

TURNER:: Hello and welcome back to Wisconsin Law in Action, a podcast where we discuss new and forthcoming scholarship with the University of Wisconsin Law School professors. I'm your host Kris Turner and my guest today is the Center for Patient Partnerships Director and Distinguished Clinical Professor of Law Meg Gaines. Thanks for joining me, Professor Gaines.

PROF. GAINES: : Delighted.

TURNER:: Professor Gaines will be discussing her recent article, How HIPAA Harms Care and How To Stop It, along with a future forthcoming article that we're just going to discuss a little bit about as well. She [inaudible 00:00:32] both the current article and the forthcoming article with Dr. Donald M. Berwick from the Institute for Healthcare Improvement in Cambridge, Massachusetts. So before we get into these articles, let's talk about you a little bit. That's one of my favorite subjects is to talk with you about what you're doing these days. Can you give us your background, what your interests are and scholarly work, and what you do here at the law school?

PROF. GAINES: : Yes. I'm a sort of criminal defense lawyer, turned healthcare advocate by virtue of personal experience and went from being on the faculty at the Remington Center to starting the Center for Patient Partnerships almost 20 years ago. And my interest is in raising patient's voices into the healthcare equation, whether it's at the micro level, their own care, the mezzo level, the sort of the institution or the provider organizations, or the macro level in the halls of Congress and in the CMS, Centers for Medicare, Medicaid Services.

PROF. GAINES: : Actually Don Berwick was the acting director of CMS under President Obama for a long time. I say acting director because he's in favor of single payer, and a whole bunch of other things that would have made it impossible for him to get confirmation in the Senate when the time was there.

TURNER:: Right, right, he was probably facing maybe a relatively hostile Congress in the Senate at the time.

PROF. GAINES: : He was, but he was acting for a long time.

TURNER:: That's good. And he was acting for-

PROF. GAINES: : And during the passage of the Affordable Care Act and was one of the coauthors of the passage of the Affordable Care Act.

TURNER:: Oh great, great. Yeah, that's very interesting. I didn't know that background. Thanks for providing that. Center for Patient Partnerships, that's one of the clinics here in the law school. Could you go into a little more detail about what kind of work you do down there?

PROF. GAINES: : Yeah, we do advocacy for people with life threatening and serious chronic illnesses from across the globe. Really, I like to say from Texas to Thailand and Portage to Portugal, and we've helped people in all those places and people call us or find us on the internet and say, "Help, I've been diagnosed with this gnarly thing, and I'd like help figuring out who's the person I should see or the people I should see and where's the place. And how do I get my insurance to pay for it? And what do I do if I get fired in the interim because that's where my insurance comes from?"

PROF. GAINES: : So a diagnosis of a life threatening or serious chronic illnesses is a potentially life altering event and we try to help people have a softer landing, that's at the sort of clinic core level. Then we work with undergrad and law students in three clinics throughout the city, including collaborative clinic, the medic clinic with the medical students, and we work with folks in those areas to address what's now called social determinants of health. So food access, transportation access, housing, employment, those kinds of things.

PROF. GAINES: : So the students interview all the patients who come into those clinics and identify needs and try to help connect them with resources, which is an extraordinary, as you might imagine, pipeline into law school, medical school, nursing school, social work, pharmacy, counseling, psych, industrial engineering, genetic counseling. We have students from all those departments in our programs. So, that's kind of a second major area.

PROF. GAINES: : And then the third major areas, we have a research component, which we refer to as National Initiatives, where we do... We are leading in the country in developing what we call the science of elicitation, which is how do you get, instead of just a survey that says, "on a scale of one to seven, my doctor did or didn't tell me everything I needed to know." Right, we can ask you a question like, "What were the three best things and the three things you think have most room for improvement that happened in your doctor's appointment and tell us in your own words."

PROF. GAINES: : And then in collaboration with the Rand Corporation, some from folks from Yale and a couple of others, we're developing a natural language interpreter that can report these as big data. So that if you're a clinician, you don't just get a form that says you're a 7.2. Good luck figuring out why, right? You get something that says you're a 7.2 and 40% of the people talked about how your hand was on the doorknob or you spent all your time on the screen or you seemed in a hurry to go or whatever the issue is.

TURNER:: It seems like a practical way for physicians to understand how to improve themselves and to help people more easily.

PROF. GAINES: : It is and it's getting patients' voices up and out in a scientifically sound way, instead of only relying on anecdotes.

- TURNER:: Yeah, because an anecdote, while it can be helpful to an extent, but this is taking it to the next level. It sounds like, to kind of give the doctors a bigger picture of what these anecdotes add up to.
- PROF. GAINES: : Right, and most of these physician review sites will have 10 or 12 reviews on them and almost all of them are people who were unhappy.
- TURNER:: Yeah. You hear the unhappiness that those are the squeaky wheels getting the grease all the time and this time provide some more balance to the feedback.
- PROF. GAINES: : That's not a good way to help professionals learn who they are and see and sort of get self-reflection, right, be able to sort of self reflect. And then have a mirror held up to them by people who... So, that's called the science of elicitation and that's taking patient's voices up to the macro level and trying to be sure that patients are heard in their own voices.
- TURNER:: That's great. I am lucky enough to be the liaison to Center for Patient Partnerships and I love hearing about this stuff. It's so fascinating to me, because as you mentioned, it straddles all these different worlds where I get to step out of the legal realm just for a tiny little bit and hear about some stuff that's happening elsewhere, especially in the medical world, which is wonderful.
- PROF. GAINES: : Right, right.
- TURNER:: Along those lines, let's start digging into this most recently published article. It was published in JAMA in 2018, How HIPAA Harms Care and How to Stop It. So, when you were publishing this article, what made you want to get this out there? What did you and Dr. Berwick want to have people take away from this article?
- PROF. GAINES: : Well in this case, Dr. Berwick contacted me and said, with a friend of his who had just lost his wife in an accident and she was in the hospital for a long time, and he was frustrated because he couldn't get access to her records and both wanted me to kind of help that person. But then also went into, was sort of triggered, let's say, I think he'd think that was fair, triggered by his frustration and by the general kind of frustration of clinicians about how quirky the enforcement of HIPAA is and the regulations, well, not even the regulations. It's sort of the training that people get who work in healthcare institutions about what HIPAA says and what they can and can't do, which often bears very little relationship to what the law says.
- PROF. GAINES: : So there's become this HIPAA kind of training and HIPAA interpretation has sort of taken on a life of its own. And I lay some of that blame on lawyers, who just kind of get in there and decide they want to sell trainings and want to consult with healthcare organizations and tell them what they can and can't do. And I lay some of the blame, or we do, on the federal government, because I think it would be easy for the federal government to say here's the standard HIPAA

form, here's the standard HIPPA training, just do this and you will comply with the law.

PROF. GAINES: : But instead they kind of leave it to the private market, and it's not always good to have many colors of the rainbow. So, sometimes you just want the light shining.

TURNER:: Right, yeah. In this case especially, the light should be very specific because this is an important area of law obviously that affects people on a very practical level. You use the word myth a lot in this article. There's a lot of myths out there I think that make people tend to go on the conservative side and say, "You know what? We're going to play it safe and not give this information out."

TURNER:: What kind of ways can they get around these myths? What can you get out there that explain why these are myths and the why it doesn't really affect HIPAA?

PROF. GAINES: : Well, I think the main thing is if you're a leader in a healthcare institution instead of saying, "What does HIPPA require and how do I need to conform to it?" I think the question is how do we want to take care of patients and their families and our community and what's going to get in our way? And if HIPAA's is in our way, then we got to figure out how to get around that, but we've got to... So it's the wrong question to ask, what are all these laws and how can I make sure I comply with them? I think what you want to ask is what kind of care, what kind of operation do we want to have here? What kind of business do we want to have here or organization or entity or whatever, and how can we make that happen and clear the obstacles?

PROF. GAINES: : So that's the first thing is sort of, if the people in your shop understand that the goal is to really pay attention to the needs of your customers, your clientele, your patients, your whatever you want to call them, and their families, then that's a very different organization. You don't find these HIPAA myths nearly as prevalent in places where they make things possible that aren't prohibited.

TURNER:: Right. I think I liked the way you put that. It's not as prevalent where they're making things possible. I think that's a very nice way of putting it.

PROF. GAINES: : Right, where they're not prohibited, and if they're not prohibited and are not prohibited, it's just about sort of what you're trying to do and whether you have your eyes on the prize.

TURNER:: Mm-hmm (affirmative), and then towards the end of the article, you have some recommendations about how to maybe balance this out a little bit more, where right now there's a lot of fines and penalties that can be levied for violating HIPAA, but there's also some recommendations to help balance this out where you're still helping out the patients that may need, or the other visiting clinicians or if you transfer doctors, to get that. There's some of these that are kind of at

the macro level and some of them are at the more maybe micro level. Would you mind going through those a little bit and discussing them and explain what you think of these?

PROF. GAINES: : No, I do think that there needs to be some research done about the importance of this problem and the prevalence of the problem and to describe the problem so we can really address them. Whether they're myths or real problems with the law, we need to know kind of first of all what they are. And then as I mentioned before, I think that there should be, the federal government, should promulgate model policies and procedures that take the mystery out of HIPAA. I mean there doesn't have to be a mystery about it.

PROF. GAINES: : And then it is interesting what you say. I think we suggest that HHS, the Health Human Services Department, should consider enforcing penalties for the failure to release information, not just for releasing information wrongfully, because that will shift the... I think the conversation and the kind of mental awareness towards how do we facilitate good care, not how do we follow what we perceive to be a the regulations, right?

PROF. GAINES: : And finally, I think there always needs to be collaboration between patient advocacy organizations and the professional society. So ultimately real reform in healthcare across the board, not just in HIPAA, will happen when clinicians and patients join together, because healthcare is a business in this country and it's largely driven by business interests. And so in order to sort of go up against big money, and it is big money, it's the biggest money industry in the United States, you really do have to have the people who are affected by that and who have power within it potentially to come together to craft a resistance.

TURNER:: Great. Thank you. So before we jump into the forthcoming stuff that you're going to be working on, this was published last year as we mentioned. What kind of reactions have you seen to the article or what reactions do you hope to see from the article going forward?

PROF. GAINES: : We got a lot of comments on the article and a lot of emails after the article. Most of them were clinicians telling us how burdensome HIPAA was for them. We got no pushback, is what I would say. There was nobody who disagreed with us.

TURNER:: It's always a nice feeling. You say, "Oh, I feel like we're probably in the right here."

PROF. GAINES: : Yeah, I think so. I'm not sure that we necessarily got representation from say high level organizational folks who wanted to say, "It's easy for you to say, but I got these lawyers breathing down my neck telling me." I always say lawyer lawyers in these kinds of situations are sort of... I wonder why people hire them, like why do you pay \$350 to \$500 an hour to someone to give you advice that your grandmother used to give you for free? Which is don't take any risk under

any circumstances for any reason whatsoever, and it's not really helpful to have a lawyer who says that, but that's the safe thing for a lawyer to say.

PROF. GAINES: : And I think one of the things we tried to do at this law school is to teach students to get interested in how to solve the problem, not just how to stay out of trouble giving people advice.

TURNER:: Right. More of the law and action, why the name of our podcast, Wisconsin Law In Action-

PROF. GAINES: : Yes, exactly.

TURNER:: ... Kind of the thesis of this whole law school, what the driving force is to say, go in there and figure out what the problem is, not just to stay away from the problem.

PROF. GAINES: : And how can the law serve the people instead of the people serve the law? That's the difference between certain kinds of societies and other kinds of societies.

TURNER:: Right. And when we want to be in one, we do not want to be in anyways. So now we'll start shifting onto your forthcoming article. So this is kind of a, this is probably not the right way to put it, but I'm going to say it anyway, a sequel to this article [crosstalk 00:14:21]

PROF. GAINES: : Well, it's as sequel in terms of the two of us writing together. This one was my idea, and Don got interested in it because I think it was surprising to him as it has been to a number of clinicians, which kind of leads to the what's the challenge of writing this article? So this is an article about what we call prior auth reversals. So everyone, all your listeners are familiar with the process of going in for care, particularly if it's something significant, the hospital, sometimes the patient too, will call the insurance company and say, "Is this covered?"

PROF. GAINES: : And they get an answer, right? Yes or no or whatever. And the hospital calls in before the care is initiated and gets clearance, what's called prior authorization to do the care. The insurance companies always, and there's a legal reason for this, but they always say at the end of those calls, and by the way, this is not a guarantee of payment, and the hospital... People on the phone at the hospital are used to saying, "Yeah, yeah, mm-hmm (affirmative), okay, see you, bye." And that's that.

PROF. GAINES: : But it has, that little phrase, has really operated as kind of a getaway car for a lot of insurance companies, because people will then have the care, the insurer will then decide it wasn't appropriate care, it's not medically necessary or it's experimental or something else. And then they'll deny the care. So we had recently a case at the Center for Patient Partnerships, where a 62 year old

woman who had had a history of ovarian cancer, who had her genetic testing come back to find that she was BRAC1 positive, so that's the breast and ovarian cancer gene.

PROF. GAINES: : She was recommended by her doctor to have a double mastectomy. Her husband called the insurance carrier to make sure that it was covered. The hospital called to make sure it was covered. She had the surgery and two weeks later got a bill for \$65,000, because now they're saying it's experimental and therefore not medically necessary as it relates to BRCA1, this double mastectomy, sort of preventive care. So we appealed it and they denied it, saying that they had a "medical expert" agreeing with them, that it wasn't standard of care.

PROF. GAINES: : Well we know it's standard of care, we just know that. So I then did, or we, my students and I, did a big whopping sort of letter brief to them, which included the national guidelines for treatment and all kinds of other things in it, and actually included these little legal arguments about breach of contract in the sense that you create an expectation, you create a reliance in this person by telling them it's covered, and then telling them that it's in hindsight, something you could've known at the time, right, which is that you think it's experimental.

PROF. GAINES: : And so of course contract arguments are irrelevant at this juncture. It's an internal appeal. But we did it anyway and they ended up reversing and agreeing to pay for it. Having consulted, according to their letters, six additional experts to determine that it was indeed not experimental and it was indeed standard of care.

PROF. GAINES: : So, this case got me really, really sort of got up in my craw, stuck in my craw, and I began to sort of look through our data and realized that we had a number of cases for different reasons. I had another one at the time that was for a different reason. It was a coding issue, a billing coding issue.

TURNER:: One of my favorites, yes, mm-hmm (affirmative).

PROF. GAINES: : Yeah. So, but in any event, the result is the same, which is the patient is left with this gigantic bill, and the provider for a while is very friendly with the patient and says, "Yes, let's get them, let's get it from the insurance [inaudible 00:18:02]" But once the provider begins to sense the insurer's not going to pay, they sort of slide around the other side of the table, become adversary but really nice. And they say, "Well, you did sign this thing that said you'd pay if the insurance doesn't, and we can put you on a payment plan and we can knock off 20% or 30%."

PROF. GAINES: : So now they're persuading a patient, and in the Midwest this is really a problem, because everybody here pays their bills, they're obsessive about paying their bills. And so now you have somebody who shouldn't be paying anything feeling like they got a break, maybe, because they're paying on a payment plan-

TURNER:: Right, with 20% off.

PROF. GAINES: : ... With 20% off, when they never should have owed this money. So, you go back into the prior auth world and you realize that right now, there's nothing legally barring them from doing this. And so this article is about the extent of the problem, which is what we're having an interesting challenge kind of finding data, because insurers, private insurers, keep this data very tight. They're not required to report it. So we're kind of digging in National Associations of Commissioners of Insurance and other areas like that and also in contact with whistleblowers, formerly at insurance companies and other places, who we're hoping can get us access to at least some data. But I'm not sure the actual collection of this data exists.

PROF. GAINES: : So it's going to be interesting in response to the JAMA edits to figure out how to frame this. Well, we don't really have data on the frequency. We're collecting the frequency of the CPP data. So we're going back two years in CPP and finding how many of these cases we've had, which is, we're pretty small. So, you wouldn't call it representative in any case. And since we do a fair number of Dane County cases and Dane counties almost 85% HMOs, we also probably aren't representative on this.

PROF. GAINES: : I mean this is probably more indemnity insurance and what's called third party administrator, so self-funded plans which have these higher these third party administrators to say yay and nay and...

TURNER:: Right, so obviously the challenge here is to find that data to help back up the... You will see it in your numbers, but the numbers might not be out there in enough, in the not numbers themselves to actually provide the more representative samples.

PROF. GAINES: : It's protected data. I mean they own the data.

TURNER:: Right. And they're not going to say, "Yeah, hear you go, use it against us in some ways." Yeah.

PROF. GAINES: : Right, right. "Yes, we've given X many prior auths and reversed on Y many." They're not to tell us that.

TURNER:: No, no.

PROF. GAINES: : No, they don't want to tell us that. And also I'm not even sure they collect it, because I know they collect prior authorizations and I know they collect denials, but I don't know that they collect reversals of prior authorization.

TURNER:: Right. And they may not, because that's not something that they want to have that if someone were able to get access to it, it would not look good for them. Or that's just an optics thing almost. Mm-hmm (affirmative), yeah.

PROF. GAINES: : Right. I don't know it... From the point of view of writing about it, it's interesting to think about how you write about a problem, and then really have to talk about how this evidence is not, the data is not forthcoming, because the data is protected and is owned, and we don't have access to it.

TURNER:: Right. And even that could play a part in the paper itself to say that this is indicative of something potentially or whatever. Yeah.

PROF. GAINES: : Right. It's the problem with having a system, "healthcare system," which isn't really a system, it's a collection of private businesses, but not until it sort of becomes a system proper will we have access to this kind of data, otherwise it's proprietary. And not until we own it, which we may or may not ever own it, and there will be a whole host of problems if we own it. But at least in my view, we'll be working on the right problems and not the wrong problems.

TURNER:: Yeah. I'm still catching my breath up to the \$65,000 bill. I'm still, whoo, that's a lot of money for something that shouldn't have been owed. And they tried to have her pay that.

PROF. GAINES: : And a hairdresser gets a bill for, goes in to have a procedure she's had done twice before, and this third time it gets denied because of a coding snafu between the doctor and the provider organization that he worked for. And then they bill this a different code and she gets a bill for \$14,500. I mean, she's a hairdresser. She doesn't have \$14,000.

TURNER:: Few people do, even if you're not a hairdresser.

PROF. GAINES: : Right, exactly, exactly, and in healthcare you're talking big money very fast. I mean, as anybody knows who's been to the emergency room, I mean, you're talking big money really fast, it doesn't... Nothing's cheap.

TURNER:: Right. I used to work at a bankruptcy firm. I worked there from 2007 to 2008, so right at the heights of all this going on. And there was just so many people that I spoke with on the phone about it. It was just one medical bill and that was all it took to push them over, into considering bankruptcy.

PROF. GAINES: : So in our article, it's in our article, that still, at least by the latest data we're looking at, still more than half of bankruptcies, the principal bill is medical debt.

TURNER:: It's just one accident is literally what it is. And that's all it takes.

PROF. GAINES: : Yeah. Or just ordinary diagnosis. I mean, diabetes. It's incredibly expensive with the way insulin is re-patented and re-patented and re-patented in this country. It's nuts. And then of course they stopped making the stuff that is cheaper.

TURNER:: Yeah. Yeah. So, you said you're in the editing process with JAMA here. When do you expect that this paper might be out or with some of the ideas out there?

PROF. GAINES: : It's almost been a more fun... It was fun writing it because it's always fun when you have a bee in your bonnet to get it down on paper. But it's been almost more fun doing the, relating to the edits or responding to the edits, because this data dive is been super interesting, like this whole world of who's who and who did what when. And I'm reading these articles about these people who [inaudible 00:24:32] blue at United Healthcare and then came out, and Blue Cross Blue Shield and then...

PROF. GAINES: : So it's just been a fascinating learning experience for me. So, when do I think we'll get, and Don is super busy as well, so when do I think we'll get it back to JAMA? I would guess probably by the end of next month, because we'll have a up or down about whether we get much data by the end of next month. And then, my guess is they'll publish it sometime in December, January, February, something like that.

TURNER:: That's great. Well, I look forward to reading that one. I enjoyed reading the HIPAA one. Now I look forward to reading the authorization reversal on this is wonderful. So, where can people find out more about your work?

PROF. GAINES: : Www dot patient partnerships, with an S, dot org, I mean that's where we are. And then I did a TEDMED Talk, so if you go to TEDMED and Google me or search me. Don't Google in TEDMED-

TURNER:: Don't Google within TEDMED, okay.

PROF. GAINES: : Search me. You can listen to the TEDMED talk, if that's of interest and...

TURNER:: And we'll link to all this as well on our podcast page here to include the patient partnerships page and the TEDMED Talk and all the other papers that you have out there as well.

PROF. GAINES: : Absolutely.

TURNER:: Mm-hmm (affirmative). Okay, thanks for joining us on Wisconsin Law in Action. We've been talking about HIPAA and how it harms health care, along with authorization reversals with Professor Meg Gaines. Professor Gaines's papers can be found on her SSRN page and in the University of Wisconsin Law School Repository. Links to both, along with links to the Center for Patient Partnerships and to Professor Gaines's med TedTalk will be posted along with this podcast at wilawinaction.law.wisc.edu.

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next time as Professor David Schwartz joins us to discuss his new book, *The Spirit of the Constitution: John Marshall and the 200-Year Odyssey of McCulloch v. Maryland*. See you then and happy research.