

Dear Ted Sarandos, Lisa Nishimura, Brandon Riegg, and Vernā Myers,

We are a group of writers, activists, artists, filmmakers, physicians, patients and scientists who write to express our profound disappointment with the recently released Netflix docuseries *Afflicted*. We are deeply concerned about its unethical treatment of its subjects and its many factual errors and omissions. Its inclusion on your platform—which reaches three hundred million viewers worldwide—will reinforce barriers to appropriate medical care or disability benefits, dampen the support of vital research, and add to the stigma and social isolation of an already profoundly marginalized group of people.

Afflicted was introduced to participants as a series that would “compassionately” represent their experiences with diseases that lack proper diagnostic tools and effective treatments. But rather than authentically depict these participants’ experiences and the biomedical research that might explain their illnesses, *Afflicted* used every creative tool and untenable journalistic practice to advance a narrative that suggests these patients’ problems are primarily psychological, a theory that is not supported by the evidence. Moreover, the *Afflicted* team engaged in multiple unethical practices to create the docuseries—from misrepresenting their intentions to showing apparent diagnoses from doctors who had never examined the subjects.

Here are the key problems in the series:

Misrepresentation of subjects and questionable tactics

Five of the subjects portrayed in *Afflicted* [shared their stories](#), which raise several important ethical concerns. According to their accounts:

- Before consenting to participate in the project, subjects explicitly asked producers whether *Afflicted* would take the point of view that the illnesses it portrayed was psychosomatic and were told unequivocally that this was not the case.
- At least one subject reported feeling pressured to continue participating or grant access based on the possibility of pro bono medical care they might not otherwise have been able to afford.
- Some of the visits to practitioners—including some that most viewers would perceive as questionable—were set up by the production team itself, including Bekah’s offers of [stem cell therapy and ozone treatment](#) and Star’s visit to a Lyme specialist.
- Some of the subjects were encouraged to undergo risky or unnecessary medical procedures. When Jamison Hill explained he was too ill to travel to a doctor, one of the producers suggested to his mother that she drug him. The production company also urged Hill to needlessly replace his midline IV—a procedure that carries a serious risk of infection—promising they would pay for the expensive and taxing procedure. Ultimately, they neither paid nor used the footage. When Bekah’s doctors recommended that she not undergo stem cell therapy, the producers pressured her to do so against her doctors’ wishes. They then portrayed her refusal as capricious.

- The filmmakers failed to show the seriousness with which the participants took mental health. Over the course of their illness, most of the subjects had been referred to psychiatrists for assessment and had been told that there was no psychiatric explanation for their physical symptoms. Many had previously tried antidepressants, anti-anxiety medications or other psychiatric or psychological interventions. Though two participants have had mental health issues such treatments were helpful for, these interventions did not address any of the subjects' physical symptoms. Yet, the question of subjects' mental health was raised over and over in every episode, and some subjects were portrayed as rejecting psychiatric help.
- Clips of doctors expressing expert opinions about the diagnosis or the cause of illness were frequently juxtaposed with footage of patients they had never examined. This is a violation of the spirit if not letter of the Goldwater Rule.

Medical and Scientific Flaws

The history of medicine shows that until illnesses are better understood, they're often considered psychosomatic. The consequences can be devastating. Multiple sclerosis was once called "hysterical paralysis" until the invention of the MRI revealed lesions in the brain. As late as the 1980s, ulcers were thought to be caused by the "wish to receive love" before the discovery of *H. pylori*. Breast cancer was attributed to holding onto negative emotional states until effective chemotherapeutic treatments dispelled the myth. Tuberculosis, epilepsy, and rheumatoid arthritis were all at one point in their history thought to be psychosomatic disorders before science elucidated their mechanisms. In the interim, untold numbers of patients were institutionalized, given inappropriate treatments, and died as a result.

Many individuals live with more than one health condition. Being physically disabled does not preclude a coexisting mental health diagnosis. Likewise, having a mental health issue does not prevent the onset of other diseases or disorders. People with mental and physical disabilities both deserve equitable, accessible treatment options but the framing of major, chronic disease as "all in your head" continues to prevent accurate diagnosis, access to care, and investment in medical research.

Afflicted offered no objective evidence backing its claim for a psychosomatic basis. And it excluded substantial medical and scientific evidence that would have helped explain the subjects' diagnoses:

- **Omission or de-emphasis of subjects' diagnoses and laboratory findings**
The frame of *Afflicted* is "Seven people suffering with bizarre chronic illnesses," yet most subjects did have positive laboratory results, physical findings or mainstream diagnoses. These were excluded, glossed over, or left unexplained. For example, both Bekah and Pilar have Common Variable Immunodeficiency Disorder, which is an uncontroversial and life-threatening disease, diagnosable through a standard blood test. Bekah tested positive for Lyme disease via a CDC-approved Western blot test. Yet the

documentarians stated in episode 1 that Bekah “believes” she has Lyme. Both Jill and Star have Hashimoto’s thyroiditis, an autoimmune disease diagnosable through a standard lab. Jake has had Bell’s Palsy, tachycardia, and low red blood cell and white blood cell counts for which he sees a hematologist/oncologist every three months to monitor for cancer. Many of these facts were omitted entirely.

- **Exclusion of research findings**

The series’ assertion of a psychosomatic cause is especially problematic because science has made significant progress understanding the pathophysiology of myalgic encephalomyelitis, mast cell activation syndrome, chronic Lyme disease, and several of the subjects’ diagnoses. Each can be diagnosed with established criteria and may be validated with laboratory testing.

- **Myalgic encephalomyelitis**

The National Academy of Medicine published a [2015 report](#) that developed diagnostic criteria for myalgic encephalomyelitis, writing that it “is a serious, chronic, complex, multisystem disease that frequently and dramatically limits the activities of affected patients.” Consistent abnormalities have been found in the immune system: patients’ natural killer cells, responsible for fighting viruses and cancer, do not work properly. ME patients show white matter hyperintensities on MRI; and autopsies of ME patients show inflammation in the brain. ME patients have disordered metabolism, and show abnormalities induced by exercise testing.

- **Mold and chemical sensitivities**

[Mast cell activation syndrome](#) underlies these sensitivities in some patients. In this condition, mast cells easily degranulate upon encountering particular triggers, quickly releasing vast quantities of histamine into the body and causing [allergic-type symptoms](#) as well as gastrointestinal and nervous system issues.

- **Lyme disease**

Patients typically use the term “chronic Lyme” simply to mean that they became chronically ill after getting Lyme disease. Although skeptics often reject the term “chronic Lyme” entirely, there is no debate that Lyme can cause chronic symptoms. The scientific literature has [clearly documented](#) that Lyme disease that is not treated early can cause lasting problems including arthritis, heart complications, neurological problems, and more. The CDC refers to these patients as having “late” or “disseminated” Lyme. The literature also shows that even in patients who are ideally treated with a course of antibiotics, 10 to 20 percent are left with lasting symptoms, according to the [New England Journal of Medicine](#). The CDC refers to these patients as having “post-treatment Lyme disease syndrome.”

- **Exclusion of research scientists**

Although the producers had access to, and even filmed, researchers who could have given strong clinical and scientific evidence for several of the conditions in the film, they chose to exclude them from the series. They attended a symposium at Stanford University on the molecular basis of ME/CFS, which included prominent researchers from around the world, including Mario Capecchi, a Nobel Laureate. Several of these scientists were even interviewed, including Stanford geneticist Ron Davis and Stanford immunologist Mark Davis. In addition, during Dr. Eric Gordon's visit with Jamison, Ron Davis sent two researchers from his lab at Stanford to set up a makeshift lab in Jamison's house. They drew his blood and processed it for a big ME/CFS study. All of this was filmed but none of it made it into the series.

- **Inclusion of alternative practitioners as the sole validation of patient experience**

By omitting the perspective of research scientists and prominent physicians, *Afflicted* crafts a strawman argument, pitting integrative, environmental, and alternative health practitioners against a single psychiatrist, Richard Alan Friedman. Friedman's speciality is anxiety and mood disorders, not any of the conditions featured in *Afflicted*; moreover, he does not appear to have met any of the patients in person.

Afflicted uses the public perception of alternative healthcare to attack their subjects' credibility, employing Friedman as the "voice of reason," and omitting other, more credible sources who would have supported patients' diagnoses and symptoms.

The problems with this film aren't just hypothetical: The participants are already suffering for their participation, receiving intense online harassment, having their professional reputations questioned, and having friends turn against them. And if *Afflicted* remains on Netflix, it will hurt many more people. Many people living with chronic illnesses, including those depicted in *Afflicted*, are routinely denied disability benefits. Some are abandoned by their families and fall into poverty, homelessness, and food insecurity when they become too ill to work. The stigma surrounding these conditions among health care providers poses a barrier to accessing quality medical care, putting patients at risk. The disbelief of loved ones—and the culture at large—contributes to the high rates of suicide among patients with these conditions.

The inclusion of people with disabilities in the telling of their own stories is essential to the creation of compelling, ethical, authentic cinema. Netflix has been an important platform for this conversation with programs such as *The Punk Rock Singer*, *My Beautiful, Broken Brain*, *To The Bone*, and *Unrest*. Yet *Afflicted* was helmed by apparently able-bodied people, and displayed the disabled as curiosities for the entertainment of others.

We request that *Afflicted* be immediately removed from the service. We further request that a formal apology be released that includes a statement of Netflix's future plans for the programming of documentaries, television, comedy specials, and feature films about disability and projects that include talent, key crew, and/or consultants with disabilities.

Signed,

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