"<u>It's hard to un-ring the bell</u>": Talking about the vaccine-autism myth (& more) with Dr. Paul Offit

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[Intro music: Jazzy synth pop music]

Anne: Welcome to *Noncompliant: A Neurodiversity Podcast*. I'm your host, **Anne Borden King**. My guest today is **Dr. Paul Offit**. We're going to talk about how vaccines are developed; the vaccine autism myth; and dealing with misinformation in a post-pandemic world.

Dr. Offit is the Director of the Vaccine Education Center and an attending physician in the Division of Infectious Diseases at Children's Hospital of Philadelphia. He is an award-winning and internationally recognized expert in the fields of virology and immunology, and is a past member of the Advisory Committee on Immunization Practices to the CDC. He's currently a member of the Food and Drug Administration Vaccines and Related Biological Products Advisory Committee in the U.S.

On the podcast website, you can read more about Dr. Offit's work and his involvement in the autism community, as well as his book about the anti-vaccine movement and fake autism cures, titled: *Autism's False Prophets*. We'll be talking about that book today too.

Welcome to the show!

Dr. Offit: Thanks for asking me.

Anne: Let's go way back. You've described how the stories you heard from your father's clients informed your approach in life in some ways. Could you talk about that?

Dr. Offit: Sure, well, he was the head of a sales force actually – a national sales force for men's shirts, and every six months he would gather all these salesmen from all over the country

together and they would have sales meetings on how best to sell. And these were engaging people, and what it taught me was that when you're selling something, it doesn't matter what you sell, because really what you're selling is yourself.

It just...I thought, *I could never do this*. *I could never sell myself*, so that's why science was so much of a draw in the end because you know you're really (in theory) only as good as the quality of your scientific studies. Your being able to influence people by your personality is much, much less a part of that.

Anne: That's interesting. Do you think over time it's changed? Do you feel that people in science *do* have to sell themselves more (or less) than they used to?

Dr. Offit: Yes. I think in the end what I've learned in all this is data don't really sell themselves. Ultimately, you have to "sell" them... what I mean is you have to be able to describe [data] clearly and compassionately, so that people can understand it.

And that can work both ways. I mean, you can have very good data and the person who's trying to explain those data doesn't do a very good job, or you could have people who are just utter quacks who are very good at explaining things and influencing people.

Anne: Isn't that the truth? Yes, and we're going to talk about vaccines now. Vaccines, we love 'em. We love 'em in the autistic community and I want to talk a little bit about the history and get into some of the anti-vax history as well, as we're dealing with reverberations from that right now.

You co-developed a rotavirus vaccine called RotaTeq. It was launched in the U.S. around 2006 and now it has the enthusiastic support of the World Health Organization because it saves babies' lives. In the developed world, and in the developing world, rotavirus can cause severe diarrhea, dehydration, and death. But, luckily, vaccination is very effective in preventing severe rotavirus, much like the Covid vaccine can prevent severe outcomes: reducing E.R. visits, hospitalizations and deaths. And researchers have had various estimations, but one is that rotavirus vaccination prevented about 55,000 infant hospitalizations in 2008 in the U.S. alone.

I wanted to ask you what it was like to get involved with this project and develop it and then go through the approvals process for the rotavirus vaccine.

Dr. Offit: Right, so...well, you never think you're making a vaccine, you know, just because that would be way too high of a bar and you'd only be disappointed. I mean, what I thought I was

doing was what hundreds of other people in this world that were engaged in trying to understand this virus were doing. Just to try and figure out what parts of the virus make you sick, what parts of the virus induce an immune response that's protective and how can we possibly construct strains that would be the best of both world – where you could induce a protective immune response without causing disease.

And so that was like roughly a ten-year effort trying to understand the selected aspects of this virus. It's a little depressing, you can actually summarize ten years of your life in about 40 seconds, but I think I just did that!

And then, you think you might have the strains that could be a vaccine, and in the world that's for trying to develop a vaccine, it's kind of like little r – research, bigger D – development and then a bigger I – implementation.

The harder part, after you develop strains that you think could be a vaccine, is doing the development of vaccines, meaning research and development, where you have to prove that each of the strains that are in the vaccine need to be there--no more, no less. You have to do dose-ranging studies to show that you have the right dose. Not too much of the vaccine; not too little of the vaccine. You have to have the right buffering agent, the right stabilizing agent, the right vial, you have got to do real time stability studies. and then you gradually work your way up – because this was a vaccine for babies, you know for babies 2, 4 and 6 months of age.

Then you work your way up from adults and then down to children who generally have already seen the virus, so therefore you're jumping with a net. And then you go to younger and younger children and ultimately babies who have never seen the virus or been vaccinated before. And you know, you test it in initially less than 100, and then hundreds and then ultimately the so-called Phase 3 trial which was you know, a 70,000 person prospective placebo controlled, 11 country, 4 year, \$350 million trial to prove that the vaccine works and is safe.

That effort – the research and development effort-- was a 16-year, probably \$1.5 billion dollar effort. And obviously, only pharmaceutical companies have the resources and expertise to do that, and we worked with a pharmaceutical company to do that.

And then comes the implementation part. You know, you want to get it out to where it's going to do the most good. Obviously, there were 75,000 hospitalizations in the United States every year that we've pretty much eliminated now with this vaccine. And in the world, there's about 2,000 children who died *a day, every day* from this virus.

The Bill and Melinda Gates Foundation was critical in getting the vaccine into the developing world. Interestingly rotavirus is why Bill and Melinda Gates got into vaccines...

Anne: oh!

Dr. Offit: ...because they had never heard of the virus and then found out that it could kill 2,000 children a day. It's been an education.

Anne: And how long from the initial seed of "let's go and see what's happening in a situation" to actually being able to develop and roll out the vaccine?

Dr. Offit: I'll tell you, the research effort was 10 years, the research and development effort was 16 years. And so it's a remarkable amount of time. Which is why it's all the more amazing that the Covid vaccine was basically developed in 11 months.

Anne: Right. Was some of the research for the Covid vaccine...some of it was done in another context prior?

Dr. Offit: You're right, it was in another context prior. This messenger RNA technology, mRNA technology, had been around really since around 2005. **Drew Weissman** and **Katie Karikó**, at the University of Pennsylvania were working to try and make an AIDS vaccine...a Human Immunodeficiency Virus vaccine, using that technology. It didn't seem to work, and when SARS-CoV-2 raised its ugly head in late 2019, they thought "I wonder whether it could work for this?" And the answer was, yes, it did.

Anne: That's a good thing. Definitely.

Getting back to the rotavirus, I remember giving it to my infant son. We went to see our doctor and she was like, "you can decide whether or not you want to do it. It can prevent severe diarrhea." And we were like, "Something that's going to prevent severe diarrhea in our baby, like that is a no-brainer. Like, *yes*! Please, let's do the rotavirus vaccine!"

But we were also locked in a time... this was in 2009... when some of our peers and friends were *not* saying yes to vaccines. They were starting to skip vaccines for their babies or they were doing very selective and extended and modified schedules of skipping the MMR... some of the people that we knew. And this is because they were afraid. I mean, interestingly, it all got kind

of couched in this idea of parents being empowered. You know, from the home birth movement to the spacing of the vaccines and the Dr. Sears Junior kind of "make your own choices" way of looking at things.

But I don't *really* think that those choices were really empowered choices because they came from a place of fear, and it was a very visceral fear about autism. And, that's a seed that was planted long ago for many parents, even then. And even now, there is this fear.

I was thinking, why don't we trace back the history a bit to that first panic about autism? In specific, what were the first murmurings or the media coverage about this false theory about vaccines and autism?

Dr. Offit: Well, the first murmurings were actually in the early 1980s when there was a film that came out in April of 1982, done by NBC news – Lea Thompson, then of NBC news. It was called *DPT Vaccine Roulette*. You know, the Diphtheria, Pertussis, Tetanus Vaccine Roulette. And what you saw in that riveting one-hour show were children who were seizing, dribbling, with bicycle helmets, withered arms and legs, staring vacantly up in the sky. And the parents all told the same story. "My child was fine, then they got this whooping cough vaccine and now look at them." And it took a while, really, for the studies to be done to show that you were at no greater risk of having these sort of neurological problems if you had gotten the vaccine or if you hadn't.

That sort of gave birth to the notion that vaccines could cause permanent brain damage. However, it took off in 1998 when in February of 1998, Andrew Wakefield, a British gastroenterological surgeon, published a paper in the *Lancet* claiming that the combination Measles, Mumps, Rubella (MMR) Vaccine caused autism. That's when it really took off.

Anne: Do you know what motivated Wakefield to do this paper, and then what motivated people to believe what he was saying?

Dr. Offit: I think Andrew Wakefield was looking for greatness... looking for that thing that made him well known, and he had published a series of papers claiming that that measles-containing vaccine could cause chronic inflammatory disease, like inflammatory bowel disease. So, that was wrong, and when it was clearly shown it was wrong, to his credit he ultimately said "I was wrong. This wasn't right."

But, see, it gave a sense that he was looking for some connection between vaccines and something bad. And then, as *he* tells the story, you know, "parents came to me, they told me that their child was fine, and then they got this Measles Mumps Rubella vaccine, you know, early in the second year of life, and now, look at them. They are not fine."

All he published in that paper were really a case series of 12 children – eight of whom had autism or developed autism and were first recognized as having symptoms of autism within a month of having received that vaccine. And it really wasn't a study in any sense of...[it wasn't] comparing groups of children who got the vaccine or didn't get the vaccine.

And that was sadly published. It should have never been published. It was a sort of thinly thought-out paper, because he made a series of sort of improbable events, which I think it's something like out of Alice in Wonderland...

Anne: Yeah.

Dr. Offit: ... but he said, he said something like "Okay, see the problem is when you give the MMR vaccine at once, you're giving three attenuated or weakened viral vaccines at once and that weakens the immune system. That suppresses the immune system."

Now, he could have done studies to see whether there was any evidence of a suppressed immune system in these children. He didn't.

He then said "Because the immune system was suppressed, that allowed the measles vaccine virus to travel to the intestinal surface--the intestinal mucosal surface and damage the intestine."

He biopsied every one of those children. He could have looked to see whether there was measles vaccine virus in those intestines. He didn't.

Then he said "Because the intestine was damaged, that allowed for the entrance of braindamaging proteins to enter the blood stream, travel to the brain, cross an *intact* blood-brain barrier and cause autism." And he didn't know what those [hypothesized] unusual proteins were going to be. It could be casein, it could be gluten – he just sort of threw out popular proteins and- and that got published. He had no evidence for any of these sort of series of hypotheses he made.

And subsequent to that, there were 18 studies done in seven different countries, on three different continents costing tens-of-millions of dollars showing that you were at no greater risk of having autism if you got that vaccine or if you didn't. And to the credit of the Public Health and academic community, they did respond to that paper.

But you know, it's much easier to scare people than to unscare them. It's hard to un-ring the bell.

Anne: That is so true. I mean, when you look at what it was, which was a few stories and a really implausible theory making its way into the *Lancet* and getting that sort of authority, and then the hype just *went* and it- even though there have been, like you said, millions and millions of dollars worth of studies that clearly refute that story that he told, it's just really hard to push back on it.

I wonder if part of it has to do with mainstream media coverage that Wakefield got. For example, he testified before the U.S. Congress, he was on *60 Minutes*, and the media ran with that story for a long time. And even some autism charities ran with the story that it was plausible what he was saying.

I'm wondering how the media coverage can propel these kind of false links – related specifically to the MMR and autism, but really, any autism myths. What are your thoughts on that?

[14:52]

Dr. Offit: That's exactly how it happened. I mean if you look at when he published that paper...I'm not trying to defend the media here because I think if they're going to do what they did they need to look a little deeper, but here's a paper published by someone from a well-respected hospital in England, who published a paper in the journal *Lancet* which was a very well-respected general medical journal, and so they assumed that this had been adequately vetted. That it had been adequately reviewed, that the data were solid, when they weren't. And you know, "here it was finally, at last you had a clear cause for autism, and therefore a way to avoid it – just don't vaccinate your child."

And as a consequence, thousands of people in England and the United Kingdom didn't vaccinate their children, hundreds were hospitalized and four died. Four children died of measles. You could argue that paper killed four children and the media coverage surrounding that paper killed four children.

And then it crossed the ocean and it was here.

And you're right, Andrew Wakefield was on *60 Minutes*. He was in front of Congressional Hearings. I actually had to testify on the other side of one of his Congressional Hearings. I was

like on the Science side, in front of [Congressman] Dan Burton's Committee on Government Reform. Not fun! [It was] not exactly a source for truth at those committee hearings, and it was just a circus. And the people who suffered the most were the people who always suffer the most, those children who are particularly vulnerable to our ignorance.

Anne: I wonder too if ignorance and a lack of understanding about autism *itself* makes it a particularly vulnerable condition for pseudoscience to latch on to. Because it's not like you go and get a blood test for autism, or we understand what is "causing it" or anything like that.

That sort of ambiguity makes it easy for someone to come along and say to parents who don't have answers, "I have the answer, this thing that I think causes it... and I have the product or the solution or the plan to end it." I think part of it might come out of that. But then of course the media and the social media coverage of Wakefield's paper also spurred a kind of protest movement, and I believe you were a witness to that. You talk about that in your book, *Autism's False Prophets* and we've spoken about it as well.

Could you describe the moment when the protests and the sort of grass-roots movement against the MMR vaccine was really hitting its early peak?

Dr. Offit: Well, I think in the early 2000s when Wakefield, who, you know, was an attractive man, he is charismatic, he is well spoken, he is convincing because I think *he was convinced*. And you know, we love the British accent, I think we're probably willing to give ourselves back up to the Queen at this point, [and] he's on *60 Minutes*, he's on morning and evening shows. He is a compelling figure and he was given his say. Ed Bradley on *60 Minutes* handled that interview as if [Wakefield] was right.

I think at the heart of this is that there are those aspects of medicine for which we don't have clear causes, or clear cures and that's where this kind of quackery or guru-ism thrives. Because Andrew Wakefield was sure he was right, and I think we're drawn to that certainty...because otherwise, what does medicine offer [parents of autistic kids]? Modern medicine is offering very little, but he offers you a lot: "Here, you want to avoid autism? Just avoid the MMR vaccine," and then, you know, "or take this magic medicine, or do chelation therapy," or any of the other sort of quackeries that surrounded this.

I feel really sorry for parents in this setting. I did then, because I was testifying at these committee hearings and you know I did meet [Wakefield] once and I just...I don't blame parents. They are desperate to do something and here was this person who offered something magical and it's hard to resist that. I understood that. I just think this, to me, was the *lowest* kind of form

of quackery. It's taking advantage of parents' desperate desire to do something, anything that helps their child.

Anne: And it seems like there's a new aggressiveness to that [pseudoscience] movement, and particularly since this re-emergence, and we're in the post-pandemic period where there's a certain level of scepticism happening and a slippery-er slope than we had in the past, in terms of distrust in medicine, because of people's differing perspectives on the Covid restrictions. And then this avalanche of misinformation and disinformation because of the opening up of social media and the lack of any restriction on social media. It feels like an angrier and more aggressive movement against vaccines.

I'm wondering if you have any thoughts on first of all why it's become the way it is with the ascendancy of [R.F.K. Jr.] in that movement, and then how we can start to combat and tamp that down before things get even worse.

Dr. Offit: Right, so I think the reason why R.F.K. Jr. has the impact that he has is he is able to appeal to something that has become a much bigger issue in [the US], which is this sense of conspiracy. That there are dark forces that are working against you. I mean, you'll hear congressmen in this country use terms like "deep state"...

Anne: Right.

Dr. Offit: and, successfully. And I think that's what he appeals to. "Here's what they're not telling you, here's what they don't want you to know, but I'm going to tell you the truth... that vaccines cause all manner of chronic disabilities." And even more recently just in the last couple of days [RFK Jr.] said that were he elected president - heaven forbid - that he would immediately get the National Institute of Health to stop studying infectious diseases and only study chronic diseases with the notion that vaccines are causing these chronic diseases.

I mean, I can't imagine that, but it's very easy to appeal to that notion that there are dark forces working against us. Between that and the internet – which is both a source of wonderful and awful information, including disinformation – someone like him thrives.

It's interesting, I ran into a guy named **Richard Besser** who used to be head of the CDC around 2009 when Swine Flu hit. I saw him at a meeting and I said, "I just want to congratulate you. I think you were great. You were out in front of the media every other day, answering their

questions that people had about that Swine Flu pandemic in 2009." He looked at me and said, "Thank you, *I could never do it today*. Between current politics and social media, I would never have been as successful then as if I had to deal with what people have to deal with today."

Anne: Yeah. What are people dealing with, people that are trying to communicate about vaccines and public health? What is the pressure that's on them right now that you're seeing?

Dr. Offit: I think there's been an enormous backlash against institutions, including government institutions. I think the way that people perceive the Food and Drug Administration, or the CDC is at its lowest all-time ebb. They feel that they're not being told the truth, and therefore they choose to ignore it. There's a paper coming up by the CDC [released November 10, 2023 one day after this interview] showing that there's been a dramatic increase in people who are exempting themselves from vaccines. Not just Covid vaccines, I'm talking about *all* vaccines, including childhood vaccines. And with that, there's been a fairly dramatic lowering of the instance of children who are getting vaccinated.

I think what happened in this pandemic is something I never would have never predicted, which is that we leaned into a libertarian left hook.

Even though there had never been a politics of the anti-vaccine movement...I mean on the left it was "I only want to experience things that are natural, I don't want to be inoculated with preservatives or adjuvants, or manufacturing residuals or inactivating agents," and on the right, it was this kind of libertarian "government off my back, don't tell me what to do, I will educate myself about what to do and therefore I will do what's best for society because I will be educated."

If you look at like the measles epidemic in 2014, 2015, that was sort of a phenomena of the left. It started in the Disneyland community – a heavily Democratic community, then spread to 25 states. That measles epidemic [affected] almost 300 people. But, now it's almost exclusively a phenomenon of the right. You are much more likely to be hospitalized and die from Covid-19 if you voted for Donald Trump than if you voted for Joe Biden. And it's because of this libertarianism... this "don't tell me what to do, don't make me get it- do anything" and I really worry for children in this climate because last year there were more than 800 legislations that were introduced to get the Public Health community to "back off", because 1. [antivaxxers] felt [Public Health] were too aggressive and 2. they thought they were wrong.

Anne: How do people who are communicating about science address this, I guess you'd call it a *credibility gap* [affecting Public Health]?

I think people do have to think a little bit differently now, since the pandemic. For example, I was talking to just my friend this morning and his wife had a bone marrow transplant and he's like "she's going to get her Covid vaccine next week, and it's good because she's going to be able to teach back in the classroom," right? But then I was at our GP and I asked her whether my son, who is 14 years old and has had Covid and had his two-series [vaccination], whether he needed a booster, and she said no. Now, I can live with that difference. I understand that my friend who had a bone marrow transplant is at a different level of risk than my 14-year-old son. But the problem with having to assess risk on an individual basis is that doesn't seem to roll out very well from a policy perspective – then it leads to a credibility gap.

And, unfortunately, this of course, this is a moving target – the novel coronavirus-- because we don't know everything about it yet, but [the backlash against Covid-related restrictions and mandates] trickled down into things that we *do* know a lot about, such as early childhood vaccines.

I guess it's a very round-about way to get at my question: "Is there a way to communicate about the complexities that we've all just faced for the past three years, and are facing now, to communicate the very, very simple understandable facts of the need for the full series of childhood vaccinations?"

Dr. Offit: I think you have put your finger on what has sort of plagued me for the last few weeks or months. You learn as you go, and this pandemic is no different.

For example, last year when Omicron hit, we thought, "okay, let's include this in the vaccine, instead of having what we had done before which was to give the original strain – the ancestral strain, let's move into the Omicron era. Let's have half a dose of the Wuhan, you know the original strain, and a half a dose of one of the Omicron strains – the so-called BA.4, BA.5." That was not an advance. It was a step to the side. Boosters boosted, it was no worse than what we had, but it wasn't better. It didn't do what we wanted it to do. It didn't induce a better, neutralizing antibody response against that Omicron strain.

We learned. Now, we never really said that. We didn't. Quite the opposite. We basically moved on from it, so this year you just have one strain in the vaccine. [Some] said, "well, it's much better even though the studies that were done out of Harvard, out of Cornell, showed that was... and studies in France showed it wasn't any better. [But] it wasn't any worse – the boosters boosted, but it wasn't any better.

And can you say that? Can you say that to the public? That "look, we've learned here, this wasn't as what we'd hoped, I think that next year's vaccine will be better because of what we

learned." Can you say that in these times? In these times that are so divided, in these times where you're either on the bus or off the bus in terms of public health. Can you say that?

I mean, I think it's hard. I wrote a perspective piece for the *New England Journal of Medicine* that did say that and when I was on national tv a couple of times I was sort of asked about that.

And I got a lot of pushback from friends in the public health community that "don't do that, don't challenge the science behind public health recommendations, because all it does is sow distrust." But see, you would argue, and I would argue at least in a better world that, that wouldn't it be more transparent to just say that we're learning as we go? Wouldn't that work well? And I think it would work well but not in the world we're currently living. It appears it just doesn't seem to work well at all in the world we're currently living.

Anne: But, I mean, I don't think [the approach of hedging on lessons learned] is working either. I really, really worry because I know there's the threat of kids not getting their childhood vaccinations and there's also new threats that we're not aware of, with climate change and everything else, we're going to have another crisis.

My concern is that I look around in my world, in my parent world, and I see people just tuning out the [Public Health] message. Because the ground shifted and because there was conflicting information, but the [Public Health] message has remained the same.

It seems like it isn't working out the way things are now, either. I'm not really offering any solution here. I just think we need to have a clear-eyed look at how average people are acting and reacting--and come up with a new strategy. And I think that with the work that you're doing and that some others are doing...I understand why people might try to push back [against it] because you know "we need to dig in our heels and we can't present conflicting information, because then misinformation comes in". But, on the other hand if you just look around at how people are relating and complying with Public Health, you realize that there does seem to be some kind of a shift in order to keep people from just totally tuning out.

[29:30]

Dr. Offit: And they are tuning out. I completely agree. If you look at last year's Covid vaccine recommendations, it was recommended for everybody over 6 months of age. Maybe one out of five Americans got it. This year, same recommendation, maybe one out of 25. And we're doing something a little differently here than most countries who target high risk groups do and I just worry that those like your friend who's had a bone marrow transplant or people who are

pregnant or people who have multiple health problems, they do need this booster, and many of them are not getting it, and they're not getting it because I think they've tuned us out.

And I'm just wondering what if anything we can do to get them to tune back in again.

I mean, I would argue that being as transparent as possible would be great. I'm on this committee, for example ,the FDA Vaccine Advisory Committee. When we look at data of who's getting hospitalized, who's dying, we often look at Canada or Israel or the UK. Those are the data we get, mostly because they have national health systems, so it's much easier to get those data. We don't have a national health system here so it's much more fragmented and **Dr. Walensky**, who is great, when she was head of the CDC said it's hard to get these data. She was honest about it. But, you know try and sell that message in a world that has Republican Senate or a Republican Congress.

Anne: Can social media be leveraged? I know that people in Public Health and science communicators are trying to leverage social media. Are there ways that we can use social media or maybe *just our social relationships* to try to move the dial back to the normal times when more people were getting their childhood vaccines, for example, for their children.

Dr. Offit: First of all, there are a lot of websites that provide excellent information in a really compelling and understandable way. People at <u>Science Based Medicine</u>, <u>Skeptical Raptor</u>... I mean, whenever I'm looking at the most recent anti-vaccine trope, they often will have a very clear explanation for that. But in the end, really, it comes down to understanding all that.

Let me try and take a step back, when for example the chickenpox vaccine came out in the mid-1990s, people would say, "you know, I've done my research and I've decided not to get that vaccine." But, what *doing your research* meant was going on the internet and looking at people's opinions on the vaccine--that's what it meant. It doesn't mean that you're looking at the 300 papers that had been published at that time to try and look at what was known about the efficacy and safety of the vaccine, because it would have required an expertise in virology, immunology, statistics, epidemiology, which most people don't have. And, frankly, most doctors don't have.

And who does have it? It's really the Advisory Committees that have at least collectively have read those papers, collectively can make a recommendation, but you have to trust them. But, then again, that is not exactly a message that sells in the 21st century: "Trust us we're experts." You want to empower people. You're trying to empower them with information, the evaluation of which they may not have the kind of background that may enable them to evaluate. What do

they do? They turn to people who are persuasive. And often those people are persuading them in the wrong direction.

Anne: Yeah. I mean and I don't know if maybe it's totally outside of the box...but what if building real world relationships could help *more*? It does seem to me like we keep looking for the answers in social media, but I'm not sure if the answer is actually in there.

Dr. Offit: I think you're right. I'll give you an example, so we can move to a more optimistic note. there is a physician in Northern Philadelphia who trained at Temple, whose name is **Ayla Stanford**. She was really, I think, the first fully-trained African-American Surgeon in the United States. So when Covid hit... she's at Temple which is in north Philadelphia, a largely African-American community...and what she did was she formed the **Black Doctors Covid Consortium**. She did the funding completely by herself – she completely funded this on her own. She [organized with] African-American physicians who then went into this north Philadelphia community and sat in people's homes- sat in their living rooms and explained to them why it was important that they get this vaccine.

And if they didn't agree with her, then she would come back and she would keep coming back until she was able to win their trust. I mean she looked like them and I think it was more easy for them to trust her. And ultimately, she vaccinated 50,000 people from north Philadelphia, from, which CNN recognized her for, *Forbes* recognized her.

But we need to have 1,000 Ayla Stanfords, a thousand points of like whether it's into an ultra-Orthodox Jewish community, or a Somali-American community...whoever in that community people look to to trust, that's what I think we need.

Anne: That's really, really true. It becomes more about connecting people in the real world and less about fighting a battle in the virtual world.

Dr. Offit: Somebody like R.F.K. Jr. when he puts out bad information, you have two choices: Number 1 is try and combat that bad information with the right information and provide that right information in a compelling and compassionate way. I've written a series of articles about R.F.K. Jr. and his comments on my Substack and at the end of which I say "Okay, on Lex Fridman's podcast you said if you were ever wrong, you would correct yourself. All right, here's all these articles that show you're wrong. Now, correct yourself." And I just sort of did that again and again, because I needed to do that just cathartically, I needed to do that. And that's 1. You can just try and get good information out there. But I think that the concern is that we have kind of crossed the line from scientific illiteracy to scientific denialism. it's not necessarily an issue of trying to convince people about what good data are, *it's trying to get them to trust the scientific process*. I mean it's science that really causes us to live 30 years longer than we did a hundred years ago.

We live in a world dominated by science and technology in terms of making for better lives but on the other hand we have a population that doesn't necessarily understand that science or technology.

Anne: Right...relying mainly on stories a lot of the time, and stories are just so powerful. What you say just makes so much sense because first of all, you do need to get the good information out there. That never goes away – the need to do that. Because people that are looking for good information are finding it when good information is put out there.

And the other thing that you talked about just now is teaching science literacy. And also imbuing a sense of trust in science. As [scientists] are sort of thinking outside the box, and beginning to use storytelling - telling *real things that have really happened* - in their science, doing plain language versions of their science papers so that people can really understand them, that all begins to move the dial.

And the third thing that you talked about that I think is so powerful is this idea of going into the living rooms, and making the change and really doing that in-person work that you just spoke about with the project in Philadelphia. It's really incredible to see something like that happening.

Dr. Offit: We're humans and we're compelled by a story, and I think anything can be a story. I remember when I was a very young researcher, in my late 20s, early 30s, I remember the first talk that really impressed me was by **Dr. Fauci** and he was talking about Human Immunodeficiency Virus back then and specifically on the virology and immunology that viruses at a scientific meeting. And what struck me about him was he made it a story. He made it a compelling story, and that ultimately influenced the way that I spoke and ultimately the way I write after hearing about that. I don't know if he ever... if I should tell him he influenced me...

Anne: yeah!

Dr. Offit: ... when I heard that talk, but you're right. We're humans. We're compelled by a story.

Anne: That's so interesting. Do you want to talk for a moment about your <u>substack</u> and your <u>podcast</u>, *Beyond the Noise*, and your project that you're working on right now?

Dr. Offit: Right, so I guess about sometime around the end of March I started this Substack (that my wife explained to me exactly what that was!) which basically like a roughly 500-word essay that you [blog] and people subscribe to the Substack... I don't charge... the subscription is free.

And then there is a virologist named **Vincent Racaniello** at Columbia who does something called *This Week in Virology.* He was also kind enough to say "look why don't I also make a video version of your Substack piece?" and so we do that, which then he puts it on YouTube. Then I put it on Twitter/X and get the message out there to some extent. Sometimes it really kind of takes off, and the key for me is never reading the comments, because I'd probably stop if I did that.

But in terms of the project I'm working on now, I have a book coming out in February called *Tell Me When It's Over: An Insider's Guide to Covid Myths and Navigating a Post-Pandemic World.* I have almost a whole chapter on R.F.K. Jr. in this book, and I really try to get at how it is that we got to this point where here you have this virus that we isolated the sequence in January 2020; eleven months later we had a vaccine, got it out there, figured out how to mass administer it in a country that isn't really good at mass vaccinating adults and then we just hit a wall and people just chose not to get it.

Now, I'm trying to understand why... I needed to understand why that happened. How it happens, what forces were in play to allow it to happen where a solid 30% of the country just didn't want to get vaccinated.

It's interesting now if you look at who is getting admitted to the hospital now and who's dying. [Most likely] to get admitted and die are those over 65 years of age, and in this country, in the United States, yes, 95% of those people are vaccinated. But if you look at who is hospitalized, 45% of those over 65 who were hospitalized were never vaccinated. You've selected for that 5% that chose not to be vaccinated, and it just amazes me the level of denialism. You know, I can understand how people how people could say, "I'm not going to get a polio vaccine – we haven't had polio since the late 70s." But this virus was right in front of us, and people still chose not to get a vaccine. It's remarkable to me.

Anne: It's... it's like a happy ending that people chose against. And it's surprising to me because when I hear that there's a happy ending coming, I expect to see a happy ending. There's something that needs to be fixed to give us the happy ending that was expected and to make

things better. It's quite something-- I mean, the story of Covid didn't follow a narrative that anybody thought it would follow in the end. And now, we're trying to sort it all out.

I think your book offers a lot in terms of a thoughtful analysis of what's happened and it's going to take us a long time and a lot of thinking and writing I think to really understand it.

<u>Beyond the Noise</u>, that's the blog. The Substack is <u>PaulOffit.substack.com</u>. we'll put a link to the <u>book</u>, we'll put a link to the Substack, and some other information on the podcast blog as well, at Noncompliant, and I really want to thank you for your time, Dr. Paul Offit. This has been a really, really interesting conversation. Thank you!

Dr. Offit: Thank you. It was my pleasure.

Anne: We were speaking with Dr. Paul Offit. He spoke to us from Philadelphia.

[Outro music: Jazzy synth pop music]

Anne: You're listening to Noncompliant: a Neurodiversity Podcast. I'm your host Anne Borden King. Noncompliant is recorded at MCS Studios and transcribed by Julie-Ann Lee. This episode was engineered by Lucien Lozon. Thanks to our team and thanks for listening.