

FACT or FICTION

Strategies for the Misinformation Age

PATIENT STORIES ABOUT MISINFORMATION

We encourage you to read the following stories ahead of the session: **Patient Stories about Misinformation**. These three true stories are rooted in mistrust, and offer just a small snapshot of the harms of misinformation on thousands of patients across the United States. You'll hear more from these brave individuals at the Forum via a short video, have the opportunity to hear reactions from a panel, and engage in conversations about possible solutions.

Rob

When Rob's oldest daughter was a child, she had a bad reaction to a standard immunization. She was diagnosed with autism later in life, and Rob attributes her diagnosis to that vaccine.

When the COVID-19 vaccine was approved, he started hearing different things about it on social media and on the news. He asked around to see if friends or family had gotten sick with COVID-19, but no one had. As a self-proclaimed anti-vaxxer, he stood firm and decided that the vaccine wasn't for him. Rob told himself that he'd rather get it, get the antibodies, and have his body build up its own immunity to it naturally. He was a healthy guy. He said, *"and I thought that would be it, but boy was I wrong."*

Rob got COVID-19. He fell into a coma, was intubated, and spent 110 days in the hospital. Nearly a year later and he is still facing the effects that COVID-19 had on his body. Rob used to describe himself as a husky man, but no longer. He lost significant muscle mass, cannot open a jar on his own, or scratch his back, or use his arms the way that he used to.

I'd tell the Rob of 2020, "Hey Rob, look what's coming, and you're not going to like it." I think that would scare me. I think that would scare me to get the vaccine almost immediately.

Laurie

Laurie's mother, Stephanie, was 75 when she died from COVID-19 last year. But Laurie says it wasn't just COVID-19 that killed her mother. In the years leading up to her death, her mother had become embroiled in conspiracy theories, finding amusement in watching thousands of videos online. And although Stephanie's fringe ideas were troubling, Laurie and the rest of her family still hung on – sometimes fighting, but often keeping the conversation on happier topics, like her grandchildren.

When the pandemic started, everything changed. Stephanie's conspiracy videos were telling her that COVID-19 was a hoax, so she didn't take it seriously. She formed a spiritual group that met weekly at her house, and most members didn't believe the virus was real. Stephanie avoided vaccination because she thought it contained tiny microchips.

I really feel for anybody in this situation, because they're probably going out of their minds dealing with it, because you feel the person you knew died, even though they're still right in front of you.

After going out to dinner with friends, Stephanie started to develop symptoms. She refused to get tested, and instead ordered drugs online – ivermectin and hydroxychloroquine – from a “natural healer”. As she waited for the drugs to arrive she got sicker and sicker. When her blood oxygen level reached 77 percent, Laurie and her sister forced their mother to go to the hospital. Even after being admitted, she refused some of the most effective treatments for COVID-19.

Laurie says that her mother didn’t have to die. Almost a year after Stephanie’s death, Laurie’s family is still confused about why this happened.

I thought her getting COVID-19 would be the only way that changed her, to finally be like, “COVID’s real.” And it didn’t. I mean, she dug in, and said no to the drugs that would’ve helped her.

Alex

Alex became pregnant early on in the pandemic. Once the vaccine was approved by the FDA, she questioned her OBGYN about whether she should get it or not. That doctor told her to wait because there wasn’t yet enough information about its safety. At her group practice, it’s standard to see a different doctor every time. The next doctor she saw told her to get vaccinated as soon as possible.

Some people said, “Get vaccinated while you’re pregnant.” Some people said, “Wait till the third trimester.” Some people said, “Wait till after pregnancy.” There was no real clear answer for me and that left me with a lot of hesitancy in terms of what was the right decision for me and my son.

Overwhelmed by the different information she was hearing from different sources – her doctors, friends and family, the media – she decided not to get vaccine during her pregnancy. Alex felt like she could not trust any of the sources providing information about the vaccine, especially because COVID-19 was already disproportionately impacting communities of color.

After giving birth to a healthy baby boy, Alex got vaccinated, but she and her son still got COVID-19 shortly after. Because of this, she has been very hesitant to get the booster.

I think that a lot of people probably felt very similarly to me – we were under the impression that getting the vaccine meant that you weren’t going to get COVID-19. Instead, the truth was that it possibly meant that you wouldn’t get it as bad, even if you did get it. And that I suppose was the case for me, though COVID-19 still felt very, very hard. I can’t imagine if I hadn’t gotten the vaccine.

