pharma companies use drug patents. And what it means.

Which is part of where this story comes home.

As John Green mentioned in his video, the story of this tuberculosis drug wouldn't normally draw a lot of attention in the U.S. TB isn't one of our top health issues.

But the mechanisms at play with this tuberculosis drug-- the patent games -- are some of the same mechanisms that make so many drugs here so expensive: Drugs like Humira, and insulin, and pretty much everything else.

And here's what's actually the most interesting part:

Behind the first impression version of this story -- nerds in the U.S. and their online posse for people in what's called the Global South--

there's a story about people and ideas from the Global South coming here to save the U.S. from our own messed-up drug patent system.

Because they've figured out that unless we save ourselves, they're screwed too.

That's a LOT! And it's gonna take us two episodes to connect all the dots.

Here we go...

This is An Arm and a Leg. A show about why health care costs so freaking much, and what we can maybe do about it. I'm Dan Weissmann. I'm a reporter, and I like a challenge. So our job on this show is to take one of the most enraging, terrifying, depressing parts of American life, and to bring you something entertaining, empowering, and useful.

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So, let's start with John Green -- YouTuber.

John and his brother Hank were among the people who invented the idea of being a professional quote-unquote "creator" on the internet- maybe kind of by accident, at first. But they were hugely successful at it.

In 2007 they started posting video messages to each other on this still-kind-a-new website called YouTube. They thought a few hundred people might be interested, if they kept it up for a year.

Then Hank posted a song about waiting for the last Harry Potter book to come out.

**Hank Green:** I'm getting kind of petrified. What would Ron do if Hermione died or a Voldemort killed Hedwig? Just for yuck.

**Dan:** It got a million views-- which, early YouTube? That was huge. And they were off. Today, that original YouTube channel, has more than three and a half million subscribers. Hank now manages more than a hundred full-time employees and a whole bunch of contractors.

It's impossible to sum up the thousands of videos they've shared.

**Hank Green:** Good morning, John. Today we're gonna be making cinnamon toast two different ways.

**John Green:** Good morning, Hank, it's Tuesday. So I need your help with the thing I'm working on. I need to learn some jokes, but not just any jokes.

**Dan:** But it's fair to say digressive, ranty arguments are kind of a staple.

**John Green:** Good morning Hank, it's Tuesday. I kind of hate Batman.

**Hank Green:** Good morning, John, you pretty much got Batman entirely wrong. Of course, I know that Your video on Tuesday wasn't really about Batman, it was just using Batman as a tool to say something.

**Dan:** The arguing may have something to do with why they call their community nerd-fighters.

But the idea is more that this is a community of nerds fighting for something. As they put it: fighting to 'reduce the amount of suck in the world.'

Partly by producing things that can be amusing and sweet and thoughtful -- but also by giving money to worthy causes and encouraging others to do the same.

So, every year, since the beginning, they have hosted a kind of online telethon called the Project for Awesome.

**John Green: Good morning, Hank. It's Thursday, December 17th, 2009. Time for the Project for Awesome! Hooray! Oh! Ow! Whoa! I got too excited about the awesome.**

**Dan:** It is SUPER-interactive: People upload videos pitching their favorite charities, they vote, they give. They've raised more than 30 million dollars. And a lot of it has gone to an organization called Partners in Health, which provides incredibly effective health services in places like Haiti and Sierra Leone.

And just to indulge my own tendency to nerdy digression here: A book about Partners in Health and its founder, Paul Farmer, is one of my favorite books of all time.

It's called Mountains Beyond Mountains, and when we finally do start a book club -- and I haven't forgotten making that suggestion here-- I want to nominate it as one of our first picks.

Anyway, the Green brothers are huge supporters of Partners in Health. And then, three years ago, John started one of his weekly videos this way.

**John Green: Good morning, Hank, it's Tuesday. So over the next five years, our families are donating six and a half million dollars to Partners in Health Sierra Leone. Also we need your help...**

**Dan:** And here's where we get to tuberculosis. In the run up to that commitment, John Green visited Sierra Leone with his wife Sarah, and met some of the folks there from Partners in Health.

Here's how he told the story to me. I'm not gonna interrupt:

**John Green: On the last day, two of the physicians from Partners in Health, who we were visiting with said, Hey, if it's not a big deal to you, we'd really like to stop by this TB hospital on the way back to the capitol because we**

have a case we're really concerned about. And I said, Yeah, of course, I'm not going to get in the way of actual doctoring. So, but I, you know, I didn't think much of it at the time. So we get to this TB hospital. And immediately upon arriving, the doctors go off to do doctor stuff. And Sarah and I are just sort of sitting there in this little nine year old boy who tells me his name is Henry, which is my son's name, at the time, my son was nine, kind of grabs me by the shirt and starts walking me around. And he takes me to the lab, shows me how to look into the microscope to see if a specimen has tuberculosis, introduces me to the lab technician, he takes me to the patient wards, he takes me to the kitchen where they make the food, he takes me all over the hospital, and then eventually I end up in the room with where the doctors are, and, uh, and the, and the kid has departed and I said, you know, I just spent 30 minutes with an extraordinary child named Henry and he gave me a tour of the whole facility and I have no idea who he is. Is he somebody's kid? Is he a doctor's kid? And one of the doctors said, you know, that's what I thought when I first got here, uh, about Henry because he does seem like that. And actually he's the case that we're so concerned about that we, um, needed to come here. And he wasn't nine. He was 16. He was just really stunted and emaciated by tuberculosis. And, um, even though he was feeling pretty good at the time, the doctors knew that his treatment for multidrug resistant TB was failing, and that he needed access to a new cocktail that included bedaquiline, this drug that's been around in the U.S. since 2013, but was, was at the time totally unavailable in Sierra Leone. And so, that was my introduction to TB and we were on our way to the airport and I said, what's gonna, what's gonna happen to that kid? And they were like, it's going to be a difficult path for him um, if we can't get, if we can't get the new treatment cocktail to him, he has a very low chance of survival. So that's the beginning of the story for me, is meeting Henry.

**Dan:** I'm going to skip to the end of this part of the story: Henry's OK. He's alive, because he did get the drug cocktail that included Bedaquiline.

But after that visit, John Green did not know that, and he started obsessing a bit about tuberculosis. Reading about it, thinking about it. And over the last year or so, he started occasionally sharing: making videos about TB. Some of them were fun, short, nerdy explainers.

**John Green:** What if I told you that tuberculosis gave us the cowboy hat?

**Dan:** Or

**John Green:** How did tuberculosis help New Mexico become a state? I'm so glad you asked.

**Dan:** But he also dug into the deeper reason he'd become obsessed with TB. Because it's a surprisingly big deal, still.

**John Green:** it's almost certain that in the last 2, 000 years, more people died just from tuberculosis than died from all wars combined.

**And before you think like, oh, but that's ancient history. No, more people died last year from tuberculosis than died in war, and every year going back to World War II**

**Dan:** We fact checked that. He's actually understating things. By a lot. And: TB is a growing problem. In the middle of the 20th Century, new medicines took TB off the list of diseases that most people in the rich parts of the world had to worry about. But it never got wiped out.

And in less-rich parts of the world, where access to the best treatments was spottier, drug-resistant strains of TB developed and developed. But no new drugs came out-- no drugs for drug-resistant TB.

Until Bedaquiline, produced by Johnson and Johnson. The drug that did eventually help save Henry, the kid that John Green met in Sierra Leone.

But Bedaquiline is expensive. So people in less-rich parts of the world often can't get it. One study estimated that eight out of nine people who needed treatment with a drug like Bedaquiline weren't getting it.

And of course medicines stay expensive when they're under patent protection: Once the patent on a drug expires, anybody can make and sell a generic version of the drug. Which, you know, competition, usually allows prices to fall.

And in one way, as John Green started making tuberculosis videos in 2022, it might have seemed like there was hope coming up:

Bedaquiline was patented in 2003. Patents last twenty years. By 2023, that patent would expire.

Except, not really. Because it turns out, patents on drugs have ways of living for way more than twenty years.

That's next.

**MIDROLL:** This episode of An Arm and a Leg is produced in partnership with KFF Health News. That's a nonprofit newsroom that covers health care in America. KFF Health News are amazing journalists-- their work wins all kinds of awards every year-- and I'm honored to work with them. We'll have a little more information about KFF at the end of this episode.

**Dan:** So, let's talk about drug patents and how they work-- and why they don't just last 20 years. And this is something my colleague Emily Pisacreta has been interested in for a long time.

**Emily:** It's true. As I've said before on the show, I'm an insulin-dependent diabetic. If I can't get insulin, I'm literally dead. And, insulin is super expensive. And insulins have become so expensive in part because of the kinds of patents on them – even though those patents are way more than twenty years old! ..

**Dan:** Right, so Emily: You've got a big interest in this question: How can a patent last more than twenty years?

**Emily:** And Dan, my answer to that question is a riddle: When is a patent not a patent?

**Dan:** OK, I give up. When is a patent not a patent.

**Emily:** When it's 74 patents.

**Dan:** Yeah, this riddle is going to need some explaining.

**Emily:** Right. So, for a while I used an insulin called Lantus. It's a once-a-day, long acting insulin made by the French company Sanofi. Sanofi first patented Lantus in 1994. So, that should mean it's out of patent protection by 2014, right?

**Dan:** Uh-huh

**Emily:** Except, according to a report from a few years back, Sanofi actually filed for 74 patents on Lantus. And a lot of those patents were filed WAY after 1994. So ONE patent from 1994 would've lasted till 2014. 74 patents could've lasted until 2031.

**Dan:** Hence the very-specific answer for your riddle. I mean, I knew the principle-- these insulin products have multiple patents on them, but 74 is ... more than I'd imagined. What are 74 things you even COULD patent?

**Emily:** I mean, for Lantus, there are patents on formulations to improve stability. All right.. But there are also patents on the pen cartridge that Lantus comes in. And inside of that, a whole bunch of patents on the drive mechanisms, like the little plastic piston that lets you pick the right dose. These kinds of things.

**Dan:** Now, I notice you said, those 74 patents COULD've lasted until 2031?

**Emily:** That's right. As it turns out, in the case of Lantus, another drug maker actually did fight Sanofi's patents and won. But more often-- and I mean a lot more often -- simply filing for a patent is enough to keep generic makers away.

**Dan:** Sure. Who wants to spend money fighting a patent lawsuit when you could just y'know, manufacture some other drug?

**Emily:** Right. And of course this is not just insulin.

**Tahir Amin:** Oh, this is the standard practice. This happens with every drug.

**Emily:** That's Tahir Amin-- one of the big global experts on drug patents. Tahir the CEO and cofounder of a non-profit called I-MAK, which stands for

**Tahir Amin:** The Initiative for Medicines Access and Knowledge. We work on building a more just and equitable access to medicine system.

**Emily:** The report that documented 74 patents on that one insulin, Lantus? Tahir's group wrote it. And Tahir says this is business as usual, because it means big money.

**Tahir Amin:** particularly when you're talking about some of the drugs that you see in the US market, like for rheumatoid arthritis, these are worth billions of dollars.

**Emily:** Tahir's group did a study on the 12 best-selling drugs in the U.S. They had an average of 131 patents each. If all the patents stick, that's an average of 38 years of patent protection.



**Dan:** So maybe we can update your riddle: When is a patent not a patent? When it's 131 patents.

**Emily:** Yeah, activists and experts call this kind of thing "patent thicketing" or "evergreening."

**Dan:** I've been reading up on this too. Drug companies have their own name for this practice: Life-cycle management.

**Emily:** What a term of art. And actually bedaquiline, the TB drug, is a great example. In 2014, Tahir did what they call a "patent landscape" on bedaquiline, mapping all the different patents J&J filed around the world.

**Tahir Amin:** we all knew that with the advent of multiple drug resistance tb, we needed to know how we're gonna get these drugs to the communities and the countries that they need them most.

**Emily:** He identified a long list of patents J&J filed -- the most important being the original formula for the drug, set to expire in 2023, and the second most important patent was on something called the salt formulation for the drug.

**Dan:** Salt formulation.

**Emily:** Yep, and it's kind of worth getting into the weeds here just for a second. Because this sort of thing is at the absolute heart of these drug patent games. So, when you develop a drug, the first step is finding a molecule that works in a test tube. Does the thing you want, like kills the germ. That's the first patent, that molecule. But the molecule itself isn't medicine.

**Tahir Amin:** You have to develop it, formulate it so that it's actually more bioavailable, that it can get into the bloodstream and, and do whatever biological activity that it does. And this is classic sort of, uh, organic chemistry stuff that is, is routine.

**Emily:** It's routine. SO what he's saying here, other experts agree, identifying a salt formulation that can work as medicine isn't where the innovation is. And most importantly, it doesn't have to take a long time. But J&J didn't apply for their secondary patent on it until a full four years after their initial patent.

**Dan:** You know, I've started reading about "lifecycle management" -- that's what the pharma industry calls all this. And this is literally the playbook. One

lawyer has advice about when to file this kind of secondary patent, here's what he says, quote:

“You want to do this as late as possible, but before clinical trials. If Company X can hold off filing for two or three years during the drug discovery phase, it will buy more time on the back end of the patent's term.”

**Emily:** Yep, and J & J waited four years. A little extra.

**Dan:** And we asked Johnson and Johnson: Hey, did you put off filing this secondary patent on the salt formulation to stretch out your patent rights? We haven't heard back.

So: TB advocates kind of had their eye on 2023. Because in July 2023 the original patent that Johnson and Johnson had on bedaquiline was set to expire. And the secondary patent, this sort of basic add on, was to become the next big obstacle.

So, back to John Green. He's learning all this stuff about TB-- including about how the secondary patent on bedaquiline is gonna keep clamping down access.

He's making all these TB videos, but it's not like he has some kind of big plan:

**John Green:** But the, for me, You know, this is all I was thinking about.

**Um, it was the first thing I thought about in the morning and the last thing I thought about before I went to sleep is how did we end up in a world where the world's deadliest infectious disease is largely ignored in the richest parts of the world?**

**Dan:** And he was getting kind of discouraged.

**John Green:** I felt powerless before it. And this is one of the real lessons for me is that I felt like, well, what, what are we going to do? It's not like Johnson Johnson is going to like abandon the idea of secondary patents, right?

**Dan:** He knew: secondary patents can be worth billions of dollars.

**John Green:** And so they're not going to abandon these attempts to make their patents last longer than they should because they're a for profit company. And I felt really. Yeah, I just felt powerless.

**Dan:** And then, earlier this year, something changed. It was not something that John Green or an army of nerds could have done, or could've done anything about.

It was done by India's patent office-- responding to a legal challenge brought by two young women who had survived tuberculosis-- one from India and one from South Africa.

It was based on legal work that our new pal Tahir Amin and others did in India almost twenty years ago.

And gave John Green an idea of how an army of nerdfighters could join this battle.

That's next time, on An Arm and a Leg.

Till then, take care of yourself.

This episode of An Arm and a Leg was produced by me, Dan Weissmann, and Emily Pisacreta -- with help from Bella Cjaskowski, and edited by Ellen Weiss.

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An Arm and a Leg is produced in partnership with KFF Health News--formerly known as Kaiser Health News.

That's a national newsroom producing in-depth journalism about health care in America, and a core program at KFF — an independent source of health policy research, polling, and journalism.

And yes, you did hear the name Kaiser in there, and no: KFF isn't affiliated with the health care giant Kaiser Permanente. You can learn more about KFF Health News at [arm and a leg show dot com, slash KFF](http://armandalegshow.com/kff).

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