Interview 2

I am looking into the topic of oncofertility and exploring the policy landscape around that issue. And so, what I’m trying to do is just interview various stakeholders, um, who advocate on this issue and just to get a clearer perspective, um, about the barriers that are faced in advocacy efforts.

Okay.

Um, so I was hoping to just ask a few, um, open-ended questions, um…

Sure.

And I will launch right in if that’s okay.

Sure.

Great. So my first question for you is, how did you get involved with oncofertility advocacy?

Um, I was, uh, an ASRM lobbyist in California for probably 3 years or so and had been doing IVF tours for people at UC San Francisco. And I had a whole different issue area I was working on, but Mitch Rosen was, was, kind of the one who brought the whole issue of fertility preservation and I think at first because we were working with something else, there wasn’t a whole lot of traction, but I think with him (inaudible) about that, and then I think it was, um, gosh I can’t remember how Alice…somehow I got connected connected with Alice Crisci.

mm-hm.

Um, but I think it was a combination of, of different connections that brought it up, and I have to get—because I’m the ASRM lobbyist—like, to work for them, you know, I have to go, go to the organization even if the member is wanting us to work on this issue doesn’t mean, you know, we can. Um, but I got permission from, from ASRM and, um, and I think that might have been about the time…gosh, you know, I’ll have to ask Alice because I’m seeing her this weekend—we’re going to the ASRM conference, um, I don’t remember exactly how I met her. Um, but, then we got, you know, then we had permission from ASRM to introduce, you know, to sponsor a bill and then she on behalf of her organization Fertile Action also, you know, was a co-sponsor with us. So that’s how we kind of started down the path.

Great. And so why is oncofertility and fertility preservation coverage important?

Um, I think in the- I think…I’m trying to think of what’s my opinion versus ASRM…but I think first of all everybody has- should have- the ability to be able to have a family if they so choose. Um, and that to have a condition like cancer, you know, take that from somebody, you know, just if you have the option to not, you know, to preserve, then you know, help you live the rest of your life the way you want to. And then secondarily, being that people choose cancer treatment options with an eye towards preserving fertility if they can’t get fertility preservation. Um, cuz that does happen. And I have doctors who have had patients that have died, you know, because they, they were trying to…and it’s like, “Well I’m going to get the mastectomy, the radiation, but not the chemo…or, damocycin…” It just depends. It’s a matter of life and death!

So if you had achieved all of your advocacy goals, how would the policy landscape differ from the way it is now?

Basically to get whatever medically necessary care somebody needs, so right now in- for breast cancer, you get breast reconstruction surgery. There’s not really a lot of fight over whether you can get the surgery or not. It’s like everybody knows it, it’s not a big deal, just to-to get coverage…um, and so to be able to not only have the coverage but have it readily accessible so that it is not- the timing of it is not a barrier to the underlying cancer treatment.

Right. So, um, if you were successful in attaining coverage, how would access look, um, across different types of insurance?

Well I think that it should be standard…I mean, it’s just the standard of care now for, you know, medically. So it should be the standard of care for-for-for coverage. Um, and I don’t know, for instance a lot of times uh, I would have to look specifically at Medi-Cal and-and their particular benefits but at least this first path that we’re trying to get to is at least to all uh, commercially insured um, plans that are regulated in California, and then separately we can’t at the state level regulate self-funded plans under, uh, ERISA.

Mm-hm.

That’s all federal funds but it seems like there’s been a lot of effort—I don’t, I don’t know if they’re continuing to work…I know they had some challenges…but at one point LIVESTRONG- and they had a, I can’t remember what they’re- Joyce would know, she used to work for them…Alice’s group is Fertile Action, I think theirs was Fertile Hope or something…

Mm-hm.

Um, they were actually going to, um, self-funded employers and making the business case of why this was smart to cover, you know, to help show it’s relatively cheap, um, and that if you have somebody choose less than recommended medical care, in all, you know, it often could be more costly. Um, so I think that’s how you have to get to the, um, the self-funded environment. Um, and then separate-separate work would need to happen with so many different kinds of coverage. So for instance, Tri-Care for military families.

Mm-hm.

Um, you know, I-I think that needs t be worked on separately.

So what are the main arguments against the oncofertility coverage?

That it- that it’s elective, um, that it um, how do you…how do you draw the line about what should be covered and what’s not? I-I um, you know, I was actually really upset about- I was at a legislative meeting with a lot of doctors, lots-lots of OBGYNs, but some other doctors…and they were like, “Well, what if you have somebody who’s 45?” and, “She shouldn’t have a family, and you know, she’s too old.” And, um, so you know, have people argue that like well, “Gee, anybody could get…” You know, basically infertility care, I think fertility preservation and, uh, getting with every care that they wanted, um, and, you know I haven’t heard anything like, “Well, you know, we’re unsure about somebody’s like expectancy…” or anything like that. It’s just been more like, I think the conflation about this and infertility, um, I’m thinking it’s important. Even with infertility, the thinking is it’s elective.

Mm-hm.

So, you mentioned the doctors…in your view, who are the main stakeholders in fertility preservation and how are they impacted by the current political landscape?

Well, I know- you know the…you know, ASRM has a-a coalition working on this as well as a fertility preservation special interest group and the Oncofertility Consortium that’s out of- I think it’s the University of Chicago- um, but the problem is you’ve got um, uh, other- a lot of other people who um, who can be barriers and aren’t really knowledgeable about fertility preservation. I think that was part of my shock when I went- the meeting I was in was a whole bunch of different doctors from across the board.

Okay.

And, so these, so they had their own misconceptions about it…about what fertility preservation was and but also I talked with an oncologist who again was confusing and conflating IVF or infertility with fertility preservation, and he was saying that it was- he-he said he told patients about, you know, fertility preservation but he didn’t really push it because he was thinking of all the IVF he knew about was for people who were going for infertility. So he was saying, “Oh, well it takes, you know, months if not years to do this.”

Mm-hm. Okay. Um…

And so, so I had to educate him about, no it’s a very different process when it’s for fertility preservation… and then you also have some doctors who are members of medical groups that have financial responsibility, you know, the-the- the health plans shift financial risk to them…so for instance, Kaiser doctors- and you know, we had already talked about in the CHBRP report it looked like Kaiser was the 15% that wasn’t covering- the Kaiser doctors kind of take the um, argument for Kaiser health plans and were just saying you know, “This is unnecessary and costly.”

Mm-hm. So, um, what role do you think health professionals can play in the larger debate?

Well, one thing that would be really helpful is to do more basic education on what fertility preservation… what fertility preservation is, what the options are, and the importance of this, um, and I’m not quite sure the right forum, um, I-I was thinking of even having a video that could be, you know, viewed online and also going to…what are the people where it really makes the- that makes it efficient? So for instance going to the oncology leadership and/or conferences and doing presentations about, we- if we have to, we can do something in a couple weeks, you know, or-or you know, less than a month, or you know, talk about findings because of, you know, just how-how-where do they ever really learn? It’s like the oncologists- where do they ever really learn about, um, what fertility preservation is?

Right. So do you consider this topic a social justice issue?

Do I consider it a what?

A social justice issue?

Oh yes—oh absolutely! Um, and I think, you know, especially when you are, I-I really, have been doing a lot more work lately on, um, reproductive justice and communities of color.

Mm-hm.

And especially low-income communities. And so somebody like Alice was able to put um, you know, I mean- she went bankrupt because of it, but she was able to- initially was able to, um, put the um, you know, the process on her credit card. And there’s a lot of people that don’t have that option.

Right.

Um, so they’re just going to either go without, or they’re going to do the thing about you know, choosing less optimal care, the cancer care, um, so yeah, absolutely—and that’s kind of how I’m framing some things, um, is, uh, that this is something that um, that they- some of those communities that may not be tied into or be as aware about IVF because they don’t do-use them as much, um, need to be, you know, aware of and um, and also that they need to trust the process and providers because there’s a lot of mistrust, especially with the African-American community, you know, rightfully so, with the history with the medical professionals and not wanting to be guinea pigs.

Mm-hm. So, um, is there any in particular that you consider a model going forward?

You know, I am not as up to speed right now… what, shoot it was just—was it Connecticut?

Connecticut, yeah.

Um, yeah. Yeah, so-so I’m not as up to speed on the specificity of-of-of their statute. I’ll probably learn more when I go back this weekend but um, so yeah I don’t- I don’t have a good answer on that.

Okay. Um, well I think that those are my- my main questions…um, is there anything else that-that you think is critical to-to understanding this issue?

Um, I-I think in terms of the-the…making sure people understand it’s not elective, it’s part of the underlying treatment, and-and just a bit more education generally, um, because, I know that a lot of patients, and like Alice in particular and I don’t know if Joyce says this as much, you know, where they say the oncologists don’t talk to um, you know, to the patients… and when I got back from the “Well yeah, we do. There’s just a lot of stuff that’s going on when I’m telling, you know, somebody all of this and this may not be something that sticks in their mind.”

Mm-hm.

But it’s one of those things that if you have the general public awareness, that if you are in the midst of this diagnosis, even if you don’t think of it, somebody else in your family might think of it…you know, I actually have- I have a- I think I’ve mentioned before- I have a-a son who’s transgender.

Mm-hm.

And, you know, I didn’t think of, um, you know, of fertility preservation before he went- underwent his hysterectomy. So like literally he’s driving off to get his hysterectomy, I’m like, “Oh, shit!” You know? I actually called Mitch Rosen and he’s like, “No, there’s nothing you can do now.” And my son was fine because he’s like, “I don’t want to be a mom, I want to be a dad,” and you know, so, but I’m working in this area!

Mm-hm.

I did not think of that.

Mm-hm.

I just am flummoxed about that so in terms of, like, for other people to be, “Hey!” You know? “What about this?” And so moving it into, um, you know a lot of things with social change and especially medical, I think they do a lot about trying to weave the stories, awareness, into TV shows or movies.

Mm-hm.

And, so, that would be something that would be really great to see, um, this becomes normalized.

Mm-hm. Yeah. Um, okay. Well thank you so much. I-I really appreciate your time and you provided some really valuable points, so thank you for that.

Okay. Well have fun.

Alright, thank you. And I’ll be sure to keep you in the loop. Thank you very much.

Alright.

Bye.

Bye.