

## **Vaccine Hesitancy: Part 2**

And I chose to accept a few select interviews hoping that I could help connect with other moms cause I kind of had a message to both groups. To the pro-vaxxers, I wanted to tell them, you guys need to tone it down. You're pushing people away with your understandable fear and anger. And to the people who are hesitating about vaccines. I wanted to say to them, it's okay to have hesitations about vaccines. You've got to get to the bottom of this by checking your facts so you can make a confident decision before like me, it's too late and your kids end up suffering because of it. So in the midst of a medical crisis, we also had this two week international whirlwind of limelight that I didn't want. But I guess if I felt like it was the least I could do to help others who are very hard to connect with, parents who hesitate to vaccinate are probably not likely to really even talk about it with hardly anybody.

In our last episode, we talked about the origins of vaccine hesitancy and anti-vaccination. And as it turns out - neither of these viewpoints are new. So on this episode – we'll focus on how people are responding to solving this problem.

I'm Yasmeen Agosti and this is The Antigen.

We met Tara Hills, a parent-advocate, in our last episode. She talked about being a new mom, and talking to other moms, and getting lost in a sea of misinformation, especially from social media. On top of all of this - she also didn't have a good picture of how serious vaccine-preventable diseases can be. It's easy to see how all of these things combined can lead to a sense of uncertainty and the decision to not vaccinate.

Anyway, long story short, I decided to just settle the matter once and for all, basically to prove I was right not to vaccinate. So my parents would lay off cause they met well and they love their grandkids. And it was an awkward conversation to have with somebody who didn't vaccinate. So I set out in early 2015 just privately to find all the research I could find and give fair hearing to both sides. Just, you know, in my evenings on Google, what could I find?

These days, 80% of internet users are seeking health related information. That's according to a recent study by the Pew Internet & American Life Project. Why? Well, here are a few reasons: it's easy to access, there's an anonymity and privacy factor, if you want it, and there is also a chance to seek community and support from others with similar experiences.

Whatever the reason – on the surface, the internet seems to be an easy way to look for answers. The challenge, is that there is a lot of information to sort through, including a lot of bad information,

which can be hard to recognize.

But during that time, a health advocate, sort of a friend of a friend, she connected with me and said, "Hey, I heard you're doing this research. Um, could I be a resource to you?" I was hesitant at first because I was like, you're a pro-vaxxer. You're just going to be rude. So no.

But she disarmed me by saying, listen, it's okay to have questions about vaccines. Any responsible parents should ask questions about a medical intervention. So it's okay that you have questions about vaccines, can I help you? And it totally disarmed me because she validated it was okay to have questions and to be nervous, but she urged me to keep going. So that was a real tipping point. Looking back now, everything changed after that point. She urged me to do other research I needed to do, read whatever I wanted to read, you know, go on the internet, read books. But she told me this big one thing, it was life changing. She said, just makes you scroll to the bottom and check the links. And I was like, huh, Oh, that's pretty intuitive. Sure. And I did. And within two evenings, I did a complete 180 changed my mind and called the doctor's office.

Checking the links provided on a website is just one of several important digital health skills that everyone should be using no matter what the topic is that they are searching.

A reliable health websites should have a policy about how they choose to link to other sources of information. This policy can help you to understand the motive or the goal of the website.

We will talk more about what some of these other digital health skills later in the episode.

And that I hoped was the end of the story, but it, it continued because it's going to take a couple of weeks to get the kids all caught up and get them into the office and order everything and create some catch up schedules. And in those four weeks all seven kids came down with whooping cough.

Whooping cough, also known as pertussis, is a highly contagious disease. It's caused by a bacteria that leads to uncontrollable or violent coughing fits. The nickname whooping cough comes from the sound you that make as you take a deep breath after a bad coughing spell. Sometimes, the coughing is so severe that you can have trouble breathing or even vomit. While it can infect people of all ages, it's especially dangerous for young infants where it can be deadly. This can even happen in infants who don't have any coughing symptoms at all.

When the kids were confirmed whooping cough, public health got involved, we immediately had to go on like a five day isolation. The kids were doing a round of antibiotics to treat what had developed

into the paroxysmal stage of pertussis. And it was pretty brutal. My youngest was eight months and so he was just beyond the most dangerous zone for children with whooping cough, but they still had to go through it. It's called the 100 day cough in other places of the world because it's a brutal cough and it's so bad that the kids were like vomiting. They would cough that badly.

What made it more challenging though was there were people in our family who had younger children. My niece was only a few months old and she was in the danger zone. So she had been exposed, her parents didn't vaccinate, like us, and I can't even describe like the self-incrimination and the guilt and the fear that I was going through feeling so directly responsible for in my, you know, my well intentioned ignorance. I felt completely responsible that I had made choices that led to her being at risk and it could not have illustrated the reality of vaccine preventable illnesses and how scary and real they are.

And on the irony being, I didn't need the illustration. I had already crossed that bridge and changed my mind very confidently, but I wanted to help others because I realized how easy it was for me to get to that place and I wanted to help others not be in it.

Nobody likes to be lectured about anything, especially if there's fear involved. So my big piece of advice is ask questions, listen and just talk with, you know, gentleness and compassion. You'll be far more effective even if it's just planting a couple seeds. Even if they don't make a decision right then and there, you've maybe helped them move a little bit further along and that's huge to help somebody and to be a resource to them.

As a parent advocate, Tara is now very focused on parent to parent communication, which is one type of conversation and source of information that's happening when it comes to talking about vaccines.

There are a few things you can do to help determine if the information you are reading online is reliable. The National Institutes of Health or NIH provides a set of important questions to ask before you decide to trust what you are reading. Questions like...

Who runs or sponsors the website? And is that information easy to find?

Who wrote the information and who reviewed it to make sure it is accurate?

When was it written? Is it current?

And what is the purpose of the website? Are they trying to sell you something?

Dr. Steven Salzberg, the Bloomberg distinguished professor of biomedical engineering, computer science and biostatistics at Johns Hopkins University encourages people to be skeptics.

So what I mean by the term, it's used in a variety of ways, is I would say critical thinking. Um, the ability to think critically about claims that you hear, is what I would look for in someone who is a skeptic. I often identify myself as a skeptic. Some people associate that with a word, with negative terms, but it's pretty much part of built into our training as scientists. All scientists are taught to be skeptical of any new claim that's, uh, even a little bit surprising. And by skeptical, you don't mean you refuse to believe anything. You just mean. You want to see the evidence, you want to know what, what does this based on and is it based on a foundation of solid science that, um, is going to hold up over time. So, um, when someone comes and says they have a new treatment for a disease or, or claims that something causes a condition, like vaccines causing neurological problems, you, if you hadn't heard that before, you should say, well, why do you say that instead of just accepting it. So that's, that's all this skepticism really means. It means to question the sources that you're getting information from.

While it's important to practice skepticism, it's also important to have a trusted source of information.

Well it is, but in a realistic way, you know, the average person and the average parent isn't going to be able to go and, um, really vet the sources that say that, that prove that vaccines are safe. They, they could, um, there's many, many, um, studies that have been published. They're all freely available on sources like pub med. You can Google it and find them and there's, there's summaries of these, of these articles that you can find in other places. And I would encourage people to do that if they can, if they have time, if they have the wherewithal to question things. But what we also do in, in our lives is we rely on trusted sources. So you identify sources that you trust for certain kinds of information. And when it comes to vaccines, I would encourage people to think a little bit more critically about where you're getting information about vaccines.

Dr. Salzberg suggests that your most trusted source should come directly from a recognized expert trained in that topic.

So you should ask your pediatrician, who is probably someone you trust. And there's, at least in the U.S., a system I know best. Most pediatricians are well trained and are able to explain, um, what vaccines are about and how they work and are usually able to assuage the concerns of parents. But if you're getting it from your neighbor on the sidelines at a kid's soccer game, that, which is a place where I've heard anti-vaccine sentiments expressed, you should question that you should be not, don't confront people but just don't believe it either. You know, go and find a trusted source if you can't do the research on your own.

And I would just say, look, you know, you don't, when you, when you're on an airplane and you encounter some turbulence, you don't ask the person in the next seat, what should we do about this? You trust the pilot to know how to do this. So why would you trust your own health or your own or your children's health with, you know, some random neighbor or some person on Facebook rather than a physician who's been trained on how to kind of provide that advice on what to do.

Dr. Kim Schrier, who is currently serving as the first pediatrician ever in the U.S. House of Representatives describes how she approaches vaccine hesitancy in the clinic.

A lot of vaccine hesitant patients come and see me. Parents are worried, they go online to get information, they talk to their friends, they hear rumors about things tying the measles vaccine to autism or tying a hepatitis B vaccine to diabetes or tying the HPV vaccine to, um, all kinds of women's health issues. Um, none of which makes sense and none of which are born out in science. But it's the pediatrician's job to meet parents where they are, to sit down with them and say, wow, if I heard that I'd be worried too. Let me tell you that there is no basis of fact in that and here's what we know. And when parents hear that they relax, they just want somebody to reassure them and tell them that they're not doing anything that might hurt their child.

Talking about vaccines with your doctor or healthcare provider doesn't have to be a one-time conversation.

And so by having those conversations and sometimes it's a lot of conversations at two months, four months, six months and on, um, I'm able to achieve really high vaccination rates. And this is all through education, not through strong arming. And that's what we do. I mean, that is what pediatricians do. We have those conversations, we build trust with families and they count on us to give them good information and to take care of their children. And believe me, if there was ever something that would hurt a child, the pediatrician would be the first to stop doing it. Our goal is to have healthy children.

I asked Dr. Schrier if she could give an example of a question that a vaccine hesitant parent might have and what the conversation might sound like.

And so they'll come in with questions like, I heard that the MMR vaccine might cause autism and I'm worried. Um, and it's really easy then for me to sit down and say, look, people spread rumors and they're not true. And we do see increasing rates of autism, but I can tell you this much. They're not tied to immunizations that we would not give these if there were any link. Multiple studies have been

born out, these are safe and effective and we're looking for why there is an increase in autism. But I can tell you it's not this. And we can go down that path in multiple ways depending on how families are doing. Sometimes they only need one conversation. Sometimes it's multiple.

We also talked about where parents can go online to find additional information about vaccines .

I of course first tried to take that on by myself, but I also tell them to check their sources and that the American Academy of Pediatrics puts out excellent information, and is a trusted source. The CDC is also a trusted source along with the ACIP. The Children's Hospital of Philadelphia is another excellent source.

I also asked her about how she talks about another important topic within vaccines - community immunity. From her experiences, she finds that this concept doesn't always resonate. So, she prefers to bring community immunity to a place that most parents can easily relate to.

I have found that by saying, look, there might be a child in your son or daughter's class who has leukemia and can't be vaccinated. And if your child is the one child who brings chicken pox or measles or some other disease to school, you will bear the responsibility for what happens to that child. And that is a much more personal and compelling thought process for parents than looking at the whole community. In fact, patients who are vaccine hesitant tend to think, well great, I don't have to vaccinate my child because everybody else is. And so I think bringing it down to the classroom is much more helpful in bringing parents along in immunizing children.

While Dr. Schrier prioritizes face to face communication in the office, she did point out that there is more that can be done to talk about the benefits of vaccination – including tapping into the power of social media.

I think about the power of social media and how the anti-vaxxer community has leveraged that to scare patients and to put stories on there that just make parents panic and we can leverage that same social media to do so much good. And, and not to do this through a public service announcement or a really boring post.

Chad Herman, the communications director for Kids Plus Pediatrics, in Pittsburgh Pennsylvania talks about how and why their practice is leveraging social media to do just that.

But if you think about that, particularly once kids get beyond toddler stage and we're seeing them

only once a year, we're seeing them once a year for well visits, maybe a couple of times a year for sick visits. So our opportunities to have face to face conversation and build on the trust and the relationships that we have as their primary care office are really pretty slim because again, there's a lot of things we have to do in those visits. There are boxes that we have to check. Oh. And we have to give them vaccines and answer all of their questions as well.

So, Kids Plus came up with a solution.

So one of the strategies that we have at Kids Plus, which is what brought me here as a communication director now almost 10 years ago, is the notion of we have this incredibly powerful relationship with our families, our parents, our caregivers, grandparents, people who are making the healthcare decisions for our patients.

We need to take advantage of that, not just when they're face to face, but specifically when they're not face to face, which is 365 days a year. Right. Even those moments, those days when they are in our office, they're also still not in our office most of that day. So we might get to see them five, six times a year. But if we're posting twice a day to Facebook on weekdays, which we do as a minimum and once a day on a weekends, 365 days a year, and we're doing the same thing on Twitter. Now we're talking about literally hundreds and hundreds almost. I think his number is 624 roughly. Um, points of contact per year. And that's not counting if they are following us on Instagram or if they're seeing our videos on YouTube or on Vimeo. So we are all over social media because we know that we want to be able to have this kind of impact.

Kids Plus not only provides their families with reliable information about vaccines and pediatric topics in general, they also help their families to sort out good from bad information that they find online. They provide this service, because they recognize how important it is to respond to bad information very quickly.

We also want to be a place where our families, our parents, our caregivers can come and they have been, um, for the last 10 years where they can come. If they see something, they read something online. If they see something that's scary, some tweet or some Facebook post that someone in their circle has tweeted or retweeted or repost or shared and really is scary, it's fake, but they don't know that they can come to us and say, "Hey, I read this, look at this article, look at this post. Do I have to worry about this? Is this true?" So we are, we are also sort of the fact checkers virtually for our practice.

Dr. Todd Wolynn, CEO of Kids Plus and a general paediatrician, works very closely with Chad on ensuring that their families have the support and information that they need. He also has an important message for other healthcare providers when it comes to communicating about vaccines.

And to Chad's point, as he just made, people literally use us to help vet disinformation or information that they see, which otherwise we think would go unchecked. Because there is clear data to show that the most trusted influencer on vaccines and vaccination are trusted healthcare professionals. And the problem is if you're banking or relying on that once a year interaction, and as we know for later at elementary school and all the way through teens, those visits drop off to the point where you may not see them at all for a year or two. If you're banking on that visit, which may never happen or happens quickly, but there's other distractions. You are really putting yourself at a disadvantage. And so we need to be, and this is my call to action for anybody listening to this podcast, my call to action for researchers and clinicians is that we develop and grow our virtual voices.

In the last episode, we talked about the difference between those who are vaccine hesitant and those who are actively anti-vaccine. This is an important distinction, especially when it comes to where communication efforts should focus. Here is Chad Herman again from Kids Plus Pediatrics.

If 75% of the population is vaccine accepting, we're continuing to reinforce those messages. There are 1 to 2% that are, that are actively anti-vaccine. As Todd said, there are very vocal, but very small minority. The people that were really having an opportunity to influence is the 20%-ish, 20 to 23%-ish, who are vaccine hesitant, who have understandable, right? Very real understandable concerns about vaccines and who given a good, clear, concise recommendation from a trusted healthcare provider will almost certainly move to vaccine accepting.

Kids Plus Pediatrics has also experience responding to something that has, unfortunately, become more common – organized online attacks by anti-vaccination individuals and groups.

So a little over two years ago, we posted a 90-second public service announcement video that we made on the HPV vaccine as cancer prevention.

HPV stands for human papillomavirus. This is a common virus spread through intimate skin-to-skin contact and infects roughly 14 million Americans every year. While most infections will go away on their own, certain types of the human papilloma virus can lead to different kinds of cancers later in life, including cervical and throat cancers. The vaccine was designed to prevent these types of cancers.

We were really proud of it. The AAP, the CDC, the American Cancer Society. Lots of people loved it. They said it was great. It was better than Cats. They would see it again and again, and it also had its desired effect.

We saw an uptick in people posting on social media and people calling our office and people coming in to get the vaccine and we were feeling really pretty good about ourselves until about three and a half weeks later when we were victims of a global coordinated real time anti-vaccine attack, and anti-vax attacks have been going on in all media as long as this has been an issue. But what has happened in the last two years are these new tactics where, which are sort of fuelled inside private anti-vaccine social media sites. In this case there were two different anti-vaccine Facebook groups that attacked us for again, having the temerity, the audacity to post pro-vaccine, evidence-based information online. The attack lasted eight days. It was 24 hours a day for eight days, literally from around the globe.

From a single individual in a single state to hundreds of people from around the world – over 10,000 comments from a total of 36 U.S. states and 8 other countries.

The harassment was wide ranging in who and what they were targeting - not just the pediatric practice website itself, but their business ratings, their families and their supporters.

The attack started with one person from central Ohio posting our video into these groups and then we had people from the panhandle of Florida, from Texas, from New Zealand, Australia, Italy, England, literally around the globe attacking us 24 hours a day for eight days. And that is posting anti-vaccine myths and disinformation underneath that video. It's doing it all over the page. It is insulting and um, arguing with and dismissing people who've have come to your page to say positive things and good things about the video. It even took the form of people attacking our families, not just on our Facebook page but on our family's individual Facebook pages on their walls and sending them direct messages, calling them idiots and robots and baby killers. We of course were called all of those and much, much more.

Kids Plus Pediatrics organized a quick on-line response to the comments. They did this with the help of colleagues, friends and even a global Facebook network of physician moms, all of which ultimately helped to bring the harassment to an end.

They turned this difficult experience into a solution by creating "Shots Heard Round the World," a rapid response network & toolkit dedicated to countering anti-vaccination aggression on social

media.

All the voices that we've heard from on this episode have helped to paint the picture of where we are at today with vaccines, vaccine hesitancy and anti-vaccination.

We've learned about how parent-advocates, scientists, physicians and even communication directors are responding to the important need to provide people with trustworthy information.

On our next episode, we'll look more closely at the politics of vaccine decision making.

What the Supreme Court said is that governments of various levels can mandate vaccination, if they want to, it doesn't say they have to. So each jurisdiction decides on its own what vaccines to mandate and how draconian the penalty should be for not vaccinating.

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