

Vaccine Politics, Policy, and Advocacy

"I'm from California, and we've had outbreaks in Orange County, where I live. And I think it should be mandatory. I think the basics should be mandatory."

"It's my belief that vaccination should not be mandatory. It should be a personal decision that every parent makes for their own family and their own children."

"I'm all for it, because I don't want my kids to get sick. Preventing walking around with measles would be nice."

"We should have our own choice. It's our bodies."

"I don't know if it's possible to have a federal law about that, but I think it would be good to have, for child diseases such as measles and stuff like that, to have a law."

"I don't think the government should oblige you to do anything. Well, of course, drive on the right side of the road, but that's different. No, I don't think it should be mandatory."

On its own, the word 'policy' might sound boring to you. But policy can grab your attention if it's about something you consider important. Whether it's something that impacts your life, your family, or your community. That's what we are talking about today on this episode of The Antigen. I'm your host Yasmeen Agosti.

Professor Robert Field, who teaches both law and public health at Drexel University in Philadelphia, explains how vaccine policy must deal with balancing the interests and needs of the individual with those of larger society.

Well, vaccines are the natural intersection of law and public health. Public health is government programs, which obviously are based on law to try to protect populations rather than people one by one. And vaccination is one of the most, if not the most effective health interventions on a population level that's ever been devised.

Public health, uh, being government, looking out for the good of the most number of people is inherently coercive. Uh, we're looking out not for what necessarily is best for you, but what's best for the rest of us. And sometimes that's not the same as what's best for you. You may feel that vaccines are wrong and you don't want to get one, but for the greatest number of people, it's important that you do get one, so you don't spread influenza or some other contagious disease. So public health is always dealing with this conflict, with this balance. What's good for the individual, what does the individual want, and what is best for the health of society.

Here in the U.S., all fifty states have regulations which require children to be immunized before they can go to child care or to school. However, not all state level regulations look the same. I asked Professor Field how that's possible.

Vaccines are a microcosm of the complicated system of government we have in this country. The federal government plays a role generally in seeking national uniformity. And then each state picks up the ball and runs in it with it often in different directions. So we have the federal government deciding which vaccines are safe enough and effective enough, and then who they should be recommended for. But then the States in the trenches actually deciding who will get it, who has to get it, who can opt out of getting it, and other details of the policy. It's the States that run the public schools. It's the States that enforce basic public health. So we've given them a tremendous amount of responsibility in this.

You might remember from Episode 4 when Professor Field described the Supreme Court case of *Jacobson vs Massachusetts*, back from 1905. This case set the legal precedent for permitting vaccine mandates.

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

The *Jacobson* case from 1905 said very definitively that the government cannot mandate a vaccine if it might hurt you. So if you can show a potential allergy or likelihood of an adverse reaction, you can avoid the vaccine.

All states allow children to be exempt from vaccine requirements for certain medical reasons. For example, due to an allergic reaction to a vaccine ingredient or because of an underlying immune problem. These are called *medical exemptions*. The number of children with medical exemptions are few and do not take away from the important, community immunity. In fact, these children are among those who rely on it because they are unprotected.

The vaccine policy debate, which has been the focus of so many news stories is about *non-medical exemptions*. These exemptions fall into one of two types – philosophical or religious. The debate about non-medical exemptions is dealt with at the state level.

The question is philosophical or religious objections and that is really up to the jurisdiction. Each state decides for itself. Religion obviously is subject to more respect. Uh, we have a constitutional

protection of the practice of religion. And so that's been one of the more bitterly contested, uh, grounds. Uh, in terms of exemptions, the court has said though that even religion, even respect for religious freedom has its boundaries and when your religious practice can harm other people, you are no longer entitled to the protection of the first amendment. So religious exemptions are not required. And certainly philosophical objections, uh, are not required either.

Um, up until a few years ago, only two states did not have religious opt-outs, West Virginia and Mississippi. And then after the 2014 measles outbreak at Disneyland, California took away its religious exemption and not without tremendous controversy that remains. And then after the measles outbreak in New York state, that state eliminated its religious exemption and there were a couple of other states that are considering doing the same. For philosophical exemptions, um, about half the states allow you to opt out without basing on a religious belief. Just saying, I don't like the idea. Um, and that again is a question of policy not of law. It's within the discretion of legislators whether or not they will allow that opt out.

Currently there are 5 states that only allow for medical exemptions to be used – Mississippi, West Virginia, New York, Maine, and California.

Professor Field also points out that not all vaccine exemptions look alike across state lines .

But beyond the three categories of medical exception, religious exception, philosophical exception, each state decides how stringent those exceptions are. For example, for a religious exception, in some States, you simply claim that it violates your religion. In others, you need to show that it's part of an actual religious doctrine of an organized religion. And in others you need a member of the clergy to actually verify that. For philosophical exceptions, some states let you merely state that you don't like the idea of vaccines while other states make you sign a form, have it notarized and verify what that philosophy is and why it prevents you or your child from getting a vaccine. As a result, some states are fairly easy to opt out of vaccines and some states are extremely difficult. California addressed this recently on the issue of medical exceptions in 2014 it removed the religious exception. So the only way to have your child avoid vaccination was to claim that it would be medically harmful. That requires a physician to certify. There are physicians who are happy to certify that without really verifying the situation. So California recently tightened its rules so that the department of public health can oversee what the physician has done to make sure that there is a genuine medical risk involved. Um, so we have a patchwork of rules and a patchwork of requirements. And a mandate is not a mandate. It depends on the fine print.

State level mandates are one way of addressing the issue of low vaccination rates.

Representative Kim Schrier, a pediatrician and Congresswoman for Washington State's 8th district, has used her many years of caring for young patients to help develop a bi-partisan vaccine bill. The aim of this bill is to address the issue of low vaccination rates across the country. And the bill looks at not just *where* vaccine rates are low but *why* - so that the solutions proposed can fit the root of the problem.

So the vaccines bill is something I'm really excited about because it takes a very practical approach to increasing immunization rates. And, uh, I brought 20 years of clinic experience with me, uh, in crafting this bill, which I did hand in hand with the American Academy of Paediatrics and the CDC. And the idea here is that what is most dangerous are pockets of outbreaks because that's where these things spread, that an isolated person here or there who is incompletely vaccinated does not pose the threat to overall public health that outbreaks do. And so with this bill does, is it provides funding for surveillance to look for pockets where children are not being immunized at the rates that we need them to be immunized to protect society at large. And then it investigates why that's happening. Is that because a clinic shut down and so there's nobody to provide immunizations or is that because of an insular community with somebody within the community who is speaking against vaccines and endangering that group.

Um, or is this because of online misinformation, which has been a huge problem and that I've seen, um, as a growing cause of vaccine hesitancy in my own patients. So it takes that information and then, um, gives a wide band, um, of what we can do to combat that. Whether that's, um, appropriate combating of misinformation online with real information delivered in a compelling way, or whether that is providing more public health support or even, uh, a member of an insular community who can be educated and then take that back to their people. So it gives a lot of flexibility with the goal being: educate the public to increase immunization rates.

Representative Schrier believes the Vaccine Bill, which was introduced in the House in May of 2019, will have a broad appeal and a higher chance of passing because its focus is on awareness and education.

She does clarify, however, that there is still a role for government mandates but cautions that there may be unintended consequences that can undo larger efforts to address vaccine hesitancy.

In her own state, which experienced two measles outbreaks in 2019, Governor Jay Inslee signed a bill to eliminate non-medical exemptions for the MMR vaccine based on philosophical or personal objections.

Look, I think there's a time for mandates. Uh, when we had an outbreak of measles in our state, it was really important to say medical exemptions only for this particular vaccine so that we can address this immediate public health threat.

With other vaccines you can get into a very sticky situation. As soon as you mandate vaccines, parents will seek their care elsewhere. They will go and look for some other provider who will either sign a form to get them out of getting those vaccines or who will not educate them and bring them along slowly over time. And what you will end up with is probably patients getting inadequate care and ultimately not getting vaccinated.

Representative Schrier's Vaccine Bill is one of several attempts to help restore vaccine confidence on a national level.

Vaccine policy has a direct impact on everyday people's lives no matter what their position on the matter is or whether or not they chose to get involved.

I asked Dr. LJ Tan, from the Immunization Action Coalition, how and where people could get involved if they are interested. He suggests starting locally.

I think for most people, you know, like they all say all politics is local. And I think same thing with public health – most public health is local. And I think, um, if you are interested in vaccine policy, I think that's a really good place to start. If you're interested, find out what's going on with your school district. Um, what is the coverage rates of vaccines in your school – is your kid safe in that school from vaccine preventable diseases?

What is the coverage rates? Go find out. And if the coverage rates in your school are not over 90%, you should be finding out why it's not over 90%. If you're interested in then taking action and getting involved, that's a great starting point because it protects not just your child, but also all the children that are going to that same school.

Advocating for sound vaccine policy can also happen at the state level.

And I think then once you, once you kind of dip your feet locally and you're making a difference in your community, then I think, think bigger. Think about the states? Every legislative session, pay attention, find out what's going on in your state. Is there something that's going to happen in your state with let's say a loosening, a philosophical exemption so that kids can avoid getting vaccinated easier and that's going to impact you. I think if that matters to you, you should be up there talking to your legislator at the state level to make sure that you are protecting your child from vaccine

preventable diseases by making sure that everyone else, if they're going to be exempted from a vaccine, are exempted for very good reasons.

There are also opportunities to get involved on a national level.

Then federally the national vaccine advisory committee and the advisory committee on immunization practices, which makes federal policy with regards to vaccines, they meet three times a year and as mandated by the federal advisory committee act or what we call FACA, they are required to listen to the public comment. And so get involved, show up, make public comment, and you don't even have to show up. You can actually email in your public comment, uh, regarding the issues that are being considered by the advisory committee, uh, in their meetings. And then at the other level, we always need to make sure that our Congress people that represent us represent our beliefs as well. Make sure if you've got a Congressman that's uncertain about vaccine safety, show up, and go to your Congress person's office and talk to them and find out what their position is on making sure that your child is protected from vaccine preventable diseases. And if they're not congruent with what you believe in, there is a chance for advocacy right there from you to get involved.

Getting involved with vaccine policy doesn't just have to be about vaccine hesitancy or non-medical exemptions. There are many different issues all of which relate back to the importance of vaccines protecting lives. Patti Wukovitz, the Executive Director of the Kimberly Coffey Foundation, lost a daughter to a type of meningitis for which there was no vaccine licensed in the U.S. at the time. She turned this tragedy into a form of advocacy for meningitis vaccines.

My daughter Kimberly, um, was a sweet little girl growing up and she turned into a, an amazing young adult who I was very proud of. And um, her dream was to become a pediatric nurse. But unfortunately when Kim was 17 years old and in her last week of high school, she contracted meningitis B and she, her symptoms came on very, very quickly. She was perfectly healthy one day and the next she comes home from school with body aches and a temperature of 101. And I gave her Motrin and I called the pediatrician. He said it could possibly be the flu, let's, you know, keep an eye on her and you may end up bringing her in in the morning. And she was fine the rest of the day. But by the next morning she woke up and she said, mommy, everything hurts me from my eyelashes down to my toes. I'm in so much pain. And I also feel like my ankles are bleeding. So I pulled the sheets back and I saw her ankles and she had a few petechiae on one of her ankles. Being a registered nurse, I knew this was very serious and I also saw her condition deteriorating very, very quickly. And I rushed her to the emergency room. Once I got her there, they knew what she had.

They pulled me aside and they said, we believe your daughter has bacterial meningitis. And I told the doctor that's not possible because my daughter had been vaccinated with the meningitis vaccine. So I couldn't understand at all what she was saying. It made absolutely no sense. And I later found out that she had meningitis B and at the time, this was in 2012, and at the time we did not have a meningitis B here in the United States.

Meningitis, is an inflammation of the lining that covers the brain and spinal cord.

Fever, headache, and neck stiffness are classic symptoms but there can be others. Meningitis can be caused by different kinds of germs including bacteria, viruses, fungi and parasites.

Kimberly, had meningitis B, caused by the bacteria *Neisseria meningitides*, also referred to as *meningococcus*. There are actually 12 types or serogroups of this bacteria, 5 of which cause the majority of this life-threatening infection in the blood and the brain. They are named with letters - A, B, C, W, and Y.

Once Kim got into the hospital, she was admitted to the pediatric intensive care unit and things happened very quickly. She was in multiorgan failure, she was septic, and eventually she went into a coma. And, um, I had to make the decision to remove her from life support. She was a perfectly healthy 17-year-old and I buried my daughter two days before her high school graduation in the prom dress that she didn't get to wear to her senior prom. So it was absolutely devastating.

Meningococcal disease, commonly referred to as bacterial meningitis, can be rapidly fatal.

So in 2014, I created the Kimberly Coffey foundation. It's a 501c3 non-profit organization in memory and in honor of my daughter, Kimberly Coffey. And through that, I do a tremendous amount of work. Um, but our mission is to inform the public as well as healthcare professionals about meningococcal disease, including the symptoms, how the disease is transmitted, who's at high risk, and the importance of prevention with now not only one meningococcal vaccine, but with two the men ACWY vaccine. And the men B vaccine.

Patti works on multiple levels, with different groups of people to raise awareness— parents, students, school administrators, lawmakers and healthcare providers.

The first reaction I get from parents when I tell them Kimberly's story is they immediately say, oh yes, my, my son or my daughter has gotten that vaccine for meningitis. And I say, but remember, Kimberly had that same vaccine but it didn't fully protect her. Now we have a meningitis B vaccine as

of 2014 and if you don't know about it, you can't have that conversation with your doctor. So, you know, knowledge is power.

Patti also works to raise awareness on college campuses with the help of another foundation called the Emily Stillman Foundation.

As far as, um, college campuses, we're developing advocacy programs across the United States to include college campuses to require meningitis B immunization. We want them to update their policies to mandate men b vaccination. All of the college outbreaks since 2011 have been meningitis B. So it's a huge, huge problem.

But I would just absolutely love to see colleges mandate. Right now there is about 29 colleges across the United States that mandate the meningitis B vaccine for their incoming freshmen. On the meningitis B action project website, we have a men b college tracker. So we have a map and it shows the colleges that have had outbreaks and the colleges who are now requiring men b vaccination.

She and her partner foundation work with vaccine advocates across the country to change meningococcal vaccine policies at the state level.

Another thing that we have with the meningitis B action project is what we call our B team. And we have 2 or 3000 plus vaccine advocates in all 50 States. And with that we have them engaging with state officials and legislatures, legislators to emphasize the need for strong, meningococcal policies in their states. And that in turn will help us to achieve our goals for healthy campuses, healthy communities.

She recently was involved in development of a meningococcal vaccine policy in her own state of New York.

I had the opportunity to work with a large group of stakeholders on the 2016 New York state meningococcal vaccine law. Um, that was an incredible experience and I'm really, really happy with that law. It now requires all 7th and 12th graders in New York state to be vaccinated with the men ACWY vaccine. However, it falls short because the New York state law does not include the men B vaccine, yet. Let's hope that that happens in the future.

Vaccine policy in the U.S. has many layers, but Patti's story is an example of how one person can effect change – in a school, a community, or even a state. Next time on The Antigen, we look at the

future of vaccines – and some of the innovations we are seeing in the laboratory and in the field.

So one of the things that I think it's really important to do right now is not just look at vaccines as they are in the here and now, but think about what they could look like in 10, 20, 30 years. And I think one of the most exciting developments is micro-needle patches. These are effectively like plasters. And it could mean that in 10 years, possibly even 10 years. Yes, as soon as that you could see vaccines being delivered through band-aids, plasters on people's arms, that could fundamentally change what immunization looks like.

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