

## Family Building Using Assisted Reproductive Techniques (ART) : Legal Aspects

A modern couple has various options to build their family at their choice of time with the advent of ground breaking reproductive technologies made available by our scientific fraternity. For either medical or non medical reasons, more and more couples are choosing assisted family building using assisted reproductive techniques (ART) like the use of donor eggs, donor embryos, donor sperms, or surrogacy. However, this assistance comes with its own share of legal issues, which everyone involved should be aware of. We are having New York licensed attorney Amy Demma; Founder of Gifted Journeys – an egg donation and surrogacy agency – Wendie Wilson Miller; Founder of The Center for Egg Options Nancy Block; and ‘Eggspiration Date’ author/blogger Alia Paige, to discuss questions related to legal aspects of assisted family building.

### Full Transcript:

**Shweta Mishra** – Hello and welcome, everybody. Welcome to CureTalks. I am Shweta Mishra, your host, joining you from India; and today on this 108th episode of CureTalks, we are going to discuss about the legal aspects of assisted family building using artificial reproductive techniques. Assisted reproductive technologies have aided a modern day couple's choice to start a family at their own preferred time in life. Techniques involving the use of donated egg, sperm, or embryo or those like surrogacy have helped many couples successfully build their family; however, if not dealt with cautiously, these technologies also hold the potential to destruct families emotionally and physically as they can give rise to their own share of legal issues, issues like who would get the custody of the frozen embryos if a couple divorces; issues pertaining to the legal rights of the surrogate, the sperm donor, the embryo donor, or the egg donor; or issues arising out in cases of a disagreement between the intended parent and the third party involved. Due to such social and emotional complexities involved in the process of assisted family building, it becomes imperative for all the stakeholders to be educated about the associated legal aspects in order to be well equipped to take informed decision.

**Shweta Mishra** – Today, on this show, we have with us our eminent guests, Amy Demma, Wendie Wilson Miller, Nancy Block, and Alia Paige to discuss questions related to the legal issues entailing assisted family building. Earlier, Amy was with us at CureTalks last year to discuss about the options available for the use of remaining embryos left after successful IVF cycle. Amy Demma is a New York licensed attorney and founder of Law Offices of Amy Demma, providing services to those engaged in assisted family building, specifically egg, embryo, and known sperm donation as well as compassionate surrogacy. Amy is actively engaged in many infertility patient advocacy groups and non-profit and professional organizations. She served for many years as Vice-President on the Board of RESOLVE New England and in 2012 completed her tenure as President of the Board of Directors at RESOLVE New England. Amy is an admitted fellow to the American Academy of Assisted Reproductive Technology attorney and an active member of the legal professionals' group at the American Society of Reproductive Medicine. She is the legal adviser to parents via egg donation and to the society of ethics in egg donation and surrogacy.

**Shweta Mishra** – We also have Wendie Wilson Miller who has been working in the field of assisted reproduction for over 16 years. An egg donor herself, she is the Founder and Co-founder of several profit and non-profit organizations, which include Gifted Journeys, The Society for Ethics in Egg Donation and Surrogacy, Fit-4-Fertility, Nest, and Nest – Egg Fertility. She also co-wrote a book titled “The Insider's Side to Egg Donation,” a compassionate and comprehensive guide for all parents to be, which won a gold medal, Ben Franklin Award in 2013 for its LGBT chapter. Wendie is also an executive sports member of Parents Via Egg Donation and The American Society of Reproductive Medicine's LGBTQ Special Interest Group.

**Shweta Mishra** – Nancy Block, on the panel, is the Vice-President of International and Major Client Relation



at the Fertility SOURCE Company. She founded the Center for Egg Options in 2000, an agency specializing in gestational surrogacy and egg donation, now acquired by the Fertility Source Company. At the Center for Egg Options, Nancy managed over 2,300 matches, made with intended couples, their intended pairing couples, singles, and same-sex couples worldwide. Prior to opening the Center for Egg Options, Nancy spent 17 years as a nurse, staff educator, or resource coordinator at the OB unit, Northwestern Memorial Hospital Prentice Women's Pavilion. Today, Nancy is a national spokesperson and guest speaker for many events in the infertility industry and sits on the board of Parents Via Egg Donation as well as The Society For Ethics In Egg Donation And Surrogacy.

**Shweta Mishra** – My co-host for today's show is Alia Paige, who is a speaker, an author, and who blogs at eggspirationdate.com. She is working to educate women regarding their limited reproductive lifespan and how to beat their eggspiration date. Alia and her friends who have personal experience with assisted reproductive technology procedures and selecting a fertility center started this blog to provide friendly and easy-to-understand information about preserving female fertility. They aim to educate people from the girlfriend's perspective. I welcome you all to this show today, and I extend a hearty welcome to all our listeners; and before we begin, I would like to remind our listeners that we will be discussing questions sent in via email at the end of the show. You can also..., you can email your questions to priya@trialx.com and if you want to ask a question live, please press 1 on your keypad and we will bring you on air to ask them or you can also post your questions on CureTalks' website as you listen.

**Shweta Mishra** – Now, let me begin this discussion by asking a very highly debated question to Amy that even the courts have struggled to answer and that is about defining an embryo. Now, what is the definition of an embryo in legal terms, Amy, and is an embryo considered a child?

**Amy Demma** – Good afternoon! Good evening! Hello to all of my colleagues who are participating in this wonderful discussion this evening and welcome, welcome, welcome to all of our listeners. Thank you so much, Shweta, for this wonderful opportunity to address these current issues. Before I start, I want to be sure that your listeners understand that the matters that we are discussing today, while there are some universal standards, we are talking about matters that are specific to the United States. So, I will be providing general information from my many years of working in here, but the takeaway from this must be that anything which is destroyable and within legal aspects of assisted family building should be speaking with an attorney licensed in their state. So, let me just throw out two folks to get more specific paid, centric information available to them. So, the American Bar Association has a committee of attorneys that do the work that we do and one can access their members to find an attorney licensed from the same which a patient list or a surrogate or a donor list and also, the American Academy Of Assisted Reproductive Technology attorneys also has a directory. So, listeners should take note tonight and learn much, I hope, from Wendie, Alia, Nancy, and myself, but also understand that with respect to specific matters, one needs to understand the law in their state.

**Amy Demma** – So, with respect to embryo, the defining of an embryo, we actually go to Tennessee, that's where we are going to start our discussion. In 1992, there was the first ever Supreme court, paid Supreme court analysis of what an embryo is. The ruling in that...case was Davis versus Davis. The ruling in that case is relied upon today and essentially and this was a marriage dissolution case where there were, in fact, frozen embryos, remaining embryos and the parties were fighting over the ultimate disposition of these embryos and the Tennessee Supreme court held in 1992 that embryos are property entitled only to be handled in a careful manner and that embryos occupy an interim position, entitling them to special respect because of their potential for human life and that's where I underline that statement, because they are central for human life. They are not even life, they are not frozen, but they are more than just property because of this potential for human life. Now, just recently in California, we had a very important case, the Findley case, which I'll talk about later and the Findley case basically said the same thing some 14 years later, actually some 24 years later, that Davis said, and the Findley court said, embryos are not property, nor are they fully formed human being. So, whatever the phase is between property and human being is a very vague area where embryos reside, but if your listeners and my colleagues can take away this notion of embryos having the potential for human life, I think that's the better understanding of what an embryo is.



**Shweta Mishra** – Okay. Thank you so much for your answer, Amy. Let us..., let us move to some legal..., talk about legal considerations around the modern fertility patients. Have the legal considerations evolved as a profile of the modern fertility patient has evolved and have the courts in the US evolved in the ruling on assisted family building matters? And how have the other countries responded basically to the modern fertility patient?

**Amy Demma** – Yeah. So, I will answer this from the legal perspective, but I would love for my colleagues, Wendie and Nancy, to also share their perspectives on the modern fertility patients is different from mine and that we respond to different needs of the patient. So, I'll answer your last question first. Globally, frankly, I don't see much that's encouraging. Globally, there are such tremendous barriers. There is a significant lack of legal infrastructure around assisted family building in many, many countries around the world. I am going to suggest that perhaps the United States is the most progressive in the way we provide services to those hoping for baby and needing assistance. So, there's certainly no universal statement that I can make, and I certainly hope that what we are doing here in the US can be influential globally. The modern family building effort from a legal perspective is really very interesting in terms of the modern family structures. So, we..., we not only have same-sex couples who are attempting family building. It was something that was relatively rare when I entered the field. We also have single persons who are pursuing parenting on their own, either with their own gametes and a donor or the use of donor or embryos, so that's the profile of the modern single..., of the modern fertility patient from my perspective. The law, however, has moved rather slowly and the law has moved rather consistently with respect to things like embryo disposition. We'll get into that later in the discussion. We'll talk about some high-profile cases involving celebrities. The two cases that I just referenced, both the Davis and the Findley case, do not involve celebrities. They ended up being high profile relatively speaking from the media, but the courts have been slow, the courts have been conservative, and the courts have been consistent with some exceptions and we'll talk about those exceptions.

**Shweta Mishra** – All right. Okay. Okay. Let me.... Let me just hand it over to Alia now for..., to take this discussion forward. Alia, are you there?

**Alia Paige** – Yes. Sure, I am. Thanks so much, Shweta. I appreciate it. So, Amy, just have...

**Shweta Mishra** – All right.

**Alia Paige** – ....some question. Just to make sure that our listeners have a really clear baseline understanding of the concepts that we are discussing today. Let's just start out with having you define what is informed consent and also, what are the typical questions that a patient may have to answer in order to give informed consent?

**[00:13:58] Amy Demma**- Okay. As I was preparing for our lovely talk this afternoon, I went in two directions in..., in..., in terms of providing comprehensive responses to these questions. I want to be sure that we understand that informed consent is actually a different issue than embryo disposition directive signed at clinic. So, I will answer your..., your question, first about informed consent and then we can talk about these embryo disposition directive that tends to be at the core of the cases that I am going to be referring to today. For the most part, we don't see assisted family building matters ending up in court, I am happy to say. Typically when they do, it is the parties who came together to create the embryo who have had some sort of change in status. So, two parties come into a clinic with the intention to get a family as a result of technology, embryos are created and..., and they will fill out certain documents at that clinic. Sometimes that relationship dissolves. We end up in court and that's where we are getting our..., our..., our case log that we rely on for counseling client.

**Amy Demma** – Informed consent is something different. So, informed consent is a document that almost any patient in the United States, hopefully every patient in the United States, will be submitting to a physician for a medical procedure will sign prior to engaging in the procedure. Essentially, an informed consent is a document that states that the patient has full knowledge of risks and benefits and..., and..., and..., and..., and



these consents can be anything from one page to I have seen consents that are 25 pages at fertility clinic. There are not... There is not a universal informed consent that is used at infertility clinics, but I will share with you that the Society for the..., for the Assisted Reproductive Technology, the society, the assisted reproductive technology, SART, has, in fact, issued a model informed consent form through its clinic members. That model informed consent form is widely used, and I took a quick look last night at their model egg donation informed consent form and its 22 pages. So, there are..., informed consents are bulky documents that address the procedure that the patient is presenting for, the risks related to the procedure that the patient is presenting for, statistics related to those..., to those risks, that can address things like short-term risk, long-term risk, pain, discomfort. In the SART, egg donation, model egg donor consent form, there were even matters of psychological and mental health issues addressed, lifestyle issues addressed, financial issues addressed. An informed consent should be that comprehensive. It should give the patient everything he or she needs to know to balance thoroughly in an informed and knowing way to see forward. Again, that form is different from the embryos disposition form.

**Alia Paige-** Okay. Thank you so much for clearing that up. I appreciate that, Amy. So, as far as the embryo directive consent and those sort of shared consents, what should a patient do if their spouse or partner is not in agreement with some aspect of the consents that are being signed?

**Amy Demma-** Yeah. Okay. So, I made reference before to a California case, the Findley case, that just was resolved within the last several months. Findley was a divorce case, Mr. and Mrs. created embryos prior to the wife, her name is Mimi Lee, prior to Ms. Lee being diagnosed with cancer. Eventually, the marriage dissolved. Mimi Lee only had those embryos as an opportunity to fill the family with her own genetic material despite the dissolution of the marriage, who went to her husband in..., in hopes that he would agree to allow her to use the embryos. He refused to allow her to use the embryos and litigation ensued. One of the matters that the Findley court looked at and this is the most recent ruling we have here in the United States, there is a current law. One of the matters that the Findley court looked at was whether or not the embryo disposition directive that they signed at the clinic was in fact legally enforceable and the Findley case, in fact, tells that these contracts are binding between the parties. So, embryo disposition directive forms, assuming that its not a faulty or flawed form and we will talk about a faulty or flawed embryo disposition directive when we discuss the Sofia Vergara case, but assuming that the document is as it needs to be and meets all the standards for legally enforceable document, the court held that this was a binding agreement between these two soon-to-be divorced folks and so I would say to a party who comes to me and says, I don't agree, my emphatic directive would be, do not proceed, do not sign. These embryo disposition directives will be enforced in court unless, of course, there is some flaw in the..., in the form and so you are entering into a signed agreement. You are signing rather a legally enforceable agreement and you will be bound by it. So, if you are not in agreement with your partner about embryo disposition, please seek the support of a mental health counselor who will help you work through your differences of views.

**Alia Paige-** Okay. That's just really sound advice. You know, its interesting. Back in 2011 when I froze my eggs, the forms that I was provided and signed were actually for IVF procedure. They didn't have forms at that point in time for vitrification or egg freezing. Its just, you know, it just wasn't being done at that time. So, I also know of several other legal cases where same-sex couples, for instance, have decided to have one partner provide the egg and the other carry the pregnancy; however, their paperwork at the clinic that they went to was not specifically for their situation. So, in..., in those kinds of cases, what should a patient do if the practice they are going to does not have legal documentation to address their particular fertility plan?

**Amy Demma-** Yeah, so, I hear those as two separate questions and let's address the first. A party goes in to any medical facility for a particular procedure and is asked to sign a consent form that is not reflective of that particular procedure. Again, I would emphatically counsel a client not to sign that document and in fact, I would argue, I think there is just one legal argument to be made that informed consent was, in fact, not given. Informed consent is indicated by signature on that form. If that form is not addressing the particular procedure that you are going to receive from the medical provider, you are signing a form for a different procedure will not be informed consent. So, I am certainly hoping that clinics that are now providing oocyte cryopreservation have updated their consent form.



**Amy Demma-** The second is a little more tricky. First of all, I will share that I..., I read an article quite recently and it was just..., I read a lovely, lovely statistic. Apparently, there is an entity in the United States called The Human Rights Campaign Foundation; and in a recent finding, The Human Rights Campaign Foundation found 500 US fertility centers to be the leaders in LGBT healthcare equality. That is quite a bit encouraging. So, if I had a client that came in to me, a same-sex couple, and if my clinic doesn't have people work that reflect modern family building, I might be going to advise them to consider working with another clinic. If we have 500 clinics in the United States that are leading the standard of LGBT healthcare leadership, other clinics would follow that leadership. Having said that, that would be my advice that that clinic may not be the best place for the same-sex couple if they are not accommodating the unique needs of that same-sex couple. Having said that, it is not as concerning to me if two women sign an otherwise comprehensive consent form and one of them signs on the line that says father or husband or male. I am not as concerned about that, don't think that's going to disrupt the enforceability of those documents. I am... I think its a matter of..., frankly, its a..., its a..., its a personal or perhaps an ego issue if you can get past that and sign a form that doesn't indicate your particular gender, for example. If patient really loved this doctor and he really loved this clinic and he wants to work with them, then I would support that, but I would also have the bigger discussion of possibly working within a clinic where the culture is much more progressive and accommodating to the modern family.

**Alia Paige-** Makes sense. So, you know, you kind of referenced this a bit earlier. There have been several celebrities that have been in the news regarding their various fertility battles. We have had Sherri Shepherd and her, I believe, now ex-husband separated during their donor egg in a surrogate pregnancy. We also had Sofia Vergara and her ex-boyfriend separated while having frozen embryo stored. Will we continue to see more of these legal battles in the news and is this a reflection of our society in general?

**Amy Demma-** We know the matter of media coverage and I look forward to hearing both Wendie and Nancy's input on this, I think is a..., is a reflection of a..., of a culture that we are seeing now here in the States. There is a particular push for whether its just interest. There are conservative, political agenda being pursued. Our media tends to find those issues quite interesting. There is a lot of controversy around assisted family building. So, I think we are going to hear more of the cases in the media. I think these cases sell magazines and, you know, capture the interest of the general public. So, unfortunately, I think the media exposure may, in fact, be on the uprise. Do I think that necessarily is a reflection and an uptick in litigation around assisted family building, I do not. I think that my law colleague and myself are more committed than ever to establishing their practices and more committed than ever to educating and partnering with medical and mental health colleague to be sure that we are proceeding in a manner that is safe and protective of all parties including a child, by the way. So, I don't think that we are in a..., at a place or time where we are going to see an increase in litigation, but I do think we may, in fact, see much more mainstream media coverage of these things simply because they capture the general population.

**Alia Paige-** Sure. Its definitely salacious. That's for sure. So, Wendie, what is your feedback and..., and thoughts in reference to how this is changing in our society in general?

**Wendie Wilson Miller-** I am... I am going to have to agree with Amy on a lot of it. I think a lot of it is..., is the media exposure, but where I can jump in on it and..., and talk a little bit about the organization that I co-founded with some other colleagues, The Society for Ethics in Egg Donation and Surrogacy, is kind of another response to a lot of the..., the media coverage you are getting, but its not just the media coverage. Its..., its what we are hearing in general. You know, whether that be in social media or any other areas that we are getting the feedback from our community. So, the response really is, how can we really streamline this industry? How can we reply and a tone of solidarity and also on behalf of our surrogates, of our egg donors, of our intended parents who are about to start this process. So, I think its really causing most of us to come together and create something that makes this a safer environment for intended parents, but I agree with Amy. I don't think its going to go away. I think its..., those type of stories sell and because this is something that more and more people are accessing, we are going to hear more in the future. Yeah.

**Alia Paige-** Nancy, did you want to share any of your thoughts in reference to this?





**Nancy Block** – Well, I have to agree with Amy and Wendie. I think social media has brought the topic to the forefront and its very interesting because when I first started, which was about 16 years ago, people didn't have the internet information that they have. They didn't have the social media information. We didn't even start with a website. So, people didn't really see what they needed to see from the internet or a web-based platform. They had to come in and meet with us and be face to face and talk with us what their needs were and how we could help them. So, it has evolved, it has changed and I think, you know, in some cases, for the better, because its bringing the topic to the forefront, but I think in other cases, the media hides with a lot of the negative situations and scenarios that have occurred aren't helping the industry either.

**Alia Paige-** Okay. Yeah and I totally agree with that. You know, this concept of intended parents, its specifically defined as people who want to have children but are not able to use conventional methods to achieve success. So, Wendie, with that said, what does the intended parent in advanced fertility look like in 2016?

**Wendie Wilson Miller-** Oh, I think its..., its really..., its really changed certainly since I started in the industry in 2000. So, there is..., there's certainly been quite a few changes in the last 16-1/2 years. Initially, when I started, pretty much all of the paperwork, anything that we talked about, the websites that you would see were always more focused on traditional couples, although I am not even sure that's a camouflage to the current family landscape, but like married male and female relationships mostly in the United States, whereas now I would say that nearly 50% of my business and I would say that quite a big percentage of most of my colleagues as well also work with people internationally and, you know, about another 30% same-sex couples. So, that's both international and domestic. So... Another thing that I have noticed and another change is that I am also seeing a lot more single fathers than ever before. Early on when I started in this industry, there were some agencies that wouldn't even work with single fathers because they felt that egg donors would have adverse reactions or..., or surrogates, whereas now that stigma is definitely changing and has changed quite a bit and I would also say how we label family in general through the agencies is the main change that I have seen from when I first started. So, most of our professionals now use the term, you hear this a lot in our industry, love makes a family, which is not only true, but its a far more inclusive to..., to the many different types of families that we see.

**Alia Paige-** Its awesome! Nancy, what has your experience like..., been like as far as how the profile of the intended parent has changed over the years?

**Nancy Block-** I would definitely say we have far more educated intended parents, more international, more same-sex couples. I think some of the cases are more predictable, but I think they are also at the same time more complicated because we can't..., we can't say that automatically when a client comes in, they are going to need to work with a donor and a surrogate. We will have to educate them. We will have to find out what their history is. I think patients though, by and large, are somewhat more educated than they used to be.

**Alia Paige-** So, you know, we all obviously know that this is 2016 and social media is how we promote pretty much anything where we want to reach a wide range of people, but, you know, Nancy, how has social media impacted the process of sourcing information and people for egg donation and for gestational surrogacy, like I say, other kind of bigger, broader question that I am sure some of our listeners want to know is how do intended parents know who to trust?

**Wendie Wilson Miller-** I am sorry. I just had to take a break. Is this question for Nancy?

**Alia Paige-** Yes. Yeah, it is.

**Wendie Wilson Miller-** I am sorry.

**Nancy Block-** I am going to start with the last question first, who to..., how do we know who to trust. That's a..., that's a really..., that's a broad... I can answer this in probably multiple hours, but I think that its very



important to talk to as many people as you are capable of talking to that are experts in the industry. Social media is certainly not always a reliable source of education and certainly not always a reliable platform to get information from that may or may not be trustworthy. I think talking to your doctor's office, talking to those people that you trust. I certainly think referrals are helpful, references are very helpful. I think talking to your colleagues. Wendie and I and Amy have known each other for a long time. We are all over the United States, but we do constantly talk to each other to find out what's new or who is new, what's going on in their section of the world, what's going on in our section of the world. Even though I am a nurse, Amy is an attorney, Wendie is also in the industry, you know, we are all in different levels, but we all still work together and I think its valuable to be able to communicate with your colleagues to make everybody's experience as best as possible.

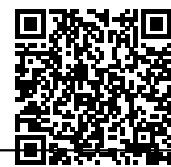
**Alia Paige-** Wendie, what has your experience been like with the incorporation of social media?

**Wendie Wilson Miller-** I think social media has..., has been both very good, almost invaluable in some cases as a source of information and education. It allows people to hear other people's experiences, who they've worked with, what the ups and downs of this journey can be, hear other people's feedback on agencies and clinics, and..., and just kind of in general become a little bit more educated, but because it is social media, obviously there's another place, there is..., there is more public shaming, there are some aggressive opinions. Some are subjected to obvious bias and, of course, there could be misinformation because you are really not always hearing back from professionals. You are just hearing other people in..., in some of the support groups. So, I think..., I think that the..., the benefits definitely outweigh the negatives when it comes to social media as a..., as a source for information, especially when it comes to the support groups, but I think if I could give advice to intended parents first going through the process and really wanting to research would be to seek out some of the non-profit groups, such as RESOLVE or PVED, Parents Via Egg Donation, contacting SEEDS and we can put people in..., in contact with various other people in the industry and as Nancy said, as well talking to the physicians and the nurses because they have often had a lot of experience with agencies if it comes to agencies, then of course agencies and other people on the support groups would have feedback regarding the physicians.

**Alia Paige-** Yeah. You know, Nancy, I guess, just as far as some of the advice, but what are some of the most important facts to consider when a couple or intended parents are selecting a reproductive endocrinology or an infertility practice and, you know, even though can feel really intimidating, what questions should intended parents need to make sure they ask the reproductive endocrinologist?

**Nancy Block-** Okay, I will go in order. I think its very helpful to get correct statistics from your fertility center. Many of the statistics that are posted on SARM..., I mean ASRM and SART are three years old. So, they're..., they are a little bit older. So, its always good when you do make your first phone call to ask the person that you speak with, what their current steps are for use with an egg donor or surrogate or both depending on what they perhaps need or based on their age. I think its important to have an office that's acceptable for you. Hours are really important. Everybody works crazy hours, many offices open up early before most people have to go to work. If you are an insurance-mandated state, that is, if your insurance will help pay for some of your IVF treatments, I think its good to know if they accept your insurance and appointment wait times. Its also important that they seem to be organized and responsive.

**Nancy Block-** I think its really important when you go to a doctor, not to be tongue tied. Its..., its very important to ask questions that you need to ask when you are there because you have such little time with your physicians these days that you need to get out what your points are. So, I think its important to know how long your first appointment will be, what will the first appointment entail. Do they get to meet the doctor at their first appointment? How many times will they have to come in? Will you verify if insurance covers any of the testing? Some patients will have to go to their OB for some of the testing, which many patients, women obviously, don't know until they get there. So, there would be another appointment that they would have to go for before they get answers and followup calls. Who makes followup calls? Is it the nurse? Is it the doctor, or is it via email? I think in this day and age when patients, like I said, have few moments with their doctors, its important to get as many answers as possible that first time or even before the first time they go



in.

**Alia Paige-** That's a really great question and I wish I..., wish I would have talked to you before I started my process. So, you know, just sort of really looking at the industry itself, Wendie, what do you think are the advantages and even disadvantages to embryo donation and do you think that this is a real viable option for most intended parents?

**Wendie Wilson Miller-** I will start with the advantages for embryo donation. At this point, I would say the number 1 advantage would be the cost of the process. They are going to save significantly on..., on that because they are not going to be paying for donor egg or donor sperm and, you know, I..., I would say it probably saves them somewhere in the thousands and in most cases, I would say at least at this point, with embryo donation, there have been previous successful pregnancies achieved with the embryos. So, in most cases, I would say they are probably more or less proven..., proven embryos. So, there is some comfort knowing that there is a good chance to have a viable pregnancy. The disadvantages, more than anything, is probably information, that and choice. So, information..., information and choice would be the..., the biggest disadvantages. With an egg donor or sperm donor, you have a lot of opportunity to choose both the health history, what someone may look like if they..., if there is somebody that you feel you connect to and that's not always going to be the case with embryo donation, less likely of a chance for there to be future contact with embryo donation. There could be centers that hold embryos that oversee this, but a lot of times, people do embryo donation through their actual clinic. So, there would be less information that way. So, those, I would say, are the main advantages and..., and disadvantages and do I..., the other question is, do I think that this is a viable option for parents in the future?

**Alia Paige-** Yes.

**Wendie Wilson Miller-** I think what we want to be careful is not to get into embryo creation, which is probably we could do a whole other show on and there is a bit of controversy about that in our industry as a whole, but I think..., I think it is a viable option because there are several intended parents that I work with, who over the years, have come back to me and asked if I know of anyone who would want to use any of their leftover embryos and they didn't feel like they wanted to destroy them, especially when they had children through those same genetic connections. So, they felt very..., they felt that it was very important to give someone else the opportunity to do that, but you have to go back to in that situation, what did the..., what legal contracts did the donor sign because its about 50-50 and half the cases will go back and will read the legal contract and the donor will clearly state that she doesn't want the..., any of her eggs to go to anyone other than..., than the intended parent she agreed to and in the other half typically say its fine. In most cases, they want to at least be informed if the embryos have been donated. So, I think its a viable option. Do I think its going to be the number 1 option? No, I don't think so.

**Alia Paige-** Okay. You know, I personally followed a very secured circuitous path to fertility success, which included two rounds of IUI and two rounds of IVF and ultimately we did not have to use a donor; however, I have to believe that using donor sperm or a donor egg or even donor embryo or using a gestational carrier can be a very difficult thing emotionally to personally manage. Nancy, how..., can you share with our listeners how you counsel people and work through these difficult issues with them?

**Nancy Block-** I think not having gone through fertility issues myself, I had suffered multiple miscarriages, but I..., I didn't go through fertility or the same fertility issues that many of our clients go through. I do think that there are emotional ups and down when we work with clients who are considering egg donation, sperm donor, and a surrogate or all of the above. There have been clients who have come to us, who I didn't feel were really ready to proceed. They came in teary. They talked to me on the phone teary. They..., they really weren't ready to proceed and I do tell clients, patients, that when they consider working with a donor, most people aren't a 100% sold on the idea. Most people even going through the process aren't a 100% until they see their baby. So, its okay if you are not a 100% into the thoughts needing to work with an egg donor or a surrogate. We do understand its maybe you have very good alternatives, but not everybody is ready. So, some people need to go through either their grieving process or they need to go through additional steps





before they can move on to the next step, which would be using a donor and/or surrogate. We also give referrals for intended parents to talk to other intended parents who are, like I say, on the fence about their decision to work with someone. I have never had intended parents who have ever said that they have regretted their decision. Multiple intended parents have said that they have felt that they wish they'd come to these conclusions sooner and started this process sooner, but I tell them, really until you go through certain phases of fertility treatment, you may not be able to move on to the next phase and that's okay.

**Alia Paige-** And that was definitely my own personal experience as well. I really appreciate that. Wendie, how..., do you have any thoughts about like you would counsel people working through these same issues?

**Wendie Wilson Miller-** Yeah. There is a couple responses I have to that. One of the things that all of us realize when we work in agencies is that the people that are coming to us are often times experiencing grief and letting go of their own biological connection, while at the same time keeping that energy and hope alive with us to move forward with their family and it's our job to the best of our ability to be able to know when they are ready to move forward and when they need a little additional support, when to suggest that they speak with a mental health professional, specifically who works in this industry so that they know and feel informed about what the process of assisted reproduction, egg donation, surrogacy is like and to be prepared for it. I am with Nancy. I..., I haven't personally gone through assisted reproduction. So, I can only go by my experience, my colleagues in the industry, our mental health professionals, and pretty much, you know, others who..., who really discuss with us what people need and how we can support them as an agency and how not to push them through when they aren't ready.

**Alia Paige-** There's another... Go ahead, sorry.

**Nancy Block –** I am sorry. It's Nancy. I think there is one more key piece. As a patient, you want to feel that you have some control. As a client, you want to feel that you have some control. So, I think it's really helpful to give our clients the ability to make their choices and I think we all do that and assist them and support them as they go through and I think mental health professionals do a great job in working with patients.

**Amy Demma –** I have something to add as a followup to both Nancy and Wendie, in that really the best strategy in moving through this really emotionally, psychologically, often spiritually complex journey is to build a proper chain. There are so many different disciplines that one can bring to one's family building, assisted family building. Obviously, we are going to need medical professionals. In many cases but not all, we will need legal professionals. I think a valuable part of the team is our mental health community. I see the mental health..., our mental health colleagues being as integral in the process as the medical team and then after some support from the various consumer advocacy groups like PVED, like RESOLVE, like Path2Parenthood, so resources are out there and I think one of the reasons why Nancy, Wendie and I were so willing to participate tonight is because the role of an advocate as part of the role of team advocacy is raising awareness. So, if folks are out there who are feeling disconnected, lost, confused, worried, afraid, please know that there are folks who have walked the path that you have. I had my own fertility journey with putting together a team that would provide the resources that you need really is the best strategy.

**Alia Paige-** Definitely agree with that. You know, any... One other question is, you know, for those intended parents that are fortunate enough to be successful, a pretty typical, ethical issue that those individuals have to consider is, you know, what to do with the eggs or sperm or specifically embryos that are left after they are successful? What are the options for patients in this situation and any specific considerations as well?

**Amy Demma-** Well, the option as the patient who has created the embryo are as follows: One could choose to have or cryopreserved gamete. One could choose to have literally cryopreserved. As long as you are willing to pay storage fees and likely have to move your embryos from storage facility to storage facility because they will only, typically only hold the embryos for a certain amount of time. By the way, the amount of time that they will store embryos should also be referenced in that embryo disposition directive form we have been talking about. So, the patient should be put on notice as to how long the clinic will keep the



embryos frozen before they will have to make a next decision about how they are intended to be used. So, obviously using them for their own family building is an option. Keeping them perpetually frozen is an option. Those are two options that are least appealing, it seems, to clients. The folks who have to resolve residual or remaining cryopreserved material tend to either consider thaw and discard, donation for research, either fertility-related research or other medical and scientific research, or donation to a third party for family building that wonderful, wonderful family building option called embryo donation we were just talking about. I am a huge proponent of embryo donation. I think families who would have been quite out of assisted family building have come to be because of the generosity of those who have chosen to pass along their remaining embryos, but the options are keep the frozen, discard and thaw, donation for research and donation to the third party. There is another option, rarely kept as an option, when women can have an embryo transferred at a time when she is unlikely to become pregnant. I don't hear too many clinics that are doing that and I know even fewer patients for whom that's an appealing option.

**Alia Paige** – Yeah. I completely agree. You know, embryo donation is just..., its..., its such a gift that people are sometimes brave enough to..., to give and so I completely agree with that and just also for our listeners, cryopreservation is essentially freezing the embryos for storage also. Okay. At this point in time, I am going to transfer this back to Shweta for listener's calls.

**Shweta Mishra** – All right. Thank you, Alia. We have some listener's questions. I will just read them out. What kind of agreement needs to be done between intended parent and embryo donors regarding anonymity? Does the donor have the right to know who is going to use their embryos and also maintain contact with them as long as they desire to? I guess, Amy, can you answer that question please?

**Amy Demma** – Sure and let's just be clear, when we use the..., the reference donor in an embryo donation, we also had to consider whether or not there was an egg donor used to create the embryos. So, the embryo donors may not, in fact, be those who provided the gametes to create the embryos. Wendie....

**Shweta Mishra** – All right.

**Amy Demma** – ....seriously...., seriously addressed that early on and I don't want to repeat because Wendie really nailed it, but if in fact there is an egg donor involved in the creation of the embryos that could be donated, we may need to go back to inform that egg donor that the embryos are being donated. If, in fact, the parties who are donating the embryos are the progenerators or the providers of the gametes, they provided the egg and they provided the sperm to release the embryo. There are no rights... There are no legal rights, so to speak, that entitle the donor to information about the recipient. What a party who was considering embryo donation can do is shop around from facility to facility, from clinic to clinic, from program to program as these programs do really vary and kind of program that sticks and feels good to them. So, I have some medical colleagues who do embryo donation through their clinic and they run a short-term anonymous program. The parties know nothing about each other and there is no exchange of contact information and no anticipation of future contact. That's one way of doing embryo donation. It is not the only way of doing embryo donation. At my office, I maintain embryo donation agreement to the known party that had some intention of some sort of future contact or needing exchange of contact information. So, there are lots of options for folks who are considering donating and lots of options for folks who are receiving donated embryos.

**Shweta Mishra** – Yeah. All right. Thank you so much for your answer. The next question that the listeners ask is, what new laws are being framed to avoid the increasingly complex legal issues arising due to more and more people deciding to create embryos and then separating?

**Amy Demma** – Yeah. So, I don't know of too much legislation, state law, or certainly any federal legislation that is thinking about embryos in that context. There may be attending law out there, I am just not aware. A law that we have..., the legislation that we have out there related to embryos tends to move in a very conservative direction of wanting to define embryos as person and that's a..., a..., a very complex and..., and..., and..., and..., and a different discussion..., discussion that we were having. With respect to case law, I did talk



about law that's coming from a court where there was a lawsuit and the judge made a decision and the decision has been published and we now understand it's a reliable law. The most recent law is the Findley versus Lee case that came out of San Francisco just several months ago and it addressed many of the issues. It addressed what is an embryo, it addressed whether or not the embryo directive disposition or legally enforceable, and ultimately it held in favor of the husband who did not allow his soon-to-be ex-wife to use the embryos. So, if parties are looking for current law, I strongly suggest that you access that case and my expectation alone still has the Sofia Vergara case out there. That case has not yet been resolved and we are looking forward to seeing what the courts are going to do because what's interesting about the Sofia Vergara case is their embryo disposition directive form that she and the gentleman with whom she created the embryo signed at the time of the embryo preservation was in fact faulty, it was a flawed form. It did not address the dissolution of their relationship and what has happened with the embryo in that case. So, we are all waiting to see what the court is going to do with that, but if you are looking for current law, I would look at Findley versus Lee at San Francisco this year as a reliable indicator of how these matters are handled in court.

**Shweta Mishra** – Okay. All right. Thank you so much. The next question says, what are the agreements that are required by the law to be signed between a surrogate and the intended parents in the US?

**Amy Demma** – Okay. So, again, back to where we started with this conversation. This is very state specific. There are many states that have no surrogacy law whatsoever. There are states that..., that outlaw surrogacy. So, there are..., there is no universal legal requirement; however, the standard or the best practice and has been absolutely supported by our medical colleagues who will not proceed forward for the most part and should not be without a gestational carrier agreement and the gestational carrier agreement could be written under the state law that applies by an attorney who is licensed in that state, but there is no..., no legal requirement on a federal level. There are some states that can require gestational carrier agreement, not all states have same laws.

**Shweta Mishra** – Okay. All right. Okay. And the last question is, I think you have already answered it. In case a couple decides to get divorced after creating embryos, who gets control of those frozen embryos? I guess that's the most debated question, yeah.

**Amy Demma** – Yeah. We know in Findley that as long as the consent form is not flawed as we expect the court will at least consider in the Sofia Vergara case, those are legally enforceable contract and so whatever it is that parties agreed at the time they created the embryos is very likely going to be what will be the ultimate outcome of the..., of those remaining embryos. Likely, not a 100%. We have seen some courts deviate, but generally speaking the party who did not want the embryos to be used, the party who is not interested in parenting with his soon-to-be ex generally wins in these cases.

**Shweta Mishra** – Okay. All right. Thank you so much for answering all these questions, Amy, Nancy, and Wendie; and with that, I guess we need to now wind up our discussion as we have already reached the end of our scheduled time. So, thank you so much for answering our questions and finding time out and sharing your expertise with us. Alia, thank you so much for hosting..., co-hosting the show with me and for your insightful questions today. It was a pleasure having you all with us today; and audience, I thank you for your support and we look forward to having you all join us for our next CureTalk on men's sexual health and male fertility in October. I will be announcing the date and time on social media very soon. For more information on this talk and the other upcoming shows on CureTalks, please visit our website, [www.curetalks.com](http://www.curetalks.com) or you can also email [priya@trialx.com](mailto:priya@trialx.com). I would love to hear your feedback about CureTalks on fertility and reproduction; and I would welcome your suggestions on fertility topics that you..., that you feel should be covered here on this portal. Please email your suggestions on [shweta@trialx.com](mailto:shweta@trialx.com) or [priya@trialx.com](mailto:priya@trialx.com). The link for today's show will be sent via email to all the participants; and before you call it a day today, please don't forget to check out the details of the America Walks study. America Walks study is a mobile app-based research study to determine walking behaviors in individuals in the United States. Find more details about this study at [trialx.com/americanwalksstudy](http://trialx.com/americanwalksstudy). So, until the next show, thank you everyone. Bye, bye!



curetalks.com