

## The Little-Known Realities of the IVF Industry & What We Need Now

New Legacy Radio-Episode 6: Pamela Mahoney Tsigdinos

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**VoiceAmerica 00:05**

Welcome to New Legacy Radio with Christine Erickson. Are you someone who doesn't have children by circumstance, choice or chance? This show is for our collective community. Are you someone who influences policy, DEI initiatives or media narratives? Learn how you can co-create inclusive, equitable policies and environments for people without children. Now, here's your host, Christine Erickson.

**Christine Erickson 00:32**

Welcome to New Legacy Radio, everyone. This is Christine Erickson. I'm your host, and I'm also the founder of New Legacy Institute, part of which was intended to look at policy issues and what is next for the collective community of people without children. Today, we have with us a very special guest who is very knowledgeable in the areas of reproductive freedom and IVF. And we have a lot to discuss today. Pamela Mahoney Tsigdinos is the author of *Silent Sorority* and *Finally Heard*. She is also the co-founder of [reprotechtruths.org](http://reprotechtruths.org), which is a grassroots initiative dedicated to greater transparency and public health information on the full spectrum of IVF and related practices, risks and outcomes. Welcome, Pamela.

**Pamela Mahoney Tsigdinos 01:22**

It's great to be here with you, Christine.

**Christine Erickson 01:25**

Thanks. So as I said, I feel like we have a lot to get to today. And I'm so excited to have you here today to shed some truths on things that we may take for granted in this industry. Can you share a bit about what your journey from IVF survivor to really industry investigator has been like for you?

**Pamela Mahoney Tsigdinos 01:49**

Yeah, so I went through approximately a dozen years of trying to conceive. And through that process, like most women, I was learning along the way that a lot of what we take for granted, and the way our biology operates isn't necessarily relevant for you, everyone's body's a little different. And I just want to add that there's also a lot of challenges as well with male factor. So it's not just about women, it's about men and women. My experience was a little of each, but we were described as unexplained. And as each step of the way went on, I realized how little information and how much I guess transparency is missing from the whole experience. You're sort of pushed along a conveyor belt without really understanding, other than someone explaining you need this test tomorrow, how that's all going to work or not, depending on how your body performs. So, you know, after 12 years of spending time, money, just an emotional roller coaster that you really have to live through to fully appreciate, even though I've had friends who empathize with me, the emotional roller coaster, I think, in some ways was equal to or worse than the actual physical experience. By the time I turned 40, I knew that the window was closing. And we'd gone through several rounds of embryo transfers that were not successful. I'd gone to three different clinics, had multiple invasive surgeries, and by the time I actually got to what I thought would be my last round of IVF, the clinic called to say, "nope, you're going to be 40, so we're going have to throw you at the back of the line. We need to do a bunch more; you're going to be a geriatric mother. And I thought, what? And so at that point, after 12 years of throwing my body at everything I could conceivably think of, I just thought this is it. If I'm going to be a geriatric mother, this is too much. So to make a long story short, I decided at that point, that there was so little information about the entire spectrum of reproductive health, that I wanted to turn my attention to looking at how did this industry get started? Why is it so screwed up? And why are women left doing 90% of the legwork to understand the risks, and some of the potential downfalls associated with a practice that's been operating for over 40 years, and that gets glowing headlines and all the mainstream media, because who doesn't like a story that has a happy ending, with a cuddly baby? So that's where I started about 10 years ago, and I really started looking into the history. And I'll pause there, so you can ask a question, but I learned a lot that really opened my eyes and made me realize there's a need to do much more scrutiny and attention on how this industry operates, and the real risks that couples and women in particular face going through this process.

**Christine Erickson 05:07**

Absolutely. I mean, I have such respect for your work and writing, as we've discussed. I've followed your work for some time. And I think just to have been able to even shift your energy and focus onto that, after those years of experience, I mean, I so empathize with that. What a painful and long journey. I'm so grateful that you shifted your attention to this, because it's still needed, you know, 10 years later. What are we talking about? And we'll get to that a little bit later. But yeah, for some of our listeners, and people in our community who may not be aware of the history of IVF, and how it started, and along those lines, some of the misperceptions that have come at those stages, if you could share some of that with us, that would be wonderful.

**Pamela Mahoney Tsigdinos 05:59**

Yeah, so most folks may have heard about this groundbreaking thing that occurred in 1978. It literally took the world by storm. And that was the headline, first test tube baby born. And that was a woman named Louise Joy Brown. She's now 43 years old, or a little older. I think we're on 44, now. And ultimately, she was used as the poster child, along with her parents for the potential to cure infertility. And what happened was, there was a scientific race to try to understand how to capture eggs, how to transfer eggs, how to fertilize eggs, and in so many ways, these were all individual advancements. And ultimately, it rolled up over a number of years and experiments to the birth of Louise Joy Brown. In 1981, the first child conceived through IVF was born in the United States. And so the scientific world had conference after conference talking about all the wonderful things that were going on. And there were a lot of couples who had been diagnosed with infertility that thought this was going to be the answer to their prayers. Clinics started opening all over the United States and all over the world, but specifically in the United States. And about eight or nine years later, a number of doctors started to get very suspicious of other clinics that were advertising false success rates. And couples started realizing that they were being sold procedures that didn't have any real guarantee in any way, shape or form of actually achieving a pregnancy. So there were a couple of congressmen at the time, who held hearings to try to understand, what's going on here? It looks like millions of dollars are being spent, and couples are being misled. We need to apply some more scrutiny. At that time, they formed a few House committees, and try to look at this, including the FTC, the Federal Trade Commission, to understand how much

advertising was going on, and was it actually truthful. And the results were not good. There was a lot of real concern about the fact that vulnerable people were being taken advantage of. So they decided that they wanted to put in place some sort of regulatory body. That was all moving down a path through the 90s, until the industry realized, hey, wait a minute, if we're going to get regulated, we want to have a say in this. So they essentially rewrote the rules of the game, to ensure that there would be an industry led group that would act as the intermediary between the clinics and the government. And they dictated what they would monitor and what they wouldn't. So all of the consumer protections that were originally proposed, never made it into the final legislation. And that's where we are, this all happened in the mid 90s. And from there, clinics just exploded all over the United States because they thought, hey, it's off to the races. We can open up as many clinics as we want, sell as many procedures. It's all elective. So the insurance companies can't say no. And for years, women have been undergoing this procedure with no longitudinal health studies, and being led to believe that the answer would ultimately be a child. And in my case, and in millions of other cases, that's not what happened.

**Christine Erickson** 09:51

Yeah, I mean from everything that you said, I don't know how else to say it, but it's a predatory, emotional business model. Yeah, just the self-policing or the self-regulating in the medical field. I mean, for some of us that's even hard to fathom that that exists or that that is prominent in such a sensitive area. Yeah, wow. I've heard this. I've read some of it. And I still have to take it in again, when I hear you saying it, you know, the enormity of it. What do you think are the greatest misconceptions about IVF and related procedures in terms of, you know, what is advertised, or the assumptions because of the attraction to it? What does that look like? You know what are the highlights?

**Pamela Mahoney Tsigdinos** 10:45

Yeah, so, there's so many misleading elements here, it's hard to know where to begin. The challenge is that when IVF was originally developed, it was to address a very specific biological condition. And that was blocked fallopian tubes. And as a result, they were able to bypass the fact that the egg could not travel and extracted, fertilized it and placed it directly into the uterus. So for women with blocked fallopian tubes, this is a really good procedure. Doesn't always succeed, but it's a good procedure. It's when IVF became the

law, the hammer. Every woman who walked in the door was a nail, and they just started banging away and making that the first and the most lucrative recommendation. And I think that's where I have felt that there has been the most unfair treatment of consumers. There's very little actual good diagnosis. People are in a hurry, they don't have a lot of money, and they want to get an answer. And so as a result, the industry has figured out how do we fast track people. And they've got it down to such a science now that it's really easy for them to continue to upsell. And each year they're introducing new add-ons. There's one that's actually it's called embryo glue, where they say, you know, for a couple thousand dollars, we can sell you this add-on and see if it actually might contribute to better success. So there's very little in the way of scientific validation for a lot of the individuals and the procedures that are taking place.

**Christine Erickson** 12:39

So it's really connecting to this pillar of hope is, you know, the way I would look at it, I guess. And you can extend that like, like any add on sale, right? That feels like the possibility is better. And if you're hopeful, and you're not aware, you want to feel like you've done enough.

**Pamela Mahoney Tsigdinos** 13:06

Yes. And ultimately, the way things are orchestrated today, it's on the patient. There is this ethos in our American Society of "don't give up." And if you don't succeed, it's on you. And so that pressure on top of the fact that you're trying to navigate through huge physical, financial, and emotional demands, in the midst of trying to live your life, in a society that doesn't know what to do with you.

**Christine Erickson** 13:40

Yeah, I know that you have spoken and written to this, as well about, you know, just the impact on survivors. And that's, that's during the process, what you're experiencing during the process. Can you share a little bit with us about the impact on survivors and couples, families, going through this in the aftermath?

**Pamela Mahoney Tsigdinos 14:00**

There's something that that is kind of understood in the medical community and that is, it is easier to provide a certain block between yourself and the patient. And this is done through the medicalization of any kind of procedure. So rather than look at the whole human, they focus on the organ. They focus on the test. They focus on the ultrasound. And each step of the way, they're doing their job. They're checking the box to make sure that they follow the actual procedure. At the very end, all along, you're seeing progress. You're seeing eggs develop, you're seeing eggs fertilized, you're seeing embryos transferred, and they provide you those pictures of the embryo. So you bond thinking, oh my gosh, this is where it begins. And two weeks after the embryo transfer, you get a phone call that basically says whether the blood test was negative or positive. And typically, that phone call is one of 50 or more they have to make that day, depending on the size of the clinic, and the nurse is trying to get through this list and figure out where you fit in the next schedule of appointments. So the call usually comes in. "Hi, yeah, we got your test result back", and you are sitting on pins and needles thinking, this is my child in development. And the person on the other end of the line says, "yeah, the procedure was a failed", can we get you in next week? The doctor can see you, but only between two and three on Tuesday. And you're sitting on the other end of the line thinking, you just told me that this dream I had, this embryo this child you've been talking about as my baby, is no longer. And click, that's the end of the phone call. And when you show up, they want to know, did you get the blood test? You know, have you had any, fallout? Nothing emotional; it's purely, purely clinical.

**Christine Erickson 16:14**

Wow. That is very heavy. Yeah. And I just, you know, again, I keep taking it in again, you know, even things that I'm aware of to hear you say it, and that all these years later, we're still in this place of not treating the whole person, not taking care of the whole person or the whole couple as a family. It's devastating. That's a death notice, that's a grieving process. There are layers to this, it's not about the next appointments.

**Pamela Mahoney Tsigdinos 16:52**

And I think the thing that really struck me was in talking to hundreds of women around the world about this process and what they go through, so it's not just my own personal

experience, it's been mirrored by many others. There was one woman who actually had had a cancer diagnosis early in her lifetime. And she realized that the amount of care that she received as a cancer patient far exceeded any emotional support, she received going through the IVF process. And having lived through both, she was in the perfect position to assess, are you treated humanely in the reproductive assisted world, or not? And she said, "absolutely, categorically no."

**Christine Erickson 17:46**

It's part of the business model. Right? So you'll take the next appointment. I mean, you're supposed to move on, you're supposed to deepen your hope and move on. Yeah. My goodness. I know. I've spoken to women who, at that deciding point, which I've never had to make myself, but just breaks my heart, you know, of when to stop. Whether sometimes you're told to stop, sometimes you have to make that decision personally. And it's influenced by so many different things, your body, your emotions financially. I'm sure there are other things that you can add to that., but none of it is simple.

**Pamela Mahoney Tsigdinos 18:26**

No, no. And these are not decisions that get made overnight. You really struggle with them. Because we have 28-day cycles, every 28 days, you are reminded of that failure. And so even if you want to turn it off, it's living month to month with the understanding that well, there's a new procedure, should I give it a go? So I talk about it as the 'siren song' of reproductive medicine. And I was shocked to learn that when I turned 50, I was still considered fair game because they keep coming up with new ways to sell. And as we, you know, look at this holistically, there are also younger women being conscripted into the role of egg provider, and very little is done to protect their health and well-being. In fact, through a website called we are egg donors, they have sort of formed a coalition to talk about the abuses they've experienced. And a number of women who had been egg providers earlier in their life, learn that all of the puncturing that was done to their ovaries to extract their eggs that were then sold to another couple, left them infertile. So it is shocking to me that this information is so well hidden, and it's only when you spend hours looking at academic journals, going through research that you see that this information is all hiding in plain sight. But nobody ever talks about it. And that was what really drove me

to spend time figuring out, how do we shine a brighter light on this? The accountability and transparency is completely lacking in this particular branch of medicine.

**Christine Erickson 20:24**

Oh my gosh, yeah. And from egg donors to egg freezing, I mean, from the outside the marketing that I see it's, again, so simplistic, like it's an answer, when it's not. It creates all these complexities, even regardless of outcome, but especially when the outcome is not as intended. And the damage to young women's health in selling their eggs. Yes. Oh, my goodness. What was the term you used? 'Egg providers'.

**Pamela Mahoney Tsigdinos 20:56**

Yeah, I will say there's one other issue around taking young women and putting them through this process. I started when I was 30, to really understand the diagnostics of what was or wasn't happening. But when you're talking to women in their 20s, and you're asking them to flood their bodies full of hormones, younger women, by virtue of being reproductively younger, typically will overstimulate; their ovaries end up producing way more eggs than any woman should carry in any given month. In a good IVF round, you want to get maybe six or eight eggs. These women because of the flooding of hormones, can carry up to two dozen. And imagine what that does to their ovaries. They're like barbells. And so trying to then extract those eggs, without understanding what is the long-term health issue, leaves women, and this is for egg freezing as well as women who sell their eggs, because ultimately, they are going to be living long term with potential health threats that are never clearly laid out.

**Christine Erickson 22:17**

And I can't imagine just you know, being at the age I am the things that I've gone through hormonally, without doing any of that or without being pregnant, the impact on your body at those different stages. I mean, I don't even know what all those implications are, but I imagine that it is complicated, through menopause, through all the other things, let alone what that can do to someone's fertility. My goodness. I mean, as you said, the information's hiding in plain sight, but it requires somebody to look at that and to collate that. And I'm so grateful that you have done that; that you continue to do that. And again for being here today to bring more awareness to this. You know, to me it's beyond

disturbing. And to see how this is a growing market. This is a growing industry, from the way I see it on outside, I'm sure you can speak more to those numbers than I can.

**Pamela Mahoney Tsigdinos 23:19**

Yeah, and this is also one of the first medical specialties that targets healthy people. So a lot of the young women who are actually being offered this through benefits at the workplace, or who are being sort of pushed in that direction because they're not in a relationship, or they feel like maybe that's their guarantee for a future family. When in fact, there is no such thing as a guarantee in this realm. I think the thing that I find most disturbing about this is you are potentially taking healthy women and making them less healthy in the long run. And furthermore, the vitrification, the freezing of eggs, is still a very new science. They really do not know the long-term impacts of what happens when you put eggs on ice over an extended period of time. They've improved the process of freezing eggs, but they don't know what are the potential long term health impacts for the woman who has to then go through ICSI IVF, which is intracytoplasmic sperm injection, where you have to inject the sperm directly into the egg. Normally during an IVF process, they will introduce the sperm into a Petri dish with an egg, and let the fertilization happen there. This kind of coating that goes around the frozen egg requires them to inject the sperm. They don't know what the potential issues are going to be in terms of damage. And then ultimately, the woman has to go through the IVF embryo transfer, if there's a successful fertilization. So with each step of the way, you are introducing all kinds of potential threats and risks and health issues that have never been fully studied.

**Christine Erickson 25:14**

Wow. Wow. It is horrifying. I ache you know, thinking about, you know, knowing people and having read your work, what people have gone through, but that we're continuing to invite people to these experiences without the awareness of not only these horrible potential health impacts, but the numbers around outcome too. You know, who actually has a child at the end; a healthy child and a healthy woman. And, what are we valuing, and where along this spectrum of this life process really, is the question that I have; and that we have an industry that is pushing it. They don't even have to wait for people to seek it. It's a natural desire and hope and imagining that we do in our lives, that we're

going to have a child or children. If anything can feed that more immediately, with a greater assumption of a positive outcome. That's just good marketing, isn't it?

**Pamela Mahoney Tsigdinos 26:39**

It is. And you know, I think the thing that has been so troubling about this particular branch of medicine from the very beginning, is that it's virtually impossible to separate the medical, from the market forces, and the business. There are actually conferences, where MBA business managers are brought in to IVF clinics to talk about how to grow their footprint; how to compete more successfully for consumers to come to their clinic, rather than the one down the street. So when you have business managers, whose job is to figure out the sales pipeline for IVF clinics and egg freezing clinics; these egg freezing parties that were held originally, when this was first offered, they would introduce women into a discussion about taking their eggs and putting them on ice, while serving them drinks, and trying to explain to them how this would give them a safeguard a promise for a family. And don't you want to be sure that if your career is going well or you haven't met the right person, you have this backup plan? Well, a backup plan is only a backup plan, if it's going to work. And I fear for the women who have put their eggs on ice, who are under the assumption that they will have a family in the future, who are going to go through a similar process the way I did, each step of the way, believing that they would be able to successfully conceive, have a full successful pregnancy and deliver a child, only to find that's not the outcome.

**Christine Erickson 28:35**

Thank you so much, Pamela. We're going to take a short break and we'll be back with more with Pamela, and we will talk about what is current in the industry and what we can look at to change the transparency and policy around these procedures. Thank you, and we'll be right back.

**VoiceAmerica 28:52**

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**Christine Erickson 30:08**

Welcome back everyone, to New Legacy Radio. Today I'm having a conversation with Pamela Mahoney Tsigdinos about the IVF industry and the impact on survivors, as well as the marketing to young women, of these services. It has been very eye opening, and I hope that you have already learned a lot from Pamela's deep insight into these issues. Pamela, you know, coming back to what is happening today, because it doesn't feel like much has changed in terms of support and care, and transparency, and all the things that you've spoken to us about today. How, do we assess what is happening today, and even what is happening in workplaces and the financial investment of all of this. There are so many angles to what is happening that don't really bode well, but that, you know, again, prey on that emotional possibility of something very real to people.

**Pamela Mahoney Tsigdinos 31:13**

Yeah, one of the challenges right now is, there has never been an organized constituency, to take on some of these issues, and to provide some good remedy. And I think that has been the biggest challenge. Patient consumers, who have come away from this process traumatized and very deeply saddened by the whole experience they've gone through, typically tend to go into one of two directions. They will completely never talk about it again, because it is so painful, and it brings up so many horrible emotions that for them, burying it is their way of coping. There's also a group of people who succeed, and they tend to be the loudest voice in the room. And anytime anyone raises the questions of whether or not there should be more scrutiny, more oversight, typically, there's pushback about the fact that it will somehow limit opportunities in the future. So when you have a

group of people who have been truly abused by the industry, who are not able to organize themselves in a way that will prevent future abuse, clinics will enlist their favorite advocate, and say, we need you and your child to be in this new campaign we're putting together. But let me just give you a statistic, the number of IVF rounds that have happened in any given year, and this, this happens throughout the United States, as well as around the world. There's a European group that does a really good job of tracking all this. And they have actually found that each year 2.4 million cycles occur. 2.4 million. And of those 2.4 million 500,000 babies typically, are born. So the success rate is somewhere in the order of about 28% in a good day. And that's assuming, you're talking about healthy women, who are fairly good in their prime childbearing years. As you age, you get less in terms of good results. What I'm getting at here is there are very few cycles that actually succeed. And so this is the problem. The industry controls the narrative right now. And of those handful of successes, when you have 70 to 80% failure rate, those successes get magnified. And I think that's the challenge right now is there's marketing dollars. Clinics spend a remarkable amount of money. If you drive down highways, if you're in mass transit subway stations, you see billboards for IVF clinics and egg freezing opportunities. That is something that a handful of patient advocates can't compete with. So we really do need much better public policy, and investigative efforts to try to put some guardrails around this industry. And I think that the other element of this, which is absolutely critical, is that the medical profession needs to be more forthcoming about their brethren who are misleading and preying on vulnerable individuals.

**Christine Erickson 35:07**

Absolutely. Yeah, my goodness, it's the silencing. And I know, the power of the title of your first book, "Silent Sorority", I'm thinking of the group of people that you just spoke about who, you know, have gone through this process and have been traumatized and don't want to relive it, don't want to revisit. This silencing is at so many levels of this. The medical community is silencing it, the survivors are being silenced to cope, the people selling it are silencing the reality of it, and the outcomes of it. And for all these years for that to be happening, and to now read articles, where, you know, marketers are going into law firms and companies are opting to offer fertility benefits to finance part of this; it's a push, it's an attraction, it's to retain workers. That's what they're saying. And with these specific kinds of services, it's really a workaround financially for companies or it

wouldn't be attractive, I think. And even in doing so, those internal services are not being offered or built at the same time within the span of these benefits schemes. There is there is no "Well, what if it doesn't work, then what?" It's as ignored as people without children and the childless population is today, about what those needs are and what those company cultures provide. What services go hand in hand with this? It's really, not only a missing conversation, it's now a missing reality. If you're bringing those services in for people to actually bank on those things, and particularly young women.

**Pamela Mahoney Tsigdinos 37:06**

And I would say that HR folks in these big companies would do the rest of us a really big favor, if they would actually do their own primary investigations. How safe is this for our employees? What is the likelihood that we're going to deal with someone with a long - term health issue? And ultimately, how are we going to support them when they're going through the grieving process of realizing that what they had really banked on did not in fact, happen. And the grief is real. I can tell you that it took me no less than seven or eight years to not burst into tears, every time I would describe my experience. And I can even feel myself getting choked up now, thinking about it. So it's not something you can easily get over in a day or two. It lives with you. And that is something that is introducing a mental health challenge to your workforce. You are you are setting it up. And I think that as an HR practice, nobody should ever introduce anything into the workplace that could cause harm.

**Christine Erickson 38:19**

Absolutely. I mean, what a powerful, not only statement, but invitation. I mean, I can't fathom being in a position like that, and be offering this with that knowledge or with that awareness. And I do think, you know, even if the research isn't as in depth as yours, and that's available, you know, it's there, as you said. Even if you realize just the base statistics of IVF, just the base statistics, statistical outcomes, is not enough to say, this isn't something that you should bank your future family on, or your future child or your hope. It's just not. No one would invest with those statistics and other things, knowingly.

**Pamela Mahoney Tsigdinos 39:06**

I agree with you. And I think again, prioritizing safety, evidence-based medicine, and ultimately ensuring that there is good diagnosis, so that you are not introducing a procedure into somebody's potential body that may cause more harm than good, and in each step of those processes. You know, anytime you see a doctor, you don't go into the doctor's office thinking you're going to come away sicker than when you walked in. And I think that is the fundamental question is, is this particular branch of medicine, committing to the do no harm? And when you have doctors who are saying, "well, my patients are asking for it", hey, we were not the ones who went to medical school. We're looking at you and your background and your credentials to advise me on what is the most likely way to address a specific issue, around reproductive challenges. And again, I think when you start to put the market forces and the profitability ahead of whether or not this is actually medically indicated, is a really troubling question.

**Christine Erickson** 40:28

Well, and that it's been allowed to do so for decades now. This isn't the start.

**Pamela Mahoney Tsigdinos** 40:35

Absolutely, right.

**Christine Erickson** 40:39

Yeah, that self regulatory piece is very scary. What keeps going through my mind as you're speaking is, and I don't know, this is an insinuation from this. But I have to always wonder when something is run this way, from a medical perspective, is it for research purposes? Are people entering these procedures are they really, you know, submitting themselves on some level, as experiments? I hate to put words to that in such a touching and, you know, horrible thing, and heartfelt grief. The money thing is one thing, but what are you doing with all this? And what's getting better, and not? And if not, why? Because the numbers are there.

**Pamela Mahoney Tsigdinos** 41:30

Yeah, I think that there's this this real question of a lack of duty to care, when you are selling false hope. And ultimately, the best thing that can happen, for example, I have asthma, and if a doctor had told me 30 years ago, "hey, get a cat and a dog because, you

know, they provide great companions." But I have asthma, and I could potentially go into a full-blown attack and stop breathing. Would you still recommend I go with the cat and the dog? I mean, it's one of these things. Yeah, I love animals, but I can't have them in my house. I can't wish that away. So it comes back to again, where is the accountability? And, I do think that, you know, patient consumers, certainly have a desire here. And we cannot say, you know, if somebody comes in desperate and really wants to try it, you know, obviously, personal freedom, you can do whatever you'd like. But I do think it's incumbent upon the industry to provide a clear window, a clearer visibility into what's going to happen, and also talk about the very real negative downside, and the emotions that it can bring up. When I went through my IVF orientation, and I know women who are younger than me who are still doing it today, they don't start with saying, meet Pamela Mahoney Tsigdinos, who spent 12 years trying to conceive and went through multiple embryo transfers, passed all the tests with flying colors, but kept flunking the final exam, and then spent 10 years in deep grief, trying to overcome her trauma from this invasive procedure. Hey, if I'd seen Pamela Mahoney Tsigdinos 20 years ago, I would have thought twice about, hey, is this something that I should put myself through? And none of that information is ever fully disclosed.

**Christine Erickson 43:35**

Absolutely. Yeah, it's always the positive outcome, the rainbow baby, the flashy marketing, the odd celebrity; it's just not realistic. I mean, it's not realistic in numbers. And I'm curious, you know, at that time, as you mentioned, pamphlets or the literature. I'm wondering if that's even changed over time, in terms of the actual factual information, or if it's just that become kind of more flashy marketing.

**Pamela Mahoney Tsigdinos 44:08**

You know, I want to make clear, then there are good clinics that not every reproductive endocrinologist and their team is out to be a villain. I think that's very important. People have been helped. But ultimately, I think that the industry itself needs to be more accountable to whether or not they have allowed themselves to become, well, they've fallen in love with their own narrative. And in that regard, I think that's where an outside external independent oversight would provide a certain amount of grounding in reality. When most people come through the process without a child, they typically go away,

because they don't want to see that clinic ever again. So the clinic only sees the people who manage to succeed. But of those millions of cycles, and 1.5 million of them failing. That's a lot of people who are dealing with a lot of issues that never get offered any counseling. You know, the clinic sees you as a profit center. And they don't allocate any money to understand what's going on emotionally and mentally, when you go through a loss, an alpha pregnancy loss. They're done with you, they're on to the next customer, "Hey, we got someone here, who wants to freeze her eggs. Sign her up."

**Christine Erickson** 45:41

Running through my mind are all the things that we regulate, particularly in this country, and it's unfathomable, that this is something that is not more deeply regulated.

**Pamela Mahoney Tsigdinos** 45:52

I will tell you that food trucks are more heavily regulated than IVF clinics are.

**Christine Erickson** 46:01

Yes, and as you as you rightly pointed out, I'm glad you said that about you know, not negating the total. But I do think, you know, it's really important what you said too, about what these procedures are created for created to be set successful for. It's not carte blanche, but that's the way it appears, at least to somebody outside of that experience. It's well, if this doesn't happen, then you can try IVF, but that may or may not be true, let alone the statistical outcomes. And so matching those procedures to what really is possible, instead of just a business model. And recently, as I said, the marketing that is going into the workplace, and those kinds of things, that's really what I was focusing on, I wasn't trying to discredit all of the clinics, but I think it's already out of hand. I think that it's that it's entered the workplace that way, tells me that people don't have the information or they're not stopping to get it not just in individuals, but that they are being preyed on in that way. And maybe the HR professionals are too, but as a company, or as an organization, and HR professionals, we have to prioritize the health of women, not diminish it for a marketing success, or for our company's perceived, really the use of a woman's talents. It's to get the most for the longest time, right? Isn't that what it's about? Don't have a child now, or don't get into that process, because we may or may not want to support that with other things; with proper child care, maternity leave, you know,

which is a whole other conversation. So moving around that and saying, well, you can do it later, well, you might not be in that company when that happens. So it won't be their problem. It's a real hands-off, proposed solution all the way around, is what I understand.

**Pamela Mahoney Tsigdinos 48:03**

It is. I mean, they're selling a promise, and the company is only on the front end. They're not on the back end. The company probably won't be involved, once that woman is ready to have a child. It's interesting to me to think about any number of folks in Silicon Valley, who move jobs pretty frequently. So once you've left that job, what's going on with those eggs on ice, because you've got to pay to store those. And so there's a whole bunch of issues that obviously we could talk about forever.

**Christine Erickson 48:37**

Yeah, absolutely. I just think the layers, even if we can get the base information, more clearly for people and ahead of time, rather than, you know, in the moment of decision; these are deeply personal decisions, and long processes, even when they are successful. It's not generally a one off, as I understand it. So it's the commitment financially, emotionally, physically and relationally, depending on your personal situation. It impacts all of that long term while you're in it, and when you come out of it. And as you said, if you could have seen the example of your own experience then. Thank you for sharing your own experience with whoever wants access to it through your wonderful writing and books and your continued research and bringing this together and expressing it today so beautifully in a way that can be understood from the history of it to what is happening today. The policy changes and the oversight that are needed, we need to be talking about this collectively. And for consumers there needs to be representation so the people who can't come forward, who were traumatized, harmed, disappointed, in grief, that they can be represented so that they're behind that. They don't have to be in the front of it, it's not a fair ask. But those who can such as yourself, how do we support that whether we've had that experience or not? We really need to come together on this because it's dangerous. It's dangerous.

**Pamela Mahoney Tsigdinos 50:19**

It is, and ultimately, you know, the world these days is so remarkably complicated. And there are so many immediate issues grabbing headlines from wars and climate change and plagues and pandemics. You know, this has clearly been a long-standing set of problems. It's been decades in the making, and it will take some time to get it right. But I think it's incumbent upon people in my generation, I'm now in my mid 50s, to figure out how to bring this information forward. Because I worry about my nieces, I worry about my nephews, and I don't want them to have to experience what I've experienced.

**Christine Erickson 51:05**

Absolutely, yeah, I was thinking of that, too, while you're speaking, just imaging people in my life, you know, in those generations, at those ages, and I'm like, do they know? Are they aware? Well, I really want people to know where they can find your work. And, you know, if you want to speak a little bit about your books, your other work and your website, things like that, so people know where to find you. And you know, what you're focusing on now and what you might be heading toward, if there's anything you want to share about that?

**Pamela Mahoney Tsigdinos 51:38**

Yeah, so most of my work is available at [silentsorority.com](http://silentsorority.com). and you'll find there are links to other research and writing, and such. I've also done some, talks.

And I want to address one other element of this. And that is, once people have gone through this really traumatizing experience, there is a need for the rest of society to figure out how to be more respectful, and acknowledge that this was a particularly trying and difficult experience, rather than leap to judgment, rather than provide a lot of platitudes, and ultimately make suggestions that are not necessarily in the best interest of the individuals, myself included. I can't tell you the number of times people have said to me, "Well, why didn't you just adapt?", as if there are babies on standby right now, if you call the 1- 800 number, you can get one delivered tomorrow. And there is ultimately, I think, a need within society to accept that there is a very large slice of the population, that for millennia, have had difficulty conceiving 8% to 10% of the population, at any given time in any century, has always had some issue with conceiving. This is not new. But society has never made a space for people who don't have children. It's always a question of assuming

that they were making selfish decisions that put their own interests ahead of a family. Or there are assumptions about the fact that somehow, we're defective. And we don't yet we're not as valued. We don't bring any worth to society. And I find that negative set of stereotypes ends up creating an environment, where individuals like myself, who are coming out of the medical side of things, then have to face the social prejudices, and wrongheaded assumptions about how my life unfolded. I started trying to conceive in my late 20s. It didn't work. So you know, those are things that I think your listeners can take away from this. Make space for people whose lives do not look like yours. And there are a lot of us out there. I know, Christine, you can speak to percentages. I think we're representing something like 25% of women. It's not a small number.

**Christine Erickson 51:39**

Yeah. And it's growing in some other countries up to one in three, and the demographic is growing overall, of people without children. And yes, we don't need to other, each other. Everyone has a life experience and it's valuable. And thank you for what you are doing with your life and all that you have given to this and you know, coming out of such a devastating experience. Thank you for being with us here today. Please follow up with us on any of our platforms, visit Pamela's website, read her books. They are powerful. And we will speak with you again next week. Continue the conversation, okay? Bye-bye.

**VoiceAmerica 55:13**

Thank you for listening to New Legacy Radio. We hope Christine and her guests have given you the context and insight to connect with our community in new ways. What personal or professional change might you consider to acknowledge and include our diverse community of people without children? Until we speak again, we invite you to engage with us on any of our platforms.