



Diabetes Twitter: A Communal Retort to Capitalism

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Laura Marston is perhaps the most vocal and prominent advocate for people living with Type 1 diabetes on Twitter. Marston was diagnosed with the disease when she was a teenager in 1996. She routinely tells her social media followers that the insulin she first used to manage the condition—Humulin—cost a mere \$10 a month. Like many people with diabetes in the United States, Marston was later switched to the fast-acting insulin Humalog, which was more expensive (\$21) but still affordable so long as she had health insurance. But in 2012 Marston lost her job, leaving her to pay for an expensive insurance plan out of pocket that still required her to doll out hundreds of dollars a month for insulin.¹ By that time the price of

¹ Carolyn Johnson, “Why Treating Diabetes Keeps Getting More Expensive,” *Washington Post*, October 31, 2016.

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the medicine had skyrocketed even though no significant change to its formula had been developed by the industry. This specious pharmaceutical malpractice that creates a zero-sum choice between life and death for people with diabetes weighed heavily on Marston's well-being. She has sold all of her possessions at least twice and at one point even had to give away her dog, Nicky, to make ends meet.² For all these reasons and more, Marston has said that "The price of insulin radicalized me."³ Her story is all too familiar to people living with diabetes who are left at the mercy of opportunistic corporations that privilege profits and stock holders over patients and access to care.

Marston's social media feed reveals a deep-seeded devotion to making the world a more equitable place for people living with diabetes. As I write this in fall 2020, a year that has been as volatile as it has been long, it is hard not to note the intense focus Marston gives to the price of insulin in the face of so many pressing social issues. While making some reference to world events, and a few welcome appearances by her cat Bear, Marston's Twitter presence is dedicated almost entirely to raising awareness about pharmaceutical price gouging and the complications that stem from diabetes in a capitalist system. Any discussion of diabetes in the United States inevitably circles back to the exorbitant and immoral price of insulin, which can sometimes cost over a \$1000 a month. This fact is especially noxious when we consider that the patent for the medicine was sold to Eli Lilly for only \$3 so that patients could purchase it.⁴ The urgency provoked by this disaster capitalism has even led Marston and others to help facilitate the distribution of donated insulin to people in need, as was the case after the massive fires that swept the U.S.'s West Coast in 2020. Like many on Twitter eager to raise awareness of diabetes risks, Marston retweets posts that shed light on the dangers posed to people with diabetes when they are hospitalized and staff are uneducated about insulin dosing. She relays the threats posed by police who mistake hypoglycemia for intoxication and points out the complications that often arise from the shortcomings of diabetes technologies. But it is Marston's intense focus on prices, capitalism, and the mendacity of the drug industry that dominates her timeline.

²Ritu Prasad, "The Human Cost of Insulin in America," *BBC News*, March 14, 2019.

³Laura Marston, May 17, 2020, <https://twitter.com/Kidfears99>.

⁴Michael Bliss, *The Discovery of Insulin* (Chicago: University of Chicago Press, 2013), p. 178.

In this chapter I engage the rhetorical dynamics of the collective colloquially known as “Diabetes Twitter” to ascertain the ways they use the platform to intervene in, and reshape, conversations about the disease. In particular, I focus on how these communities perform a vernacular intervention into exchanges about capitalism that have grown more intense and visible as the cost of insulin has continued to soar. Pharmaceutical companies have raised the price of insulin for decades without fear of reappraisal. All the while, people with diabetes have continually attempted to intercede in these duplicitous practices to combat the mystification perpetuated by a system that constantly works against them. Social media users spotlight and rebuff the tight associations among lobbyists, non-profits, and politicians, arguing that the conventional ways of doing business actively endanger their lives. Rather than be trapped by a discourse that reiterates the familiar refrain that prices are going up and lives are being lost, those living with the condition, and their loved ones, give prominence to the matrix of capitalist forces destroying their longevity. In doing so, diabetes advocates incrementally move the language of management away from individual scripts of self-care and reliance and toward systemic critiques that highlight the precariousness of living with the disease. Rather than be gaslighted into believing that high prices will produce newer and better innovations, these critics emphatically implore industry executives and political operatives to remedy the manufactured crisis wreaking havoc on their community.

Media outlets such as *The New Republic* contend that insulin has become a metonym for the necessity of universal healthcare programs such as Medicare for All. Diabetes advocates have acted as a catalyst for this discourse by incessantly repeating arguments about cost, disseminating information about suspicious industry practices, and retorting loaded data put forth by pharmaceutical lobbyists.⁵ Using their everyday experiences to craft an ethos of expertise underscored by outrage, these self-appointed authorities have propagated the mantra that insulin prices, much more than individual management, are a death sentence for those living with the condition. They marshal their experiences with diabetes to forward an array of solutions to the crisis, which range from insulin price caps to making the medication available over the counter. Here, I look to the controversies that have underlined the ascendancy of “Diabetes Twitter”

⁵ See, for example, Natalie Shure, “How Insulin Became the Poster Child for Medicare for All,” *The New Republic*, February 27, 2020.

to think through the possibilities and constraints of this labor in the face of industry malfeasance.

A quick caveat: I am not interested in the veracity of truth claims being made by diabetes advocates at all times. With millions of users, including thousands making arguments about the cost of insulin, there is invariably some discrepancy in the metrics being used to advance their cause (including statistical evidence about price increases). But this contestation of facts is also true when we look to the data presented by corporations eager to protect their profits. Rather, I am compelled by the form of the arguments that tend to resonate on Twitter. Subscribers to the platform fabricate a Manichean dichotomy between good and evil to enliven their cause. This narrative, when collectively assessed, ultimately calls for a complete shift in capitalistic practices that are facilitating the slow death of the population. In this way, these forumites follow the trajectory of disability movements that spotlight the political and relational forces that produce and reiterate reductive medicalized scripts about the body.⁶ This analysis unfolds by looking to critiques made against pharmaceutical companies, diabetes advocacy groups, and politicians. Although any of these could merit a book-length study about the interrelationship between diabetes and capitalism, I argue that these three are central to understanding the impulses of Diabetes Twitter and the changes that collective aspires to instigate.⁷

SOCIAL MEDIA AND THE CRAFTING OF A COLLECTIVE DIABETES PERSONA

Social media activism has been a centerpiece of debate about the role of advocacy in the public sphere for well over a decade. Academics and public intellectuals alike have pondered the degree to which participating in on-line persuasive efforts is similar to face to face or “in-the-street” activity, as well as the limits of these analogic frames. Thinkers such as Malcolm Gladwell, for example, have dismissed the potential of on-line activism, arguing that it tends to foster “weak ties” in movement organizing, rather

⁶ Alison Kafrer, *Feminist, Queer, Crip* (Bloomington, IN: Indiana University Press, 2013), 4–10.

⁷ I have made the choice to reproduce the tweets as they appear in their original form on Twitter. The rhetorical choices advocates make highlight variations in voice, reflect emotions otherwise lost on the medium, and sometimes signal their variable uses of the technology as a means of identification.

than “strong ties,” that catalyze citizens to action. He points to the 1960s lunch counter protests as an example of these “strong ties” while remaining skeptical of home-bound participation in a cause.⁸ Others, such as Henry Jenkins, have suggested that internet activism is an extension of practices that have long existed among groups of people with shared interests. He insists that we only need look to the history of resource sharing and collective intelligence among internet enclaves to find noteworthy parallels to traditional movements.⁹ In my own classroom, students eagerly embrace inquiries about the degree to which expressing support from their screens is a form of “slacktivism” or an extension of moral commitments to be celebrated.

The choice between “slacktivism” and “real” activism is, to my mind, a false dichotomy that reduces complex and conflicting behaviors for purposes that occlude the varying functions of social media and the complicated identities of actors using such sites. Nonetheless, critics continue to be captivated by the implications that people might be retweeting or posting content to social media sites out of self-directed affirmation and not necessarily the public good. Social media scholar danah boyd, for example, recently asked, “What constitutes the public when we’re each living in our personalized world? How do we engender public-good outcomes when our tools steer us toward individualism?”¹⁰ boyd was engaging in dialogue with her co-authors (Mizuko Ito and Jenkins) when she posed this question. Each of them agree, to different extents, that mediums such as Twitter can be used for both egocentric purposes, as well as collective action.¹¹ Their consensus on this point might suggest that the idea of “public” should be pluralized, constituting not simply *a* public but *multiple* publics and variable ways of being public, sometimes simultaneously. This seems particularly true when people living with chronic conditions and disabilities utilize the internet as a space of resistance. As Heather Walker observes, being on-line has changed the fundamentals of protest by allowing greater flexibility in the construction of

⁸ Malcolm Gladwell, “Small Change: Why the Revolution will not be Tweeted,” *The New Yorker*, October 4, 2010.

⁹ Henry Jenkins, Joshua Green, and Sam Ford *Spreadable Media: Creating Value and Meaning in a Networked Culture* (New York: NYU Press, 2013), 30.

¹⁰ In Henry Jenkins, Mizuko Ito, and danah boyd, *Participatory Culture in a Networked Era* (Cambridge: Polity Press, 2016), 28.

¹¹ *Ibid.*, 28–30.

identities but also decreasing the risks typically associated with conventional demonstrations.¹²

Jenkins contends that the medium demarcating political communities is less important than mutual practices of identity formation, such as the collective ownership of stories and the development of sharing economies.¹³ The narratives embraced to constitute communal identities, for example, are not exclusive to face-to-face communicators and illustrate both the strategic uptake of identification by on-line cohorts and the tactical use of these assemblages in situ. Diabetes Twitter has adopted many of these precepts to forge a social media presence. The story about the sale of insulin's patent, for instance, is a staple of on-line storytelling and one that has not been easily manipulated by pharmaceutical companies. The commonalities expressed among people with Type 1 diabetes on the social media platform, be it with their origin stories, their experiences with the high cost of insulin, or their cantankerous relationship with big pharma, help to cement a collective identity.

These community collaborations echo the ways people with disabilities have seized opportunities brought by technological shifts to intervene in the social world. Such developments have often been accompanied by political, legal, and social challenges but have also illustrated the variable identities assembled under the broad rubric of "disability" and the divergent ways access might be understood.¹⁴ Katie Ellis and Mike Kent argue that technological engagement has redefined concepts such as the "social model of disability," which casts disability as a product of the environment and not simply a medicalized projection of the body. "The production of disability," they assert, "is a dynamic process that is shaped by technology, culture, and the underpinning moral order" and these practices and ideas are not easily captured by a singular theoretical heuristic.¹⁵ Alison Kafer likewise contends that, "What we understand as impairing conditions—socially, physically, mentally, or otherwise—shifts across time and place,

¹²Heather Walker, "#CripTheVote: How Disabled Activists Used Twitter for Political Engagement During the 2016 Presidential Election," *Participations: Journal of Audience and Perception Studies* 17 (2020): 147–171.

¹³Ibid., 28.

¹⁴Katie Ellis and Mike Kent, *Disability and New Media* (New York: Routledge, 2011), 16, 94; Sarah Parsloe and Avery Holton, "#Boycottautismspeaks: Communicating a Counternarrative Through Cyberactivism and Connective Action," *Information, Communication, and Society* 21 (2018): 1116–1133.

¹⁵Ellis and Kent, 97.

and presenting impairment as purely physical obscures the effects of such shifts.”¹⁶ Whereas Kafer notes that more work needs to be done in the humanities to understand diseases such as diabetes as a disability, users to platforms such as Twitter use the medium to energize such identities and thereby reposition a slew of political, medical, and communal relationships.¹⁷ They spotlight the creation and maintenance of debility as a central component of the capitalist enterprise.¹⁸

Twitter, in particular, lends itself to the constitution of a specific style of address and identity formation, even as it serves multiple functions not reducible to simplistic classificatory schemas. Jean Burgess and Nancy Baym observe that “Twitter remains a site of uncertainty and contestation not only over what kind of communication it should be used for, but over the purpose and value of different kinds of human communication in general.”¹⁹ The social network tends to have fewer adherents than Facebook or Instagram, though it still draws about 145 million users daily. Despite these impressive numbers, social media critics warn that the information circulating on Twitter, including its affective political attitudes and popular policy posts, do not necessarily reflect the disposition of the larger polity.²⁰ In some ways, Twitter might actually reflect the tendencies of older forms of organizing documented in social influence studies, wherein opinion leaders steer the direction and tenure of public conversation. In such models users in a network influence one another even when an opinion leader is not present by seeking out and distributing information that reinforces beliefs about themselves and the world they live in.

Additionally, the rhetorical stylistics of Twitter represent a defining component of its public disposition because it is enlivened by particular modes of address and interactive dynamics. These constraints, which facilitate the possibilities and limitations of user creativity, include the medium’s character limit and the fabrication of resonant hashtags. In their study of Donald Trump’s Twitter habits, Brian Ott and Greg Dickinson argue that the former president’s obsessive use of the medium is best understood as a mechanism for developing a curated persona. Twitter enables figures such as Trump to craft a rhetorical style that privileges an

¹⁶ Kafer, 7.

¹⁷ Kafer, 12.

¹⁸ Jasbir Puar, *The Right to Maim: Debility, Capacity, and Disability* (Durham: Duke University Press, 2017).

¹⁹ Jean Burgess and Nancy Baym, *Twitter: A Biography* (New York: NYU Press, 2020), 13.

²⁰ Alexis Madrigal, “Twitter is not America,” *The Atlantic*, April 24, 2019.

aesthetic character over a conceptual one and allows him to stress affective rather than rationally plotted thoughts.²¹ It perhaps goes without saying that Trump's rhetorical style reflects some of the worst tendencies of white rage grievance politics, which has helped him amass followers and garner a constant drip of attention from U.S. media outlets. Twitter's format, demanding simplistic messages, but underscored by an impulsivity and incivility in its users, has depersonalized interactions and enabled exchanges that are not always productive, especially for the purposes of democratic deliberation and the civic good.

Whereas Ott and Dickinson study the rhetorically-crafted persona of a notorious politician to note the drawbacks of the medium, I ponder the extent to which a collective persona can be cultivated among a multitude of users to redirect conversations about a social issue such as healthcare. Does the simplicity of message construction that is so harmful to some portions of our democratic culture serve an important function when contemplating the bureaucratic red tape erected around pharmaceutical corporations that engage in price gouging? Advocates on Twitter turn to the platform for a variety of reasons but I will contain my analysis to three topics that appear frequently in their rhetoric: First, these social media monitors openly retort the pharmaceutical industry for the high price of insulin and the outlandish cost of diabetes technology. Second, they lobby politicians on the state and national level to make insulin more affordable. Third, they critique diabetes organizations such as the American Diabetes Association (ADA) and the JDRF (formerly the Juvenile Diabetes Research Foundation) for being too closely aligned with insulin manufacturers. After examining each of these subjects, I illustrate the extent to which Diabetes Twitter offers broad critiques of capitalism to advocate for changes to healthcare policy. Each of these foci attempts to move the language of management from the individual mechanisms of discipline to one that emphasizes the complications of treatment in a system that views them as profit-generating consumers, not citizens worthy of care.

²¹ Brian Ott and Greg Dickinson, *The Twitter Presidency: Donald J. Trump and the Politics of White Rage* (New York: Routledge, 2019).

RETORTING PHARMACEUTICAL CORPORATIONS

Three pharmaceutical companies, Eli Lilly, Novo Nordisk, and Sanofi, control over 90% of the global insulin market. Healthcare advocates such as Marston are quick to note that these businesses gross billions of dollars in profits annually from the medication.²² For years, people with diabetes have pushed the leaders of these entities to reduce the list price of insulin and bring biosimilars, which are essentially generic insulins, to the market. Time and again, however, these multi-national corporations have raised insulin prices, often simultaneously, and forced people with diabetes to ration the substance to make ends meet. To be more specific, roughly a quarter of all people with diabetes have resorted to rationing insulin, putting themselves at risk of diabetic ketoacidosis (DKA), hospitalization, and death.²³ It is little wonder these entities are not often regarded as partners in diabetes care but enemies to the cause.

The sharp contrast between financial ruin and debilitating complications for people with diabetes and the bottomless well of corporate greed exhibited by pharmaceutical executives has established a dramatic us/them dichotomy that resonates on a medium like Twitter. Contributors with diabetes provide a profusion of testimonials about the suffering derived from corporate exploitation and those stories carry tremendous weight on a medium that thrives on short, easily digestible anecdotes. Critics on Twitter literally provide the receipts that illustrate they are dying from the effects of unchecked capitalism rather than contrived notions about individual management. For example, on August 1, 2020, Twitter user Michelle Fenner pointed out that promises to reduce insulin prices during the COVID-19 pandemic had been retracted. She tweeted a picture of a pharmacy receipt, commenting, “Remember the \$35.00 insulin by @LillyDiabetes for the pandemic. Yeah they raised the price again. It’s 1102.30 for 4 vials so if you were on the special due to COVID or assistance it’s over. So far 4 people have had it increased from 35.00 to 275.00

²² Marston noted on October 15, 2019 that Eli Lilly made “24.5 BILLION (with a B) in revenue in 2018 and got a \$186.2 million dollar TAX REFUND along with paying 0% federal income tax. While diabetics die bc we can’t afford basic insulin.” Marston, October 15, 2019.

²³ Darby Herkert, Pavithra Vijayakumar, Jing Luo, Jeremy I. Schwartz, Tracy L. Rabin, Eunice DeFilippo, Kasia J. Lipska, “Cost-Related Insulin Underuse Among Patients With Diabetes,” *JAMA Internal Medicine* 179.1 (2019): 112–113.

a vial #T1D #Insulin4all.”²⁴ A Lilly representative replied to the tweet and claimed that the co-pay cap had not ended: “Many factors affect pharmacy experiences, like changing from employed to unemployed or new insurance.” The company faced immediate push back from patients who supported Fenner’s observation and testified that they shared similar experiences. One forumite pointed to the disclaimer at the bottom of a Lilly press release that stated: “There is no guarantee that we will be able to continue uninterrupted insulin supply or that our insulin and/or glucagon affordability programs will significantly lower or cap monthly out-of-pocket costs for people.”²⁵ The company, unable to defend its practices in the face of this collective intelligence, offered a canned response to the complaints. “We want to Help. Please call the Lilly Diabetes Solution Center...to learn about our cost-saving solution.”²⁶ But for people living with the disease, refrains about aid or faux solutions to the insulin crisis have never materialized as long-term fixes to complications that accompany capitalism.

Interestingly, the cost of insulin is never sidelined in such exchanges. Price remains the focal point of the conversation for each interlocutor, offering presence to the issue and cementing the interpretive lenses employed by those on social media. Lilly itself raises the issue of affordability in each of its tweets, thereby reinforcing the framework drafted by the advocates about personal expenditures. Lilly never has the appearance of holding the moral high ground in these disputes. In another instance, a company spokesperson posted: “Whether you’re uninsured or have commercial insurance, the Lilly Insulin Value Program could reduce your out-of-pocket costs for Lilly insulin. Download the co-pay card at [their web site] to access these savings.”²⁷ The tweet received few responses, but those who engaged it were highly critical of the sentiment. Molly King, for example, replied, “Or you could quit charging people over \$3K for insulin that costs less than \$20 to make. I get needing to make a profit but that profit margin is ABSURD and criminal.”²⁸ Another monitor responded, “Instead of devoting this time and money to pay someone to help you brand yourselves as a company that ‘cares,’ why not just ACTUALLY

²⁴ Michelle Fenner, August 1, 2020, <https://twitter.com/FennerMichelle>.

²⁵ Elizabeth Snouffer, August 2, 2020, <https://twitter.com/ElizabethType1>.

²⁶ Eli Lilly and Company, August 2, 2020, <https://twitter.com/LillyPad>.

²⁷ Eli Lilly, August 3, 2020, <https://twitter.com/LillyPad>.

²⁸ Molly King, August 31, 2020, <https://twitter.com/yesthismolly>.

make insulin accessible for people who need it to live? Your CEO is worth \$22mil and my dead friend's blood is on his hands."²⁹ In yet another lengthy exchange, Curly Andr0id, wrote:

I applied for this program since I am type 1 & uninsured. I received two discount cards to purchase both my long-acting, & fast-acting insulins via email. When I went to pick up both my insulins at the pharmacy...the pharmacist explained I am only allowed to use the \$35 copay card on one of my insulin prescriptions at a time. The pharmacist even called your customer service line because she couldn't understand why you would give me 2 different discount cards but I can't even use them? I would assume you realize most type 1 diabetics need BOTH insulins to survive. so I'm put in a situation where I have to choose between which insulin I can pick up under you 'assistance' program.³⁰

Lilly extended a perfunctory expression of thanks to the user, insisted that she was mistaken, and claimed to be looking into the problem. For people with diabetes, their dismissive response exacerbates the long and arduous process of attempting to access insulin and the unnecessary barriers erected to prevent them from doing so. A medication that is affordable and readily available over the counter in other countries is weighed down by a complicated and costly process that puts this person's life at risk.

In one of the more baneful developments I encountered during this study, the Pharmaceutical Research and Manufacturers of America (PhRMA), the lobbying organization that represents the nation's largest pharmaceutical companies, attempted to block a Minnesota law aimed at bringing down the price of insulin. The influence group claimed that the state's new emergency insulin program constituted "an unlawful taking of private property without compensation" because it requires corporations to reimburse retailers that provide emergency supplies of insulin to people with diabetes and "to offer insulin to low-income patients through companies' charitable patient assistance programs."³¹ The law was named after Alec Smith, who died at the age of 26 after having to ration his insulin due to cost. His mother, Nicole Holt-Smith, has become a tireless advocate for insulin affordability. She responded to the suit by noting that insulin

²⁹ Molly King, August 16, 2020, <https://twitter.com/yesthismolly>.

³⁰ @Curly Andr0id, August 3, 2020, <https://twitter.com/Andr0idCurly>.

³¹ Peter Callaghan, "State says PhRMA doesn't have standing to challenge constitutional-ity of Minnesota's emergency insulin program," *MinnPost*, September 1, 2020.

manufacturers and their lobby have persistently refused to participate in talks that would lower the cost of the medication. She wrote, “we have tried speaking with the pharmacies but without direction from the board of pharmacy they are reluctant to participate, its frustrating because they have all been sent the information and were invited to participate in a zoom call, i think its more about the law suit.”³² Time and again pharmaceutical companies attempt to deflect attention away from their profit-generating machine and Diabetes Twitter points to their malfeasance in equal step.

CORRECTING AND EDUCATING POLITICIANS

Social media users fighting for a more equitable and transformative approach to healthcare have repeatedly been daunted by the institutional gradualism that prohibits the success of forward-looking policies. Despite wide-spread public support for access to affordable care, attempts to alter entrenched cultural practices can prove overwhelming for proponents of change, especially when engaging politicians who are seemingly unmoved by the effects of deleterious policy decisions. Ellis and Kent contend that people with disabilities are frequently marginalized in policy discussions due to ableist scripts of productivity.³³ Diabetes Twitter highlights the burdensome work that advocates must perform in order to intervene in conversations about their lives and mitigate the risks posed by uninformed public servants. Politicians are often ignorant about the kinds of insulin on the market, its variable uses, or its centrality to the everyday lives of people with diabetes. Donald Trump, who has frequently contended that his policies would solve the insulin crisis (they have not), offers one of the more egregious examples of this obtuseness. He said during a press conference, “I don’t use insulin. Should I be? Huh? I never thought about it.”³⁴ Further, in the first presidential debate against Joe Biden, he remarked that insulin is “so cheap, it’s like water” (it is not). Such attitudes illustrate why Twitter users often provoked exchanges with politicians who were at best blissfully ignorant and at worst purposefully dense. This included representatives on the state level in places such as Colorado and Minnesota, where lawmakers had drafted legislation to reign in the price of insulin.

³² Nicole Holt-Smith, July 8, 2020, <https://twitter.com/NSmithholt12>.

³³ Ellis and Kent, 94.

³⁴ Daniel Dale, May 26, 2020, <https://twitter.com/ddale8>.

Healthcare reformers often worried that bills being introduced into session were not expansive enough to cover all people with diabetes, even when press coverage made it appear otherwise. Following the passage of Colorado's insulin price capping legislation, for example, several influencers argued that the law did not go far enough to protect patients because it was explicitly tied to insurance. Colorado's bill dealt with co-pay caps and not list prices, meaning only a fraction of citizens would be covered. Marston noted, "This is why copay caps are BAD POLICY. They help less than 20% of citizens, leave the uninsured paying the most, and lawmakers deem them as a panacea for the insulin price crisis. WE MUST STOP LETTING ADA RUN THE SHOW WHEN OUR LIVES ARE AT RISK."³⁵ I'll return to advocacy groups such as the ADA in the next section. For now, I want to draw attention to the policy decisions being made at the state level and how those maneuvers were not extensive enough to satiate advocates. If one looked only to the national media or to the press releases of state lawmakers, they might believe that a major social problem had been solved when, in fact, it had not. If anything, the Twitterverse highlighted that the law actually contributed to income inequality rather than leveling the playing field.

In a separate but highly publicized controversy, Diabetes Twitter was quick to correct a Minnesota state representative who was spreading misleading information about the accessibility of affordable insulin. In September 2019 Republican Jeremy Munson posted a video to social media and claimed that people with diabetes need not ration their insulin because, he insisted, they can simply go to Walmart and buy an older form of the medicine for less than \$25. This is a common, though false, argumentative trope well-known to people with diabetes who champion price caps on insulin. The substance that Munson was peddling is an outdated insulin that has not been in wide use since the early 1990s. "Walmart insulin" gives people with diabetes substantially less flexibility than newer forms of the substance. As a result, it puts people at high risk of death when changing medications without the strict supervision of a physician (which many patients cannot afford if they are switching to such insulins). I have written elsewhere about the dangers of so-called Walmart insulin and its propensity for harm.³⁶ Social media users pointed out the

³⁵ Laura Marston, February 17, 2020, <https://twitter.com/Kidfears99>.

³⁶ Jeffrey Bennett, "Why Telling People with Diabetes to Use Walmart Insulin can be Dangerous Advice," *The Conversation*, November 14, 2019, <https://theconversation.com/why-telling-people-with-diabetes-to-use-walmart-insulin-can-be-dangerous-advice-125528>.

recklessness of Munson's arguments, including his repeated use of testimony from a disreputable physician to back his unscientifically supported claims.

Lija Greenseid, a self-described "passionate healthcare advocate," and whose daughter lives with Type 1 diabetes, was among those who publicly retorted Munson. She was especially critical of the lawmaker's embrace of the aforementioned doctor who had routinely profited off the pharmaceutical industry's fleecing of people living with Type 1 diabetes. She wrote, "Let me say this more clearly. Rep Jeremy Munson frequently cites testimony from a Dr Richard Dolinar to argue against the Alec Smith Emergency Insulin Act. Since 2013, Dr. Dolinar has been paid \$700K from pharma, including about \$120k from Lilly and Novo Nordisc in 2018 alone."³⁷ Greenseid posted testimony that Dolinar had delivered to the Minnesota legislature, in which he called Walmart insulin a "viable option" for people with diabetes experiencing an emergency. She contrasted that with an opinion piece Munson had published in the *Star Tribune* that leans heavily on Dolinar's words, and linked to a site that highlighted how much money the endocrinologist had scored from insulin manufacturers.³⁸ Munson's remarks eventually drew the ire of numerous legislators, including one who actually lived with Type 1 diabetes.³⁹ Ultimately, Munson's declarations were rejected when the Alec Smith insulin bill was passed into law in April 2020.

Holding Diabetes Nonprofits Accountable

Diabetes non-profits such as the JDRF and the ADA have long pushed for increased federal funding for research, lobbied Congress to support the Special Diabetes Program, and brought together public figures that are invested in finding a cure. The ADA has traditionally been identified as a physician's lobbying group while the JDRF is composed of children living with diabetes and their families. In more recent years organizations such

³⁷ Lija Greenseid, October 4, 2019, <https://twitter.com/Lija27>.

³⁸ Jeremy Munson, "Counterpoint: Over-the-counter insulin is a viable option," *Star Tribune*, October 3, 2019, <https://www.startribune.com/counterpoint-over-the-counter-insulin-is-a-viable-option/562115132/>

³⁹ Adam Uren, "GOP lawmaker's Walmart insulin video criticized as 'irresponsible,'" *Bring Me the News*, September 24, 2019, <https://bringmethenews.com/minnesota-news/gop-lawmakers-walmart-insulin-video-criticized-as-irresponsible>

Beyond Type 1 (founded by Nick Jonas of the Jonas Brothers) and T1 International have appeared as noteworthy players in diabetes advocacy, though with discrepant messages and varied methods for reaching their audiences. T1 International, in particular, has become an essential voice in the fight for accessible insulin, including its widely used Twitter hashtag #insulin4all.

Those active on the platform have increasingly criticized the ADA and JDRF for their close ties to pharmaceutical companies and the compromising position such affiliations may engender. Rather than agitate on behalf of people with diabetes, there is a persistent worry that such sponsorship will, at the very least, mute necessary critiques of multi-national corporations that have facilitated immeasurable harms. Importantly, these corporate associations are well known in diabetes communities and are generally made public by the nonprofits. On their web site, the JDRF notes that they have been partners with Eli Lilly since 1997 and have collected contributions from the manufacturer that soar above \$13 million. They have likewise collaborated with Novo Nordisk since 2000, generating roughly the same amount of cash. Other frequent partners include diabetes conglomerates Medtronic, Dexcom, and Sanofi.

Social media advocates frequently spotlight how these non-profits appropriate the struggles of people with diabetes without necessarily putting pressure on drug manufacturers and lawmakers to make insulin more affordable. For example, Smith-Holt took to Twitter in June 2020 to relay a negative encounter she had with the JDRF. The organization wanted to highlight her son Alec's story and the legislation that was passed in his name. But Smith-Holt decided to include in her narrative the JDRF's and ADA's silence about the high cost of insulin.⁴⁰ The group attempted to rewrite a 250 word story that she submitted and asked her to be in a video using a script they composed instead. Smith-Holt rejected the offer and aired her grievances on Twitter. She remarked that she was disappointed in the nonprofit for not more vocally supporting efforts that would make insulin accessible for all. She insisted that the JDRF never lobbied the Minnesota legislature to get the bill passed and said resolutely that she would not "support an organization who is in bed with PHARMA."⁴¹

Sharp critiques like the one Holt-Smith made of the JDRF have also been directed at newer groups such as Beyond Type 1. In summer 2020,

⁴⁰ Nicole Holt-Smith, June 23, 2020, <https://twitter.com/NSmithholt12>.

⁴¹ Ibid.

the non-profit's Twitter account posed the following question: "What is the main reason you're NOT using a Continuous Glucose Monitor? Tell us in the Comments!" Following the query, there was an additional tag that noted, "Posted in partnership with Abbott FreeStyle."⁴² Immediately, a self-described parent of a person living with Type 1 replied with a screenshot of the tweet. "Amammamous" retorted, "You cannot convince me that they do not expect the replies to be overwhelmingly about cost...and that the 'low-priced' Libre 2 is going to be an answer in a future post."⁴³ The casual dismissal of the tweet exacerbates what many people with diabetes have come to see as a problematic coupling of organizations claiming to lobby in their name but with the intent of pushing products and not productively transforming the politics that dictate their lives. Rather than being hailed as passive consumers in a seemingly corporate shell game, this social media advocate anticipated the absurdity of the tweet and discarded its market logic. The capitalistic enterprise underlying the message does little to make life more livable for people with diabetes—it simply positions them as customers in a marketing-scheme.

This is not the first time Beyond Type 1 ran into problems on Twitter in 2020. In May the organization's front man, Jonas, himself a person with Type 1 diabetes, tweeted, "Are you or someone close to you impacted by diabetes? The @JDRF and @BeyondType1 Alliance has brought over 100 partners together to protect those most vulnerable to COVID-19. Guidance + important info at: coronavirusdiabetes.org #BigLittleChanges."⁴⁴ Marston, unimpressed with the outreach, replied: "Literally FUCK YOU @nickjonas. Your fellow diabetics are dying from insulin rationing and you're pushing a website sponsored by every insulin company and every Phrma shill group ever? Is money more important than your life? Or is it just more important than ours? #PhrmaShill."⁴⁵ Another user wrote that Beyond Type 1, "has brought over 100 partners together to take the money of people with diabetes until they die.*"⁴⁶ And yet another person with the Twitter handle "the moody diabetic" wrote: "Are you or someone close to you impacted by diabetes? The @JDRF @BeyondType1 Alliance has continued to ignore the fact that price gouging insulin kills several people a year.

⁴² Beyond Type 1, June 28, 2020, <https://twitter.com/BeyondType1>.

⁴³ Amammamous, June 28, 2020, <https://twitter.com/Amammamous>.

⁴⁴ Nick Jonas, May 12, 2020, <https://twitter.com/nickjonas>.

⁴⁵ Laura Marston, May 12, 2020, <https://twitter.com/Kidfears99>.

⁴⁶ @autoimmuneallie, May 12, 2020, <https://twitter.com/autoimmuneallie>.

if you want to actually make a difference, please join your state's #insulin4all chapter:)."47 Although some applauded the coalition, the majority of posts displayed little sympathy for the tweet. At every turn, it would seem that people with diabetes have become averse to the capitalist tendencies that continually put their lives at risk.

CAPITALISM AND DIABETES TWITTER'S DISCONTENTS

This chapter has explored the ways that people with diabetes navigate and retort a matrix of capitalist forces that put lifesaving medications such as insulin out of reach. Although capitalism is not always explicitly mentioned by Diabetes Twitter, it is unquestionably implied in daily threads that appear on the platform. Advocates point to the vacuous nature of claims about insulin prices leading to further innovation, they call out CEOs like David Ricks of Lilly or Steven Uhl of PhRMA (who has a child with T1D) for the lifestyles they are subsidizing, and they breathlessly demand an end to exorbitant prices. At every turn, a system underwritten by capitalism is heckled for its murderous effects. On January 11th, 2020, a user by the name of Jerry Coyne noted that it was the 98-year anniversary of then 14 year-old Leonard Thompson being given the first injection of insulin. Marston retweeted the post and noted, "98 years later, many insulin-dependent diabetics in the United States can't afford the insulin we need to survive. Could you come up with \$1,000 a month every month for the rest of your life to save yourself from certain death?" The question is not merely rhetorical. For many living in the United States this answer is abundantly clear: absolutely not.

Proponents of change, such as Marston, highlight the capitalist exploitation of people living with diabetes to show that no amount of individual management can account for the structural impediments foisted upon them. In February 2018 the American Enterprise Institute posted a "chart of the day" listing the long-term consumer price change to numerous U.S. goods and services. Among the most expensive changes were the costs of hospital services, college textbooks, and tuition. Twitter user Hannah Crabtree modified that chart to include the price of insulin and has since circulated the graphic several times because it so quickly goes viral. Whereas hospital services went up by well over 200%, Crabtree

⁴⁷ @whatsarave, May 12, 2020, <https://twitter.com/whatsarave>.

illustrated that the price of insulin has risen by almost 1200%.⁴⁸ In another vein, a Twitter user with the handle “Miss InsulinDependent MD” relayed that she had saved \$6,000 by switching to her “insurance preferred insulin.” But this was not a happy tweet. She wrote: “You too can significantly increase your A1C and decrease your quality of life when you live in a country with private-for-profit healthcare.”⁴⁹ Users to the medium incessantly and insistently communicated that capitalism was destroying them, enlivening public claims about the inaccessibility of insulin and the ravenous effects of consumerism on the diabetic body.

From a communication perspective, the intense focus on disseminating a particularly narrow message about insulin prices, rather than adapting those claims to potential audiences, raises questions about the effectiveness and influence of actors on Diabetes Twitter. Eschewing organizations that have any ties to pharmaceutical companies, for example, is challenging in the U.S.’s capitalistic-driven system, even if the motivation for these concentrated directives is both laudable and understandable. People with diabetes have repeatedly witnessed multiple members of their community die without cause and efforts to persuade representatives on any other terms must feel like an exercise in cultural charades. Still, just as there is no denying that the political sentiments expressed on Twitter are not always reflected in the larger public sphere (few people on Twitter were arguing for Joe Biden to be president during the 2020 primaries), the work of these forumites might foresee something yet unrealized. Diabetes Twitter is a necessary and welcome voice but one whose effects may be limited in a system built on gradualism and capitalist exploitation. Unlike the saccharine glow of Diabetes Instagram, these advocates do not picture the disease and its technological accompaniment as aesthetically productive—they imagine the condition and insulin’s outrageous list price as resolutely fatal. And while fatalism can be potentially generative in the political sphere when confronting the realities of diabetes, it is yet to be seen how effective this collective effort will be.⁵⁰

The coming years might prove to be exceedingly difficult for people living with diabetes. The Affordable Care Act, which has offered legal

⁴⁸ Hannah Crabtree, “The Price of Insulin vs. the Price of Other Goods,” *Data for Insulin*, June 18, 2019, <https://insulin.substack.com/p/the-price-of-insulin-vs-the-price>

⁴⁹ @msinsulindpndnt, July 7, 2020, <https://twitter.com/msinsulindpndnt>.

⁵⁰ See, Jeffrey Bennett, *Managing Diabetes: The Cultural Politics of Disease* (New York: New York University Press, 2019), 77–111.

protections to those with pre-existing conditions, may be dismantled by the Supreme Court, thereby facilitating the slaughter of people living with the disease. Even with the law intact, the high cost of insulin in the U.S. has continued to escort people to an early grave. The public advocacy performed by lay experts on Twitter may not be able to prevent the slow death of their community. Yet it will remain a source of anger and moral righteousness in the face of a system that has little regard for the lives of people living with this most precarious of diseases.

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Editors

(Un)doing Diabetes:
Representation,
Disability, Culture

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