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Writer v. Big Pharma: How John Green, Author and YouTuber, Fought the Evergreening of a Drug Patent

By: Rachel Bier



Tuberculosis (TB), an illness caused by the bacterium *Mycobacterium tuberculosis*,^[1] is the deadliest disease in human history.^[2] In the 1950s and 1960s, scientists developed several drugs that could treat TB.^[3] These developments meant that TB became a curable disease.^[4] However, TB remains a terrible epidemic in poor communities around the world.^[5] About 4,000 people die from TB *every day*,^[6] with over eighty percent of those deaths occurring in low- and middle-income countries.^[7]

To tackle this enormous global health crisis, on September 26, 2018, the United Nations (U.N.) held the first high-level meeting on ending TB.^[8] At that meeting, the participants drafted a resolution that set forth commitments for Member States to follow to reach the goal of ending the tuberculosis pandemic^[9] by 2030, which was then adopted by the General Assembly.^[10] Since the first meeting, some progress has been made in combating TB.^[11] However, the global Covid-19 pandemic has slowed progress and further strained healthcare systems around the world.^[12]

In order to set updated and more effective goals to fight TB, the U.N. General Assembly held a second high-level meeting on September 22, 2023.[13] The subject of the meeting was to end the plague of tuberculosis, “in particular, by ensuring equitable access to prevention, testing, treatment and care.”[14] In attendance at the meeting were world leaders, TB survivors, and representatives of civil society organizations. One of the civil society representatives was John Green,[15] a famous YouTuber, YA novelist,[16] and TB activist.[17]

Green, working in partnership with other TB activists like the global health and social justice organization Partners in Health (PIH),[18] and his community of online followers known as Nerdfighteria,[19] has played an important part in the fight to end TB. Most notably, Green’s activism has directly made the critical medication Sirturo, known generically as bedaquiline, [20] more accessible to patients in developing countries.[21]

Bedaquiline is a medication that targets forms of TB that are otherwise drug-resistant, making it a highly important tool in combating the TB epidemic.[22] Bedaquiline was developed and patented by the pharmaceutical giant Johnson & Johnson (J&J) in 2012.[23] The majority of the funding for bedaquiline’s research and development came from public funding, but J&J held a monopoly on the drug.[24] J&J’s patent was set to expire in 2023, which would allow the manufacture of cheaper generic versions and could save the lives of millions of low-income patients. [25] In an attempt to “evergreen” its control over the supply of bedaquiline, J&J slightly modified the drug’s composition in order to be able to enforce a secondary patent.[26] Imposing this secondary patent would mean generic bedaquiline would remain out of reach of scores of TB patients for several more years.[27] Hundreds of thousands of people who could have otherwise been cured would die of TB.[28]

Determined to stop this from happening, on July 11, 2023, John Green posted a video on his YouTube channel Vlogbrothers entitled, *Barely Contained Rage: An Open Letter to Johnson & Johnson*. [29] In the video, he described the great injustice that would occur if J&J enforced its patent and allowed thousands of people to die from lack of access to generic bedaquiline.[30] He called on J&J to remain true to its corporate credo: “We believe our first responsibility is to the patients.”[31] Green then called on his followers to pressure J&J not to enforce its secondary patent.[32] In response, J&J put out a statement denying that it was acting in bad faith.[33] Green, however, did not back down and continued to speak out against the company across his various social media platforms.[34] After only two days of Green’s vocal online pressure campaign, J&J caved. Stop TB Partnership, a U.N.-hosted TB-fighting organization, announced that, after negotiating with J&J, the company would allow the manufacture of generic bedaquiline in low- and middle-income countries where it was so desperately needed.[35]

When John Green spoke at the U.N. high-level meeting in September, he explained how today, tuberculosis deaths are not the results of a bacterium.[36] When patients of TB, a curable disease, die because human-built socioeconomic systems prevent them from accessing the treatments that would cure them, their deaths are “caused by ... human choice.”[37] Green went on to urge the other participants of the meeting to change this reality: “We have chosen the world that we share today and we can choose a better world. We are currently choosing a world where 1.6 million people die of tuberculosis and I believe that with your help together ... we will choose a world where no one dies of tuberculosis.”[38]

Green and his fellow activist’s work has been impactful. At the conclusion of the meeting, Member States approved a political declaration renewing their vow to end TB by 2030.[39] The declaration, which they drafted for General Assembly adoption, frequently stresses the importance of guaranteeing access to TB medications.[40] The new resolution mentions the necessity of ensuring access to generic TB treatments three times; the 2018 version only did so once.[41]

J&J is a company worth over 300 billion dollars.[42] And yet, in a matter of days, hardworking activists, a passionate author, and a social-justice-oriented online community were able to bring a megacorporation to its knees. This advocacy blocked the evergreening of a patent, impacted policymaking at the highest intergovernmental levels, and saved thousands of lives. Looking to the future, it is clear that grassroots activism is a key tool in the fight against TB and healthcare injustice.

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- [33] Johnson & Johnson (@JNJNews), Twitter (July 12, 2023, 12:38 PM), <https://twitter.com/JNJNews/status/1679168314986094592?lang=en> (“It is false to suggest—as some recently have—that our patents are being used to prevent access to SIRTURO® (bedaquiline), our medicine for MDR-TB.”).
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