**Interview 3**

Well thank you so much for agreeing to talk to me I really appreciate it.

Of course, of course. Yeah… So-so this is part of your thesis, is that what it is?

Yeah. So I after some personal circumstances I kind of delved into the topic and then got connected to lovely people like Joyce and from there it just kind of escalated and I ended up testifying on a bill in California here, um, and since then my interest has piqued so…I chose it for my thesis topic.

Ahhh…

Yeah.

Okay.

Yeah. So, um, if it's OK with you I just have- I have some kind of big broad over-arching questions, um, that just will get your qualitative answer and what I'm hoping to do is just compare notes across different stakeholders and different advocates and see what approaches are successful, what the barriers are, um, as you hope to increase insurance coverage for those needing oncofertility.

Gotcha, OK.

Yeah so I guess my first big question for you is: How did you get involved with fertility preservation and oncofertility?

Um, so, um, what is- I’m so sorry- what is the oncofertility? Is that also fertility preservation or is that for just regular infertility?

Yes so that's specifically for cancer patients, um…

Oh, ok. So, um, so I personally…I’ve had three miscarriages and so, um, we’ve-my husband and I-have been dealing with infertility for over nine years now, I mean, the first couple of years we didn’t realize we had infertility. We were kind of, um, um, we-we- I mean we were just like well for five years, if it comes, it comes, if it doesn’t, it doesn’t, but we were naïve in thinking that, “Well, it just wasn’t timing.” We didn’t realize it was an issue, and then we got pregnant three different times and lost it. And then when we got pregnant last time we learned that we have low hormone levels and um, and basically to prevent from miscarriage, we would have to have these hormone levels in our system before we got pregnant. And that was the only way to kind of—so basically if we get pregnant naturally, we’re pretty much deemed to miscarriage because we don’t have the proper hormone levels. Sorry, I just got home, so…

Take your time.

I’m running around. But, um, and so-so that kind of like began this huge like, “Okay, well this just can’t be right. It can’t be that way.” Like how is it fair that our insurance won’t help sustain a pregnancy? And it’s because anything before you get pregnant is considered infertility and Arizona is a strong Republican state and they’re very much against any, any infertility.

Mm-hm.

So, we went through a lower-level treatments, and with those lower-level treatments, um, we ran out of money quickly. And then I just got really upset once it didn’t work. And then I just thought to myself, “Why isn’t-why isn’t our insurance covering this?” You know? It’s kind of crap. And so, I decided to just start emailing every house member, senate member, anyone that would listen—I just started writing people. And so, from, um, November to March I sent out probably 120 emails a month.

Wow.

And, it was kind of just like I was emailing people about my progress and where I was going and then it just seemed like around March of this year, the stars just kind of aligned…same thing with you, you get in contact with people and they point you in this direction. So I got with the Resolve organization—have you met with them and talked to them?

No.

Okay, so they are the national infertility association and they’re an amazing organization and so they do a lot of group movements. Um, I have your email… I’ll forward you Betsy. She’s like a constituent engagement person, and so what she does is she helps you in your area, like with other people that are struggling with infertility and then other people that are in the grass movement-grassroot movement, she’ll help connect you. And so, um, we spoke to her and she said that there really wasn’t anyone in Arizona doing anything and so she just said, “Here’s the tools, this is how you do it.” And so from there I met with a couple senate members and house members and, um, honestly I thought that you went to your local, you know, your local representative and say, “Here’s a bill, here’s what I think you should do, and you do it.” And it’s not that—you have to do everything, including drafting the bill. And so, when I was drafting the bill, um, I looked at the other states that had infertility and a couple of them had fertility preservation in it. And so, personally, I don’t have any experience with it, I mean I don’t have cancer—I didn’t have cancer treatments. My infertility is all based off of a birth defect, is what is. But it made sense to me if someone is facing infertility—I mean, the chemotherapy or radiation—they should have a chance to preserve their fertility. Because it’s not fair, you know, they’re going to fight this disease and then three, four years down the road when they’re ready to start a family, they’re going to have to go through another struggle and it’s just not right. So, I, um, so I looked at some other states that offered infertility coverage and basically for—or not infertility coverage, but um, fertility preservation, and so then that’s how I added it to my bill.

Okay. So what was the title of that bill?

Um, so it’s not introduced yet but it’s basically, um, Arizona fertility coverage.

Okay. So as of now your state does not have any infertility mandate?

No it does not.

Okay so it’s not one of those 15. Okay.

No, nope. I keep telling them, cuz we’re a Republican state, so of the fifteen, fourteen are Democratic, one is Republican. So the Republican one is Mississipp, and I think we can do better than Mississippi, but…

So, so if you were able to achieve all your goals how would the policies differ from their current state? Who would be covered and then how would that look?

So right now in Arizona, um, so on the um, the individual exchange you can’t purchase, um, any, um, insurance that has fertility—you’re not even able to purchase it. It’s not even offered to you. And then, um, from a private standpoint of having like employer coverage, unless your employer has 100 plus employees, they’re not even allowed to ask for a policy to cover infertility and um, so this, so my bill just affects private insurance and the exchange. But anyone that’s like, on Access, it does not include them, um, just because it hits a huge deficit, and people…and it’s just a tough spot. So basically my bill is for anybody who has private insurance they have to have infertility coverage and then, um, with infertility, it’s mandated that you have IVF and then fertility preservation is in there. Um, it does not cover donor sperm or donor egg. If you want to use those procedures you can, but you have to pay for that donor sperm or donor egg or donor embryo.

Um, okay.

But, so, I mean you can still have IVF with donor sperm, you just have to pay for the donor fee.

Mm-hm. And so…sorry go ahead.

No, and right now, my bill does not cover LGBT, or LGBTQ. It’s for- it’s for people that are affected by infertility. And, I don’t, for cancer preservation, I don’t think it really, I don’t think it talks about anything like that, um, but there’s nothing- there’s nothing that specifically eliminates them, but there’s nothing that specifically includes them. So, um, I-I know I’m not saying that properly…but, um, so that’s like one hard point for some people is that it doesn’t include for like, unfortunately a lesbian couple can’t go in and have it covered by insurance for their IVF.

Mm-hm.

But would the-the gender identity or sexual orientation matter for a cancer patient who’s looking for fertility preservation because that will be a separate issue…

Nope.

So they could maybe be included.

Totally separate. Yeah, yeah because the whole is that generally-I mean not generally- but when you have people that are going through cancer, I mean, when you need to preserve fertility, they might be married but they might not even, you know, they might be 15 or 16, I mean they have their whole lives ahead of them that they don’t if they’re going to be married or whatever.

Right.

So, no. So that’s not part of the fertility preservation.

Okay, so I mean you kind of hinted at this but do you consider this topic social justice issue?

Oh absolutely!

And why is that?

Well I just think—so my insurance will pay for an abortion and my insurance will pay for birth control, but my insurance won’t do anything to help, um, to help me sustain a pregnancy. And again this is probably a little way from fertility preservation, for me it’s—for anyone…so you, this is like my golden example of cancer actually is it, um, this is how I explain it: So if, when you’re diagnosed with breast cancer you're given your stages, you know? Stage 1, stage 2, stage 3… You go in, you meet with your doctor, and your doctor has a treatment plan for you. And your insurance will cover that treatment plan unless it’s some experimental drug therapy, your insurance covers it. And you have all the choices. You can choose to do chemotherapy, you can choose to do radiation, you can choose not to do anything—those are all your choices. And depending on your stage, if you’re stage 4, you have to accept that you’re stage 4 and you’ve got to live your life to the best ability that you can, but you still have treatment options. People that are faced with infertility, they’re not given that. They’re given, “Here’s your testing, here’s your diagnosis, now it’s time for you to accept it.” You either have the in your pocketbook or you move on. And that’s the problem, there’s so many things with infertility that can be like lower-level treatment, and you're not even offered that. You can have those treatments as long as you have the money in your bank account or you're able to finance your home or get a loan or whatever…you can get those treatments. But it's about…it’s just not right. You know, when you’re told you have cancer, you’re told to fight and when you have infertility, you’re told to accept it and move on quietly. You know, it’s a private matter, it shouldn’t be discussed outside your family, and-and that’s kind of how it’s left for a lot of people. It’s a disease—the world health organization deemed it a disease in 2005 and, um, all these larger organizations have said that, you know, insurance should cover infertility and they should because so many families could be, like high-risk pregnancies wouldn’t be as high-risk…um, it’s proven that states that have the fertility mandate, they have lower high-risk pregnancies, they have lower multiple births, they have lower premature birth rates. So, it’s obviously working in those states.

So, um, what would it look like across different types of insurance if your bill went through?

Um, it would be the same for all insurance. The only difference is private versus state-funded access. So if you’re on the exchange, or you have insurance through your employer it would be all the same. So the minimum requirement will be…um, um, there would be no lifetime max on fertility benefits. The only lifetime uh, you know, it’s like a dollar value, um, the insurance will only pay for 3 rounds of IVF. That’s it.

Okay.

Once you’ve done your three, then you’ve maxed out. But it’s not like… some of the plans say after you’ve hit $25,000 or $30,000 that’s your max. So this wouldn’t, um, you know the goal is to try lower-level, but if you can’t do lower-level then you have IVF and then, um, it will only pay for three rounds of IVF.

Okay. Um, so what are some of the biggest barriers you’ve faced in your efforts?

Um, conservative men that don’t know the struggles of infertility, that haven’t had to deal with it. So it’s um, I’m 34, and you meet with these men that are 60, 70, one of them was even 80… and um, um, most of them in Arizona they’re-they’re very conservative Republican. And, um, it’s- some of them it’s things that they’ve never faced before, they’ve never had to deal with or see someone struggle with and um, and the whole science of it- it sometimes puts people off. Catholics are very difficult, um—they believe that life happens at the moment of conception and they don’t believe life should be created outside of the womb. And so, um, if you have a Republican Catholic it’s very difficult. They um, their church itself is generally against IVF so then they’re naturally against IVF. And, um, so I… it just, it just depends…one of my meetings, it was with an 80 year old man, and he didn’t even know what IVF was and so I had to explain to him how you get the sperm and how you get the egg, and how you fertilize it outside of the womb in a petri dish, you know. And then even lower-level things like IUI or how to freeze eggs, any of that stuff he didn’t know. So a lot of it is education and then a lot of it is, um, you know, most people think of IVF back in the 80’s where they used the left-over embryos for um, stem-cell research. So there’s that negative connotation with it—everyone thinks IVF, stem cell research. But that’s not the way it is now. Now you can freeze your eggs. Or freeze your embyros. So it’s not wasted. And um, and now you can take the time to implant one embryo at a time because they’re not going to waste. And you don’t have to discard those unused embryos. And you can put them up for adoption—other couples that can’t um, you know, that they have poor egg quality or whatever it is, they can adopt those embryos. So there’s no more discarding and um, and some people see it as a form of abortion when you discard an embryo, because technically it’s a baby, and a lot of times people just don’t understand the four-day embryo is just cells coming together and just because it’s a four-day embryo doesn’t mean that it will survive in the uterus. It still has a chance of miscarry.

Mm-hm.

So a lot of it’s education. And some people, they just have their own bias. I met with a (inaudible) year old Mormon and he was the co-chair of the insurance committee. And he, um, had seven children and of his seven children he had thirty grandchildren, so he’s been very blessed. And um, and he said to me that while his family have been over productive, I have been under productive and that just might be how the population works to keep it even.

Hm.

And so, I think a lot of it is education.

Yeah, absolutely and how do you how do you see this tied to a person's quality of life? Or do you see it tied to quality of life?

Oh absolutely—it’s totally…I um, personally I’m very strong and I can handle a lotta things. My father died of brain cancer when I was 15 so at a young age I had to learn how to deal with sickness and things not being a perfect home or a perfect family, and I think everyone does, but people learn how to handle things differently. Um, and I’ve seen many people with the struggles of infertility, break. I mean, it is the ultimately soul-crushing thing that I- it’s one of the toughest thing I’ve dealt with because you have so many people telling you their opinions: “Why don’t you adopt?” “You’re being selfish because you don’t adopt.” I’m not being selfish by not adopting. I want to have a pregnancy. I am able to get pregnant. I want to see this through. I’m not being selfish. And you have to constantly defend yourself. And then, infertility itself, the treatments, the going to the doctors every three days…and then getting your hopes up and going through all that stuff. It’s just a lot, and if you took- I mean, you’re supposed to be the least stressed when you’re trying to get pregnant…and you’re paying, you know, $12,000 for IVF and then 4 grand for medication…if you took away the stress of money and you’re able to let people get the treatment that they need and not have to make a decision of, “Let’s try IUI 4 times, and then after that if it doesn’t work, then we’ll go to IVF.” Or, “Let’s do this because it will save us money.” If you take those things away, people can make decisions that are proper for themselves. And I think you have a lot of women that struggle- and men- struggle with depression. And, um, and, a lot—I know that I’m on these support groups and you see people that are just completely broken by-by what they’ve been given. It’s just kind of—if we treated it as a disease and we were more proactive in helping people understand it, and-and-and in testing instead of waiting for everything to fail, I think it would help so many more people. Plus, like um, when I had my third miscarriage they thought a blood clot went to my lung. And so it’s not just dealing with the mental effects of having a miscarriage, it’s also dealing with the physical effects of what happens to your body when you have that miscarriage.

Mm-hm. Right.

So I definitely- I think it is.

Absolutely. I know, um, just…

What if? And it doesn’t leave you. It doesn’t go away. And you know, like right now on facebook, everyone’s like, “Oh, tag if you’re happy if you’re a mom,” or whatever. And you get tired of seeing it, and then, you know, it doesn’t go away. When you become a grandmother, I mena, how many times do you see, “Oh, I’m so thankful that I have my grandchildren!” I mean, it’s not something that just goes away…

Right.

…or becomes any easier.

Right. So that- it seems like that’s kind of a big impact with the quality of life question is just that it’s not something that you can forget.

Yeah. Absolutely.

Um…

I’m so sorry.

Oh, no! No, no not at all I just—that’s kind of what got me interested in it and um, so I got really interested in the policy of it. Similar to how you’re feeling about it. So how do you impact, at a broader, larger level, right? So, um…

Right.

Yeah so that's kind of my angle on this, because there's a lot of literature about the treatments themselves, about their efficacy, about, you know, how many people need it, but there's not a whole lot on what's working at the policy level and does-are-is everybody talking? The people who want this to be passed, are you guys communicating with one another, are you sharing information and building upon those best practices? So that's kind of where-where I'm coming from.

Gotcha.

Yeah well I am so grateful that I got to speak to you. I really appreciate your insights— definitely unique, um, so far. I think you have a really interesting take on it so thank you very much for sharing your story with me.

Absolutely, and you know I will email you (removed) information.

Great.

And um, and so they’re-they’re the national infertility association, but they also deal with fertility preservation. So, like when I drafted my bill, that was one thing they told me, that I needed to put in there—you have to put fertility preservation in there because it needs to be in there. They’re big proponents for it.

Gotcha. Yeah cause most of the people that I'm speaking to are in states with the mandate for infertility and so then they're coming at it from a different angle, um, where it's just redefining infertility to also encompass fertility preservation or, um, to specifically define, uh, oncofertility as a separate issue from infertility, so that's it -you're coming from a different angle…

Um, did you want me to send you my bill that we drafted up so you can see the exact language?

I would love that.

Okay. I’ll send that to you. And then, in Arizona, we’re the only state that makes you do this so you won’t get this from anyone else, but we have what’s called a Sunrise application. And so you have to discuss the social aspects and then the fiscal aspects of the proposed bill. And so, um, I’ll send you the um, we haven’t done the fiscal part of it but we’ve done the social aspects of it. And I’ll send that to you, cuz it talks about facts about fertility preservation. It’s very brief because it’s supposed to be brief, so there’s not like a lot of detail but… I’ll send you the bill and then our Sunrise application.

Thank you, I really appreciate that.

Yeah, no. And good luck on your thesis!

Thank you.

That’s exciting.

I guess! Yeah, it’s great.

It’s a lot of work.

It is, but it’s well worth it.

Right on. Well thank you very much.

Yeah absolutely. If you need anything else. Or if you need- if there’s like a bill that’s going out in um, New Jersey, no- Delaware- in Delaware, I can send you her contact information, the girl that’s drafting the bill for Delaware. It’s about to get introduced in January.

Perfect. I would love that.

And I believe she has fertility preservation as well.

Well, you’re great. Thank you very much.

Yeah. Have a good night.

You too.

Bye.