



Reframing Trust

A PATH TO ADDRESS MISINFORMATION

Patient Stories of Lost Trust

We encourage you to read the following stories ahead of the session **Patient Stories of Lost Trust**. Four patients share first-hand accounts of the consequences of mistrust, and offer a glimpse into what happens when communication, empathy, and transparency are lacking while navigating health care. You'll have the opportunity to hear from these four brave women during the session via a short video, hear reactions from a panel, and participate in discussions to develop possible solutions to the issues shared.

Lydia

When Lydia was pregnant with her first child in 2008, she had questions about vaccines – she worried they might cause more harm than good. Coming from a background in health care, she hadn't always questioned vaccines, and was vaccinated for the flu while pregnant.

I was pro-science and pro-vaccine. I worked in a chemistry lab setting as a career before having kids, so I was not your typical uninformed parent.

But having a baby made health care more complicated for her, and she weighed the pros and cons of vaccinating her baby while settling into life as a new mom. She struggled to breastfeed, and found comfort in an online forum for new moms after her doctor told her to “*not be so brokenhearted about it and give her formula.*” The members of the online forum helped her solve her breastfeeding issues. During the same period of time, she did decide to move forward with the vaccine schedule, and her pediatrician gave her 8-week-old baby three shots.

A few hours after leaving the doctor's office, her baby was inconsolable. Even though her doctor told her the reaction was normal, Lydia wasn't convinced. She took her questions to the same forum that helped her breastfeed, where she read about unfounded beliefs about harms of vaccines – including high-pitched screaming.

She questioned her decision to vaccinate, and dove deeper into the forums. She didn't finish her baby's vaccine schedule and she didn't vaccinate her other two children.

I had a group of people that were willing to listen to me and my concerns...and they showed me vaccine inserts and scared me out of vaccinating my daughter.

Then the COVID-19 pandemic began. Lydia began to worry about diseases resurfacing that she had not vaccinated her kids against. She once again turned to the internet for answers, but this time the answers were different, and she did her own research. Lydia realized that everything she had believed for more than 10 years was a lie.

When you're so used to the idea that vaccines can hurt your children and you have to come to terms with potentially putting your kids at risk because you didn't vaccinate...psychologically, I had many sleepless nights just digesting all the information I was taking in.

Lydia made appointments to get her children caught up on their vaccines, and she got the COVID-19 vaccine. In 2021, Lydia enrolled in nursing school so she can help parents who felt the way she once did about vaccines and health care in general.

Hannah

When Hannah was a child, she had a host of health problems – including fatigue, rapid weight loss, upset stomach, and throat infections. Her parents took her to see multiple doctors, but they couldn't figure out what was causing her symptoms.

My parents brought me to the doctor and time and again, I was told an excuse for those symptoms. I was told that I was just an anxious kid and that's why I was having stomachaches. I was told that the scale must have been broken, that I probably didn't lose that much weight.

As a result of those conversations, Hannah not only lost trust in her doctors, but also in her own body.

After years of doctors' appointments and no diagnosis, Hannah was eventually referred to an endocrinologist. She was severely anemic and had to be hospitalized. An emergency scope was performed in the hospital, which clearly showed that she had Crohn's disease.

In her early twenties, Hannah was still experiencing various symptoms, including ones traditionally associated with endometriosis. She was already scheduled for a Crohn's disease-related surgery, and asked if her gynecologist could observe to see if there was evidence of endometriosis. Her surgeon was adamant that Hannah couldn't possibly have more than one serious condition.

Lo and behold, they did the surgery and I had severe endometriosis. After the surgery he came and thanked me for having a gynecologist in there to handle the situation.

Sondra

Last October, Sondra had a regular check up with her primary care physician, during which the pair agreed that she needed several referrals to various specialists. Sondra scheduled a follow-up appointment, assuming that all of the referrals would be taken care of beforehand. Over the next several months, she repeatedly called the office for an update on their status. But Sondra never received the referrals she was promised.

By February, when my follow-up appointment approached, I was livid. I went to this appointment loaded with anger and frustration that I had not gotten the referrals that I needed, and here I was already at the follow-up appointment.

At the follow-up appointment Sondra told her physician that she never received the referrals despite repeated attempts to get them.

My primary care physician could sense my anger and basically asked what was going on, and I unloaded. I told the primary care physician that I had been waiting for four months for the referrals, that I seemed to be the only person responsible enough to follow up and ask about the status of the referrals.

After that appointment, the office took ownership of the mistake and apologized. She was told that when her call notes were reviewed by the office manager, they saw that Sondra had provided all of the information needed to fulfill the request multiple times and that the office staff had dropped the ball.

Sondra believes that the office staff may have paid more attention to her requests if she wasn't a woman of color.

I have definitely experienced biases or stereotypes in my personal health care. As a person of color, I think that some of the solutions to my issues, I have felt like the responses or the solutions have been unsympathetic or even indifferent.

Sherrie

After Sherrie's husband retired, they purchased a farm in rural Virginia and she planned to open a horse rescue. They couple had saved their entire lives for retirement, and had good health insurance.

With a history of gastrointestinal issues, Sherrie eventually had to have her colon removed. The initial surgery went well, but three months later she went in for a second scheduled procedure. When that surgery failed, she went into septic shock.

I barely made it into recovery...I was septic and they told the family I wasn't going to make it.

After three months in the hospital, Sherrie went home to recover but eventually needed additional surgeries. She decided to see a new doctor at a different hospital, and learned that she had surpassed the \$1 million cap on her health plan. Her hospital bills had been piling up, reaching more than \$850,000.

When she couldn't pay her bills, the couple had no choice but to file for bankruptcy.

It's just the hospital bills, the follow-up care that I need, I can't have. I'm just holding my own, I guess you could say.

Sherrie currently pays about \$900 per month toward her medical debt and cannot afford to carry health insurance. She is supposed to see her gastroenterologist for regular follow-up appointments, but cannot afford the office visits.

I suffer from PTSD with hospitals because of all I went through. It wasn't supposed to go like this, but I guess I should be thankful that I have a life.