

# Psychosocial and Emotional Aspects of Infertility w/ Helen Adrienne and Amy Demma

Childlessness due to infertility can be devastating and is on the rise. More and more couples are finding it hard to become pregnant and carry a pregnancy to term.

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The emotional trauma and hopelessness that come with infertility and recurrent miscarriages can only be best described and understood by people who have been through it. But, unfortunately, not many people open up on this issue, which is considered to be a social stigma.

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We are discussing this grave issue with Helen Adrienne, a Psychotherapist and the master of her craft who will tell us about her tested mind-body techniques that has helped many come out of the guilt and depression of infertility and living a life again.

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We also discuss about the legal, ethical, and emotional issues of deciding the fate of the remaining embryos created after an IVF procedure, with Amy Demma, a New York licensed attorney and founder of Law Offices of Amy Demma, who counsels many clients on this issue everyday.

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**Full Transcript: Shweta Mishra :** Good evening and welcome to Cure Talk. I am Shweta Mishra, your host, joining you from India; and this evening on Cure Talk's 87th episode and our third talk on fertility and reproduction, we are discussing psychosocial and emotional aspects of infertility and deciding about the remaining embryos. Mayo Clinic defines the disease of infertility as the inability to conceive despite having frequent unprotected sex for at least a year for most people and six months if the woman is above 35 years of age or the inability to carry a pregnancy to live birth. Being diagnosed with infertility may take one on a roller coaster of emotions, embarrassment, shame, guilt, grief, inadequacy, and hope and then disappointment very month. These are the feelings that one fights through when dealing with infertility. Infertility may be like a dementor, if you will, that soaks up all the hope and happiness around and pulls people down the abyss of depression, guilt, and sorrow so deep that the sufferers tend to lose self-confidence, stop socializing and making friends, and in some extreme cases find themselves just incapable of sustaining daily lives. According to the CDC's 2006-2010 National Survey of Family Growth, one in eight women are going through similar pains of not being able to conceive or sustain a pregnancy to term and build their families. Unfortunately, the stigma attached to this issue makes it all the more difficult for the





sufferers because they do not open up and share the emotional trauma that they are going through. To do our bit, to help those searching for valuable information on this issue, and with the hope of giving hope to those going through the pains of infertility, we launched our talk series on fertility and reproduction last year in July, where we intend to discuss topics ranging from actual medical issues involved to the emotional aspects of infertility with our invited experts and panelists.

**Shweta Mishra**: On our first show, we had Dr. Mousa Shamonki of UCLA who discussed the risk factors associated with infertility in men and women. We also discussed fertility preservation in young adult cancer survivors with Suleika Jaouad and Dr. Andrea Reh this March. In this series today, to discuss the psychosocial and emotional aspects of infertility, we have with us our very distinguished guest and eminent expert, Helen Adrienne, who is a psychotherapist and is in private practice since 1979. Helen who is called the master of her craft, specializes in working with men, women, and couples dealing with infertility and conducts mind-body stress reduction classes for the NYU Fertility Center. Helen is a charter member of the New York City RESOLVE and educates mental health professionals on the parameters of infertility. She is also trained in clinical hypnotherapy, teaches hypnosis, and is an approved consultant for the American Society of Clinical Hypnosis. Helen has authored many articles on infertility which are available on her website, www.mind-body-unity.com, and her blogs. Her book "On Fertile Ground: Healing Infertility" is launched as number one best-seller on Amazon and is available there. Welcome to CureTalks, Helen.

Helen Adrienne : Thank you so much. It is a pleasure to have been invited.

**Shweta Mishra**: Great! We also have Amy Demma, an inexperienced 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. She is also a Fellow of the American Academy of ART Attorneys and an active member of the legal professional group of the American Society of Reproductive Medicine. She is also a legal adviser to parents via egg donation and to The Society for Ethics in Egg Donation and Surrogacy. Amy is actively engaged in the nation's most established infertility patient advocacy group and other non-profit and professional organizations. She served for many years as Vice-President on the board at RESOLVE, New England, and in 2012 completed her tenure as President on the board of Directors at RESOLVE, New England. Welcome to Cure Talks, Amy.

Amy Demma : Thank you for having me.

Shweta Mishra: My co-host this evening is Fran Meadows. Fran is an author and infertility advocate and became a mom through IVF to her one son. Meadows is one of many women that struggled with infertility and the devastation of a late pregnancy loss. She works with women fighting infertility by providing hope, inspiration, and strength and a friend to lean on. She has authored the book titled The Truth Behind The Secret "Infertility". Supporting us on the panel is Candace Wohl, an infertility blogger and survivor, who became a mother through the gift of surrogacy after seven long years of struggle. Candace and her husband started their blog called "Our Misconception" in 2012 to overcome the adversity and stare directly in the face..., stare infertility directly in the face with humor and positivity. The couple was also featured on MTV's True Life documentary named, "I'm Desperate to Have a Baby." Candace works closely and volunteers for the non-profit organization, RESOLVE, for infertility advocacy and has written various articles featured on the Huffington Post, Still Standing Magazine, fertilityauthority.com, Surrogacy Pride, adoption.net, and various other online sites. I extend a hearty welcome to all the panelists and to all our listeners. Before we dive into the questions, 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 email your questions to priva@trialx.com; and if you wanted to ask a question live, please press 1 on your keypad and we will bring you on air to ask them. With this, I hand over to Fran Meadows to take the discussion forward. Fran, over to you now.

**Fran Meadows :** Thank you, Shweta, for the wonderful introduction and I am excited to be here co-hosting the show tonight. Its a great honor to be here with the wonderful experts and panelists. Thank you, Helen; thank you, Amy; and thank you, Candace, for being here tonight. We are going to be discussing a very





important topic; and I think its something that is where we need to educate people because I know myself, going through infertility and being there and knowing what needs to be done, you never really think about what the future brings when it comes to legal aspects of embryos; and I think that's where we are going to, you know, get a lot of great information from Amy as well as Helen on the emotional aspect side and the mental health side. So, for... for you, Helen, I am going to begin. Thank you again for being here tonight.

## Helen Adrienne : Its my pleasure.

**Fran Meadows :** And I mean like I said, I know when I was diagnosed with infertility, it was difficult to hear the diagnosis and I mean my journey going from infertility to being pregnant and then experiencing a late loss, it was very difficult and I felt very hopeless. So, I mean, when struggling with infertility, just hearing the diagnosis alone, it can be devastating and I know with some of your patients, have you encountered patients that have long-term emotional and social effects when faced with multiple failed cycles, maybe elevated anxiety, and possible miscarriage or loss. Have you had patients and what tips can you share with us?

Helen Adrienne: Well, this ranks up there as one of the all-time great stressors. Its been measured to elicit stress on the same level as life-threatening illnesses such as cancer. HIV. AIDS and so this is not for the lilv-Along the way, it is a..., a complete roller-coaster ride, livered. You know, this is not at all. that's the common phrase that people use. People feel completely out of control, but I am kind of interested in providing hope, which is what Shweta had said, and invariably the crisis gets resolved somehow or another; and once the crisis is resolved, it kind of reminds me of an article that was in the Times not long ago, where they were measuring those who were in these wars that we have been involved in and it turns out that 75% of..., of people who come back from combat do not suffer from PTSD and when I wrote my book, although its absolutely true that you can't unhave your history and the black place that you described going into, Fran, I mean this is, you know, I..., I don't know that there is any way if you are a feeling human being, that you can just go through it as if you are made out of concrete and you can't unhave that history, but what I found from the people that I interviewed is that they said things such as "I have graduated now," which is someone who felt that..., that she could be with her family as she got it. It may not have been with the biological child and they have been at an ovum donation or an adoption, but she had graduated On the other hand, there were women who said, "Well, its diminished. I have my child, but will I ever now. have another child?" There are people who said unequivocally yes and on the other side of it, others who said yes and no because there are triggers that are inevitable in this process, that bring you back to the..., the pain that you suffered and one woman actually was pretty sophisticated. She said, Yes, I do feel left over with unresolved place, but I know its because I am a perfectionist" and so she was looking back at her history through the filtration system of a personality trait that she had so that, you know, the..., the thing if you want to focus on having hope, you are not going to be in this place for ever.

**Fran Meadows :** Right. Right. So, do you feel... So..., so you feel like, I mean obviously everybody experiences individualized and you know with different, I guess you say like, you know, you have graduated or this..if you know, where my journey ends or I have had my child, so do you feel that people just..., you know, couples they basically have their own way of dealing with the cycle of this particular, you know, conceiving and, you know, cycle here, where they deal with it in so many different ways and they heal in different ways?

**Helen Adrienne :** Yeah. I..., I think that the people who navigate this process by themselves are not people that I see, but the people that I see are, you know, touring the solar system, I mean they are not..., not even in their bodies. They are just so distraught and so frenzied and so desperate and so panicky and everything else, which is how come I can have a job and..., and..., and the..., the... tools that I teach are extremely effective in getting people who are, you know, so desperate and so focused on..., on a goal that they are just, you know, they are not living in their body anymore, get them to come back into the place where they are not donating anywhere from six months to six years or longer and being in that frenzied place where they can pendulate back and forth between now I am in a cycle and now the drugs are driving me crazy, now this cycle didn't work or yay, this cycle did work, or here's a miscarriage, you know the ups and downs and everything else and then in between be able to remember what it was that brought these two people together





in the first place and..., and turn them in the direction of what can we do to have fun now, what..., so that we are not donating all of this time to being miserable. Its a real... Its a real challenge to learn how to live around something as gigantic as the infertility challenge.

**Fran Meadows :** Right. Right. And now, I mean since we will be talking more about the legal side of, you know, these decisions that couples have to make and, you know, whether its from, you know, going through infertility or going through your cycles, you go to the other side of it where once you are at a point where maybe you are storing your embryos or you are waiting to have another child, you know, these are many decisions that couples may not think when they are in, you know, in the cycle or in the present. I know, you know, many couples that don't. So, I mean with their remaining embryos that they are..., they are storing, you know, can this type of decision be stressful or emotional for couples and how can you as a mental health professional help them get through these, I mean, even harder decisions here to, well, you know, what they can do with their remaining embryos?

Helen Adrienne: Decision are an ordeal of... Decisions of this magnitude are an ordeal to begin with, but when you are dealing with two people who are involved in this decision making process, 1 plus 1 is not 2 and I am not even sure its 3. (Laughter) It could be, (laughter) you know, even more intense than that and so the question is how..., how can two people navigate to the place where they are on the same page if they are not on the same page. If they are, that's great and then the waiting game can be nerve wracking, you know, am I going to conceive again with the frozen embryos, though? You know, what does my future look like? What is my family going to look like? All of these things, but where I come in is to get couples to be able to communicate clearly and to communicate, I'll say this purely, right, because if you are communicating just how you..., how you look at things, which is the factual and how you feel about things, then you are just making statements about it, that's fine, but if you are hurling pots and pans at each other, you know, because you are..., you don't know how to be in your skin with these things, then that's where I come along and..., and if..., and if there is not a meeting of the mind, I have a technique that I teach them, which is all about listening and its so interesting because when you tell people that they have to listen in a way that they are not allowed to interrupt, they have to be able to repeat back what the other person says, it takes on a whole different cast and now keep in mind, this may be two people who are not at all on the same page. Maybe if you are listening in on this thing, you know, are they even in the same marriage, are they are in the same situation, it doesn't, you know, but the point is when they have to repeat back what the other person has said, it forces them to take on the mindset even for those few minutes and there are times when you are listening to someone say what you just said, where you have the..., the satisfaction of knowing that you were heard and at times that is as good as it gets until.....things move along in whatever way that circumstances and..., and, you know, the..., the unknowns that come up and the..., the changes of heart and..., and whatever else where things can come to a resolution.

**Fran Meadows :** Right. So, communicating together as a couple or, you know, a..., a partner situation...or any situation, communicating together is a very important thing that you work with because.....like you said some might not be on the same page.

**Helen Adrienne :** And it can be learned, that's the thing to..., to know, it can be learned. I mean one of the most gratifying aspects of this work for me is when I am working with a couple who really even without infertility don't have the..., the..., they didn't have the role modeling and therefore don't have the tools to communicate lovingly with each other and for me to come in and to show them, you know, exactly, you know, we deconstruct their, their their style of communication. We break it down and put it in, in better terms and, and to be able to teach people how to do..., do something that gets them to the end where they are not only communicating better, but they are in a much better position to be appropriate, loving parents and, and role models for their, their child, for, you know, how two people talk to each other in a..., in a loving way. So its very exciting for me to be able to help out in this way.

**Fran Meadows :** That's such helpful information, I am sure......for those listening in and its really helpful and.. I mean, going on now to the legal ends of some of the things we have been discussing, we are going to bring Amy on for a couple of questions here. Amy, are you there?





Amy Demma : Hi, everybody! Ready and waiting.

**Fran Meadows :** How are you? Thank you again for being on the show and I mean, for me, I can remember when I went for my egg retrieval appointments for my IVF cycle with my husband and we were given so many forms to fill out in the office and, you know, so many things were on our minds and I remember wondering that, you know, if I would have any embryos to cryopreserve after retrieval, but I never really thought things further out into the future and can you share with us some professional advice on embryo preservation and what couples should discuss in order to make decisions when they are at the start of, I guess, their cycle and then moving forward, what could help them?

**Amy Demma :** Yeah. So, thanks for providing me an opportunity to address this topic. Certainly, residual or remaining embryos and the disposition, final decisions around those embryos, these are really hot topics, particularly the last six to eight-month weeks. Heard of a lot of high-profile lawsuits around embryos and I always say to my clients, those high-profile lawsuits look very much like the lawsuits of everyday except their high profile part, right? So, its some celebrity attachment often are some of the reasons for the media to grab hold of this, but this is common everyday stuff for all of us who are dealing with the world of in-vitro fertilization and you are right, Fran, it is very unsettling for a..., a patient who is about to go in for an egg retrieval. Should that be... (pardon me) handed these forms typically in a rushed manner, certainly not with the availability of legal counsel, often not with the availability of mental health support, an urge to sign in a..., in a not thoughtful but efficient manner.

Amy Demma : In many instances, in many ways rather, it is the egg donor recipient who is better off in terms of thinking about, deciding about processing the remaining embyros than it is the person who is going through IVF for themselves. When you are going through egg donation, typically, not always, but typically there is at least a meeting with a mental health professional, required often by the clinic or at least suggested. There also should be, for the most part, egg donation agreement, then when attorneys counsel either donors or recipients before entering into an egg donation arrangement, remaining embryos is something that we speak about and often particularly when I am counseling a donor and I bring up the issue of remaining embryos and I let her know that she has discretion and her discretion will be reflected in the agreement, if she has not yet met with the mental health professional and I don't like doing legal reviews with donors prior to them having that with the mental health professional and sometimes I will end my session with the donor if she has not yet met with the mental health professional, but if she says to me, "Gee, nobody has ever brought that up to me," then I know that she has not yet had that..., that meeting with the mental health professional. Its a heavy matter to have to think about prior to an IVF cycle, seeing all the way at the other end of that journey, being done with family building and still having embryos to content with.

Amy Demma: It is an impossible thing often to get recipient parents, intended parents in an egg donation arrangement to prepare for it; however, again, those folks have the benefit of seeing someone like Helen before they will get to my office or again I'll put them on hold and send them back out to Helen and have them come back to me, but IVF patients, myself as well, we don't have that luxury. I never saw a mental health professional in any of my infertility, it wasn't recommended at my clinic, it certainly wasn't required for my cycle. So, you are handed these forms, you are asked to sign, to make decisions about remaining embryos in the case of a death of a party, a death of both parties, a dissolution of a relationship for the most part and these are one-page forms that are check boxes. If one party passes away, then the other should get the embryo, yes or no. If both parties should pass away, then the embryos will be donated to the clinic, yes or no. So, they are short forms. They are handled in quick order. I don't know any clinic that says to their patients, "We really want you to sign this informed consent about embryo disposition, but we understand you want to take it home and see your attorney." That's not how it happens. So, we don't get to counsel IVF patients. Period. End of story. I don't ever have reasons to address residual embryos with IVF patients. I only see them when they are working with a donor and then we very much flush out this issue.

Fran Meadows : So, with..., with patients that are going through IVF, like I said, myself, with the filling out





the forms, are there.....I mean, is there any type of..., because like honestly those check boxes you were just talking about, I mean, I could see them, but I don't remember actually reading them through. It was just like check, check, rushed manner, you know, get things done. Are there are any things that you could, you know, recommend, like I mean, talking about maybe before going for an egg retrieval for a regular IVF cycle, you know, that a couple can talk about these decisions...I wish we could screen that forms ahead of time.

Amy Demma: Yeah, right. Absolutely, Fran. You are right. We absolutely, the way we give and there are just so many terrific websites out there, incredible resource that prepare patients for IVF cycles and yet we are talking very little about this matter and its a relatively minor matter on the radar when you are going to get IVF. Its not a glaring matter. In my experience with egg donor recipients, it becomes a significant matter three to five years after I have worked with them. So, at about two to four years old with whatever child resulted from the egg donation cycle that we worked on, that's when I get the call and the motivation to address this issue at that point, the financials and its simply, we have been getting these bills for the storage fees, this is causing me stress, this is causing stress in our lives. We need to resolve these embryos, what can I do? And all I am able to do is provide legal counsel. We are absolutely boxed in to what was agreed to in the egg donation agreement. Did the donor allow for donation of the embryos to someone else for family building, for example. So, all I can do is counsel them as per the terms of their agreement. The work that Helen and her colleagues do in that is so weighty and its so big, it has..., having folks make that decision. Once the decision is made, I can counsel on how to execute that decision, that's what I do, but getting folks from the..., we have been in storage for three years, we have been in storage for five years, we are done with our family building, we can't handle the financial burden, its a spiritual drain on me, an emotional drain on me. For Helen to get those folks from that point to a point of resolution, that's a lot of work to be done.

**Helen Adrienne :** Yeah. Can I... Can I just break in here for a second because first of all, Amy.....I would like to say how incredibly articulate and succinct you are being on this issue and..., and the list..., the listening audience is really..., have to be benefiting enormously from this. Where I come into this, the only thing I would like to add is that infertility itself is such an ordeal that..., you know, as I said, they are spinning around, they are flying in outer space and what not and then you have put something like a legal document in front of them you know, a legal document when you are out having dinner and there is nothing, you know, going on in your life. You are just reading a legal document, your eyes glaze over because what is this, you know, legally, but then when you are in that state and they hand you a document like this, like Fran said, she..., she doesn't even remember reading the damn thing. So, it really is..., it just... It ratchets up, you know, its another thing that puts the stress of infertility in the..., in the high category that its in.

**Amy Demma :** And just an aside, Helen probably and certainly her colleagues and this is just the flip side and we..., we don't have to stay on this side for very long, but its worth considering or at least discussing. Helen and her colleagues will evaluate and counsel egg donors in anticipation of an egg donation cycle and that is how weighty that issue is for a 23-year-old girl. ...no one has mentioned this topic to them before. Its not been something that they have been told to process through and prepare for and now there is the reality or the potential of the reality that their genetic material will end up in this cryopreserved form and decisions will be made about her genetic material through the five-year term. They can't even anticipate that and these are child..., not children, these are young women who are really not very much looking five years out. I mean its just not something.....they are thinking about. So, its agreed....complex from both the donor side, complex on the egg donor recipient side, certainly complex on the idea of patient side. It does not have the benefit of either legal or mental health counsel.

**Fran Meadows :** Yeah. I mean this is, like I said, this is wonderful information for our listeners because people don't really think about these things when they are in the present. The present moment is rush and, you know, do everything because, you know, I have to get everything done, check the boxes, sign the paper and go. You know, so I mean I think this is really great for patients that might be going through this and I mean, in the media we have been hearing so many stories of legal cases with frozen embryos involved with celebrities, you know, and even everyday couples because I recently read an article about the Chicago court ruling that a woman whose fertility was destroyed by cancer treatment could have used her embryos that





she created with her ex-boyfriend and, you know, its..., its amazing how many situations are, you know, individually treated now in the court and, Amy, I would love to hear what you thought about that, you know, ruling and how you could, you know, explain how different, you know, situations are individualized, you know, in the courts now.

Amy Demma: Yep. So... Thank you. Before we get to that case, I very much look forward to discussing it with you. Its the..., the ruling in Chicago that allowed a woman to use the embryos despite the objection of the partner with whom she created the embryo, that's an upruling that just came down this week and we are not surprised by it because there is some other recent ruling, but it is a shift in how embryos are being..., how embryo..., a battle for uses of embryos is being addressed in the court, a significant shift and we will talk about that just in... in just one minute. So, when we just laid the foundation, what are the disposition options? So..., and someone who has cryopreserved embryos has five, perhaps six options for them. They can keep them frozen indefinitely; and if you are willing to pay a storage facility to keep your genetic material frozen, I am sure they are happy to accept your checks. The particular clinic where you created the embryos may have a time limit because they..., because they probably have space limitations, so after three years they may ask you to move your embryos to another facility, but if you wanted to keep them frozen indefinitely, thankfully I don't think you would have a problem of finding a facility who is able to issue longterm storage services, though these are impractical, certainly..., certainly, I would imagine tons of screaming sirens going off right now for Helen for somebody to think..., even think to carry that burden long term but from a practical perspective, it is a disposition option, one can choose to do that should one decide to. Another option is destruction. So, you call the clinic and you ask them to allow the embryos to thaw until they are no longer viable. That's a tough one. You know, I am not even going to begin to unpass that. Helen, I am sure, will do a terrific job in talking to us about that, but those of us who have been through IVF and have created our..., our own embryos know from the bottom of our heart how difficult it is to come to that There are folks who resolve in that regard, no doubt disposition issue or option. It is an option for some. with the helplessness of health support, but nonetheless, it is there. In my experience in counseling recipients of donor eggs, it is the least opted-for disposition option in terms of the clients that I see.

Amy Demma : The next option is donation for research. That's a very appealing option until we find out that at this present time and this is a matter of the economy, this is a matter of politics. There are tons of cultural influences, but at this particular time it is very hard to find research facilities who will take embryos, who are medical or scientific research. Couple of years ago it was easier. Right now, its tough. I always tell my clients to go right back to the clinic where the embryos were created. In my experience, they will be the most likely party who are willing to accept the embryos and have them used for fertility research. So. that's another option. Obviously, using the embryos is an option for your own family building. The presumption is you have reached a point that you are done with your family building by the time you are calling me. Donating remaining embryos to someone else for family building, embryo donation. A beautiful family building option. I love working on embryo donation cases. I wish there were more of them. Also, a very weighty, emotional, and psychological matter because children resulting from that embryo donation are full genetic siblings to the donor's children and that too is a very weighty and complex matter, to have to process and resolve. There is another... There is another option. I... I don't hear much of it recently, not in the last several years. I wish we did and frankly, in my heart, it was a lovely way to resolve and that is a transfer done when there is no likelihood of...a pregnancy and I think its probably..., and I..., I just don't know how many clinics are offering this. So, those are your disposition options. Warriors stay involved when there is an embryo donation. Sometimes I will just hold my client's hand as we look for a facility to accept donated embryos for research. The other disposition options are elected outside of the attorney's office. So, you don't need to work with an attorney if reviewing any of the other disposition options, but certainly if you are donating to someone else for family building, then we have got a draft document. So... So, there you are! Those are disposition options. What we are finding in the court, in the court the scenarios that come to the public attention are when husbands and wives or the..., the parties that came together to create the embryos are now no longer in agreement about disposition option and one of the triggers for a lawsuit is one party wants to use them and the other party doesn't want to use them and historically court has held that a party's right not to parent trumped a party's right to parent and its because of financial obligation.





**Amy Demma :** So...child support is not something just... I have lots and lots of intended mothers or rather mothers who want to use embryos, they come forward and say, "Look, I don't want any money from you. You don't have to pay child support. You don't need to be responsible for any financial obligation." Well, the law does not allow that. Child support is something that belongs to the child and only the child, no parent can waive child support. So, you can't relieve the other party from child support. Only the child can do that and so the court says that, "Well, since there is no relief, we can't unburden this..., we can't burden this person with parenting." So, really, truly, historically, for a number of years, a long time, that was solid legal ground. The party who doesn't want to have the embryos result in a life to whom he or she would have any financial or other obligations always win these lawsuits. Now, we are seeing a shift.

**Fran Meadows :** I am going to bring on Candace Wohl because she is going to... She has a few questions for Helen and Amy as well and I would love to, you know, see if she is going to go further into those questioning, Amy, so you could discuss it more. Candace, welcome to the show and I would love for you to, you know, give two questions to Helen and then two questions to Amy so they could further discuss this conversation.

Candace Wohl: Absolutely. Absolutely and..., and ..., and wow! Thank you so much for having us and there was a lot of great conversation points that are brought up. So, my head is kind of swimming as to where to start. So... You know, since we are on the topic, Amy, I would..., I would like to start with you. I have a different spin on things. So, I too was like Fran. I had... I had multiple IVFs, I had six, and..., and..., and really we didn't pay that much attention to those consent forms. The main point that I did pay, I would guess, the most attention to is what if something happened to my husband, but not if we were to..., not if our marriage was to disband. So, its..., its interesting because you focused on a specific area, but those are things that you don't really consider and then our journey kind of transitioned, where I had two remaining embryos, but no longer did I have a uterus to transfer them to because I had a hysterectomy and so, we were in that weird situation of what do we do. So, we actually did hang on to our's and..., but we were lucky in the fact that our clinic is one of the few that does research and you can donate those embryos to research, but for some reason, I held on to them and fast forward a little bit longer, I had then had our daughter through the gift of surrogacy. So, this is a different topic that I am going to challenge you with because even though every state is..., is about as clear as mud when it comes to surrogacy law and I know that New York is..., is a very challenging one in the fact that their contracts are considered void and unenforceable. There are also fines, from my knowledge, that are enforced for those who arrange and assist in surrogacy agreement, I believe its anywhere from 500 to 10,000. Correct me if I am wrong. And that law also states that no person can pay or accept money in relation to a surrogacy agreement except for medical expenses. So, my question is how does an intended parent who is a New York resident go about navigating an out-of-state surrogacy if their embryos are created inhouse in the state of New York and additionally, does the New York State laws flex for this type of scenario?

**Amy Demma :** Yep. So, after the..., the road blocks for New Yorker is relatively low, I am happy to tell you. So, yes...

## Candace Wohl: That's good.

**Amy Demma :** ...in states like New York and New York, Michigan, State of Washington, and there is a fourth where actually commercial surrogacy, compensated surrogacy is criminal activity. In New York, its a felony .....punishable by fine and prison, same is the case in Washington State, same is the case in Michigan and I am forgetting my fourth and I usually know the stuff at the tip of my fingers, but its...Is it Arkansas or Arizona? Its one of those two. So, there are... Yeah, might be Arizona. There are states that have actually crystal clear surrogacy law and then there are states that... The New York law is pretty clear, I mean there is nothing muddy about the New York laws. You will not be building your family in a lawful manner if you are engaged in paid surrogacy in New York; however, I started off with the... The roadblock actually is pretty low. All New Yorkers need to do and I..., and I..., I should say that with more sensitivity. Yes, there is a burden having to leave your home state to build your family. I understand that and I acknowledge that. Once one has decided that that's..., that's just part of the journey, New Yorkers can and do leave the





state. They go as close to Connecticut and without any legal hurdles can pursue family building through surrogacy with their embryos. So, it is simply a matter of crossing state lines into a surrogacy-friendly state. One should... In a surrogacy-friendly state, it is irrelevant the state in which the embryos are created and it is irrelevant the state in which the embryos are stored. The state in which... The state law that would apply to your family building would be the state where the clinic is at the time that you are doing the embryo transfer actually and if you are in a surrogacy, to say you went to Connecticut to do your embryo transfers and I help people move embryos literally all the time. In fact, I have even personally gone to the cryo bank, strapped the tank in my front seat, and driven the tank to the clinic. So, we move embryos all the time. There are terrific and reliable services that help to move. If you were in a state where you are restricted, like New York... So, for state lines, you do your transfer in Connecticut if you are a New Yorker, but your surrogate happens to live in Massachusetts. So, your surrogacy agreement is going to be written under Massachusetts law... ...so your New York creation of embryos becomes a non-issue.

**Candace Wohl :** Amy, thank you. Thank you..and then I guess the piggyback thought, what..., what are..., what are the state legislation changes being done right now? Is there any advocacy work being done to help change the laws that are surrounded by commercial surrogacy?

Amy Demma: Well, in the non-surrogacy-friendly states, I can tell you that my colleagues at each of these states is always working on progressive legislation. So, in those states that are non-surrogacy friendly, you can be sure there are groups of attorneys working on legislation that not only will allow for easier access to surrogacy family building, but, for example, in New York, we have legislation pending The Child-Parent Security Act. The Child-Parent Security Act is a beautiful piece of legislation. It not only allows for commercial surrogacy in the State of New York, but it also defines what an egg donor is, what an embryo donor is, and what a sperm donor is. So, it is a comprehensive piece of legislation, and we are hoping that it can gain some momentum and cross over into law. Its the legislation that's pending in New Jersey right now. Its the legislation that's pending across the country to fight these barriers to family building and I guess RESOLVE is the best resource for that in terms of keeping track of what's happening in each state. Look, we are not going to see the stuff tackled on a federal level. This is really, really important stuff to all of us and the folks who are listening, its probably the biggest. Certainly, my infertility was the greatest challenge I had faced and I am about to celebrate my 50th birthday. So, I am.....knocking on wood left, right, and sideways here, but certainly infertility was the biggest..., greatest hardship I have felt..., I have faced, but for friends who aren't touched by it, its a non-issue, so I don't see this being addressed in federal legislations, so its state specific, but its..., absolutely everybody listening should get involved with advocacy in their states to support assisted family building and even those who aren't..., who aren't touched by infertility should be behind the effort.

**Candace Wohl :** I... I agree with you and..., and just kind of as aside, I actually work closely with RESOLVE and just like..., like Shweta mentioned, and I do federal advocacy work, but they do actually have, RESOLVE that is, has a grassroots advocacy project called Project PROTECT, where its to address some of these issues on a state-by-state level. So, again, I..., I echo what you said. I think that everybody should get involved with this. This is our right as an American citizen and I think that we have... That's the beauty of being..., being in America is the fact that we do have the..., the voice and we should use it. So...Yeah, and..., and, Amy, thank you very much. Just..., just to be sensitive of the time, I have a question for Helen. Helen, so one of the topics that my husband and I often write about is anxiety and how infertility can be such a huge catalyst for anxiety. After dealing with

Helen Adrienne : That's today's.... That today's understatement.

**Candace Wohl :** Yeah, you are right. I know. After dealing with multiple failed cycles myself, I remember once being at a family event where there was an extremely insensitive pregnancy announcement and..., and at that point we were very open about our..., the disease that we have and despite of all of my husband's best efforts of trying to console me during that time, my husband had a very severe panic attack. Do you find that the husbands often face similar..., similar psychological effects because maybe they are bottling up those emotions to protect their wives...





Helen Adrienne : And what happens when you bottle up anxiety is its going to come out in some form or another. In..., in your case or in your husband's case, it came out in the form of the panic in that way. Typically, the men want to protect the women and they don't let their feelings show, but the..., there is a phenomenon that I have noticed that if when the husband is a little boy, his dad is rather absent and the mother is rather histrionic, she has her needs that can't go in the appropriate place because he is either not around or he is dismissive of her and she winds up treating the son as if he were a husband and meanwhile he is 6 years old, he is 8 years old. He is no more qualified for this than he is to fly to the moon without a rocket ship and what it does is it sets up an anxiety about a woman who has emotional needs and so fast forward now, he is in a marriage, happy go lucky, terrific, terrific and boom, they are looking at a fertility struggle and now she is appropriately needy and he is back to the 6-year-old who doesn't know what to do with his mother. So, just from a psychodynamic point of view, you know, anxiety in men is both normal because he is anxious to become a parent as well, very often more so than the woman. I have... You know, I have heard some of that, but, you know, the thing with..., with my field is that its sometimes not easy to generalize because you have to know the psychodymamics of the people who are involved and it sounds like the anxiety attack that your husband had is something that I can't really comment on because I don't know him, but it does sound like he has been or had been a terrific support to you and then it just went over the top. Maybe it was the person who was insensitive that he wanted to..., you know, poke his eyes out, you know, and didn't know was holding back on those feelings as well. I... I can't comment as to why I can say that in a way, good for him, because he was letting it be known that he had needs. He may not have done it on purpose, but everybody is human unless you are made of concrete. There are people who try to do that one too, but yes, the husbands are just as vulnerable as the women, you know, and..., and they..., they are no more exempt from the intensity of emotions than anybody else.

**Candace Wohl :** Absolutely! And, you know what, I think you nailed it on the head. That..., that pretty much summed up exactly what I feel that he..., he was going through and..., and..., and really it was one of those things that we..., we were the couple that realizes this was emotionally hard. We did have a great communication, so communication and I think that you made a good, great point at the beginning of this talk, that is so important, but even with that..., that..., us having that powerhouse ability of being able to communicate, we seek out a very great counselor and from the very beginning of our journey, we went to counseling....and that was such an integral part of us coping with infertility on a....positive level and not necessarily on the negative side.

Helen Adrienne : Yeah. Well, you know, we are as human beings were organisms that have the environment and our world and whatever is going on in our world has impact on us and if it goes in and it doesn't come out in the form of verbal or journalling or people who are athletes, joggers, you know... I have had so many women say to me, "My doctor said I can't run. I don't know what I am going to do. That's how I bust through all of my pent-up emotions." So, if there is not a way to release this, then you become destabilized as a..., as a human organism. You know, I..., when I had my house I had something called a trash masher, right? So, instead of running down to the garbage everyday, you put the wet stuff in the InSinkErator thing and you put the dry stuff in this thing and then you pushed a..., a lever and it sounds just like the garbage trucks in New York City and it would compress everything and so you could take the garbage out once a week. Well, you know, we are human beings and if we put garbage in and keep compressing it, you know, its..., there has to be some way to let it go or there's going to be some kind of breakdown and, you know, even couples who have fabulous modes of communication, I think you..., you forestalled running into trouble because you recognized that what went in had to be released with this woman or man verbally, however, the style of therapy was, you were taking care of not letting it all pile up and, you know, that's a good thing and, you know, you..., certainly signs of discord would be a time to go. I don't think there is anybody, no matter how talented you are in communicating, who is going to go through this thing without being triggered, without being blindsided. I find that people vow that they are going to go through this and then they hit some kind of pothole. Certainly, the inability to communicate sexually can be a real stumbling block and not wanting to hurt each other and holding back in that way, I mean. So, if you have guidance, you are going to be better off.

Fran Meadows : I agree and there is so much great information that we are giving out to all our listeners,





but we do have 10 minutes left to this show. So, we are going to carry on and we are going to give it over to Shweta and she is going to give her final questions and wrap up the show here.

**Shweta Mishra**: Thank you, Fran, and thank you, Helen and Amy. It was really enlightening to hear you both and I will really keep my question very brief. Helen, I will start with you first. You wrote on your website, you can use your mind to change your brain. It would be great if you would.....explain it in little more detail.

Helen Adrienne: Yeah. Well, I educate people as to the..., as to the functioning of the..., of our mind-brain phenomenon, that we have a..., a brainstem that controls all of the autonomic, automatic functions, like breathing and heart rate and blood pressure and muscle tension and so forth. So, let's call that the body. Then, we have the neocortex, which on a very simplified level we can say its how we interface with the world. Its how we know what's going on, how we know what's impacting us. So, let's call that the mind and then we have between the two, the .....limbic brain, which contains structures, the amygdyla and the hippocampus, which is sometimes called the emotional brain and that's where memories and trauma are stored and we can use our mind and decide to use our brainstem by breathing, voluntarily breathing long, slow, deep and when we do that the brainstem communicates with the limbic brain and the limbic brain says to itself, "Well, if she is breathing like that, she is not in a fox hole. Right? So, we can address the..., the trauma by..., by behaving in a certain way that it..., it creates a relaxation, much of what I teach in the mindbody classes.....has to do with how you can impact the midbrain, which is basically the troublemaker. Also, you can listen to guided imagery, which is a passive thing, because sometimes when you are in a frenzy, the last thing that you feel qualified to do is follow your breath because your mind is going, you are never going to conceive, the IVF is going to fail, blah, blah, blah, blah, blah, blah, blah, blah, ..., you know, so .....its hard to keep yourself narrowly focused on that which is a positive thing to do in order to reverse the physiology of stress. But even though we have a genetic, let's say, predisposition to be anxious, a genetic predisposition to be depressed, if you decide using your neocortex that this is not what you need at this phase in your life, in fact its the last thing you need, then.....you can elect to learn these mind-body techniques which are extremely effective in getting you out of..., you know, out of space and back into your body where you can live in a way that pendulates as I said before, the necessities of what you have to do to go through all of the fertility challenges with deciding what you can do to enjoy your life and how you can be in a state of..., of..., of calm, which by the way, those are the two major coping styles - one is, you know, what can I do or problem solving coping and the other is, how can I be in my skin and the studies have shown that the lettinggo coping, being-in-your-skin coping, has a positive correlation with rates of pregnancy. So, people come.....into my classes and I teach them these things and they walk out the door greatly relieved because they no longer feel out of control. They may not go into their bedroom and come out pregnant like everybody else they know, but at least they are not a slab of meat with their legs in syrups, feeling completely helpless and..., and victimized by this whole process. So, its really very.....rewarding for me....to be able to, you know, give people a way to participate in it.....as partners with their doctors.

**Shweta Mishra :** Uhmm... Uhmm... Okay. Okay. Great! Yeah. You are just doing a great job, helping these people get..., instilling positivity in them and I know that I am glad to have a friend who did the same thing for me and she just pulled me out of the depression.....that I was in at that time, yeah, and..., and she kind of used a..., a similar technique that you just described.....of meditation and practicing breathing.

**Helen Adrienne :** Yeah. I have... I have enormous... I have enormous amounts of free information on my website. Its <u>www.mind-body-unity.com</u> and there are resources. In the resources tab, there is all kinds of articles. There is a blog. People can sign up for my free newsletter and I have been told that people who have read my book say, just reading the book they feel better. There's enormous amount of information in there that helps.....people get into that state of..., of neutrality.

Shweta Mishra: Okay. That's great. That's great. Thank you so much, Helen.

Helen Adrienne : Oh, its my pleasure. Thank you.





**Shweta Mishra :** I guess... I have one question for Amy. I mean, I had several questions, but I guess we have to wrap up the show because we are just running out of time. Amy, I would like you to comment on three-parent IVF and what are the legal issues that one should be aware of regarding the three-parent IVF? If you could just briefly respond. Yeah.

**Amy Demma :** And I will briefly respond and actually it is an..., an..., an actual brief response. Such family building is not currently available in the United States. So... It should be said that your programming is only reaching an American audience. It is not a family building option that is.....currently available. It is in intense ethical discussion right now. I don't...

## Shweta Mishra : All right.

**Amy Demma :** ...quite see it becoming available any time soon. In short, it is a process that has just been approved in the UK, whereby there are two sources for egg and if there has been determined to keep that chromosomal defect in one and I am not a medical professional, so I am probably saying this in a very crude way, but this is how I understand it. If there is a chromosomal defect in one, the physician or clinician is able to ask that the healthier egg, take from that healthier egg.....then look at the defect in the first egg, implant that into the first egg, introduce it to sperm for fertilization. So, you have got some sort of material from the healthy egg that has replaced the defective chromosomal material joined with the sperm and so you essentially have three gamete providers in the creation of embryos but still extremely controversial here in the United States. I don't expect it for several years at least.

Shweta Mishra: Okay. All right. Thank you so much, Amy. Thanks a lot.

**Amy Demma :** I think you just got terrific programming. Thank you, Fran, and, Shweta, and..., and for my other guest speakers. You know what? I think together we put out some really good information. Let's let it go viral.

## Shweta Mishra : Absolutely. Absolutely.

**Helen Adrienne :** It was a very..., very comprehensive program. I was very impressed with the layout when you sent it to me and.....and listening to it is just really a useful and important thing because this is science fiction, folks......and people need help with..., with this kind of stuff.

Fran Meadows : I think we could have..., we could have spend half a day on this conversation..

**Helen Adrienne :** Yeah, exactly...just continue it. So much great information. So, hopefully, we continue the conversation on social media and everybody gets all the great information they need.

**Shweta Mishra :** Yeah, totally. Thank you so much, Helen and Amy. It was such a wonderful.....discussion and was pleasure having you both with us today. Fran, thank you so much for co-hosting with me and I thank you and Candace both for supporting the discussion with your insightful questions. I am sure the information and advice that we have given, that Amy and Helen have given on the show, would be a good resource and help many struggling with this grave but not-so-visible issue of infertility. And I thank the audience for their support and we look forward to having you all join us for our next Cure Talk show next week. So please stay tuned and join us next week on 22nd of June, 2015, at 6 p.m. eastern, to discuss challenges and changes in life after prostate cancer with Dr. Anne Katz. More information on this show and other upcoming shows is available on our website, <u>www.curetalk.com</u>, or you can email at priya@trialx.com to avail the information. The link for today's show will be sent in via email to all the participants. So, until the next show, thank you very much, everyone.





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