PATHWAY 2 PARENTHOOD: EMBRYO DONATION—PROSPECTIVE RECIPIENTS

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THE RECEIVING LINE

Family Building with Donated Embryos. Chances are, when you were making your first serious adult decisions and planning your future, you never gave two thoughts to your reproductive capabilities. Like most people, you probably assumed that when you were ready, you'd have children. Your own genetic offspring would be the heart of a family you made with your partner. But fate didn't cooperate. A disease, an inherited disorder, an anatomical anomaly, an unexplainable situation or age has made it impossible for you to conceive. The reproductive medical interventions you could afford couldn't coax your eggs and sperm to unite.

What now? If you've grieved and accepted the true loss of a biogenetic child but you still very much want to partake in the experience of pregnancy and birth there is an option. It's called embryo donation. When you consider embryo donation as a route to parenthood, you are looking at the prospect of a full-term pregnancy, labor and delivery to bring home a new baby.

For this process to succeed, it's essential that you go into it with the understanding that this much-wanted child is the result of the combined DNA of two people you may never know. According to interviews conducted over the last two years with private donor agencies and hospital-based programs, most donors choose to remain anonymous. Your son or daughter will derive height, body type, eye and hair color - all innate physical and temperamental, artistic and intellectual characteristics - from strangers. It is how you nurture and raise this child that will be a reflection of you.

However exciting, embryo donation is terra incognita. It's a vast, largely unexplored terrain of emotional, psychological, social and legal issues. Before accepting embryos created by other people, it's critical that you have a clear head, that you are armed with the best advice you can get.
from professionals, as well as people who've already been down this road either as recipients or donors.

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The ramifications of choosing this option will have an impact on every aspect of your existence, as well as on the life of a potential child that may result from embryo donation. That makes it even more vital that you seek counseling so you will fully understand the implications and the weight of the choices you are making.

Within the pages of this brochure, you'll find a guide to the information you'll need to consider. You'll find the questions you and your partner need to ask when you are contemplating building a family with embryos generously given by others.

THE DEFINING MOMENTS: WHAT EMBRYO DONATION MEANS

Let's start with a few definitions. **Embryo donation means that one couple gives to another the early-stage cell clusters that result from the union of their gametes—sperm and eggs.** These 3-to-5 day old embryos are transferred to the uterus of the recipient woman, potentially allowing her to experience pregnancy. Both donors and recipients understand that the recipient couple will be the parents of and raise any children that may be born.

The calculus of embryo donation is complicated. It requires a many-layered effort by both the recipients and donors. You will cover the costs of blood and genetic testing needed of the donors in addition to the outlay for your own constellation of necessary blood tests and reproductive medical interventions and counseling. Both you and the donor couple must sign informed consent documents addressing relinquishment and acceptance of parenthood should children result, as well as liability, among other things.

You may have heard the term "embryo adoption", and there are a lot of individuals and institutions using that phrase. Adoption is a specific
legal framework with guidelines around parental rights and obligations and applies only to living children. A few states do have laws dealing with embryo donation, but it is not the legal equivalent of adoption. The embryos you get are a gift, plain and simple, from people who have gone through a great deal to produce them.

There are, however, some parallels to adoption if a successful transfer culminates in a live birth. As with adopted children, your son or daughter will have full genetic ties to two usually unknown adults, and possibly siblings. Expect that, someday, your child will want information about them, or his or her genealogy or health history. You must be prepared for the likelihood that your child will seek out the donors and their families even if the transaction, at the time of donation, was strictly anonymous. Decades of experience with adoption have shown that kids will go searching.

WHILE THE FAMILY YOU BUILD IS YOURS AND YOURS ALONE, EMBRYO DONATION IS A BUNDLE OF EXTENUATING CIRCUMSTANCES. AND IT TAKES A TEAM EFFORT TO MAKE IT WORK.

You also should imagine how the donating couple might feel if and when they learn you are pregnant with their embryos. All the best intentions in the world could evaporate should unexpected emotional attachments to this child arise. To protect yourself against custodial claims by the genetic parents or extended family, talk to a lawyer about the options and ways of protecting yourself in your state-before going ahead with the transfer.

The ability to confront these possible complications requires you to analyze your motivations and emotions with absolute honesty. Think about all the contingencies.

A trained mental health professional can help you identify your true feeling as you try to project how you might feel 5, 10 or 20 years down the road. Evaluate the psychological, medical and financial issues you face as recipients. Consider the range of responses that donor family might have, or that of your potential child. Think about your legal relationships.
While the family you build is yours and yours alone, embryo donation is a bundle of extenuating circumstances. And it takes a team effort to make it work.

**STATES OF PREPAREDNESS: THE PRACTICAL, PSYCHOLOGICAL AND MEDICAL ISSUES**

Couples seek embryo donation for a variety of reasons. Some have tried for years to conceive a child the old-fashioned way with no luck. Medical or life circumstances may have put expensive and time-consuming assisted reproductive technologies out of reach. For others the decision may be fueled by a religious or moral imperative. Regardless of the underlying reasons, every recipient should be clear: You are receiving fertilized eggs that have begun to divide, not a child. You are getting an opportunity to have a baby, not a guarantee.

**IF THE TRANSFER IS SUCCESSFUL, YOU WILL BE CARRYING THE DEVELOPING EMBRYO TO TERM; YOU WILL BE THE ONE WHO CONTROLS THE FETAL ENVIRONMENT, A CRITICAL DETERMINANT OF THE CHILD'S HEALTH AND DEVELOPMENT.**

**WHEN IT WORKS**

If the transfer is successful, you will be carrying the developing embryo to term; you will be the one who controls the fetal environment, a critical determinant of the child’s health and development. You'll have the opportunity to take childbirth classes, bond with other parents-inwaiting and share all the biological and emotional peaks and troughs typical of pregnant couples.

While the absence of a genetic link can be difficult at times, it may also temper parents' expectations. As one partner of a recipient couple put it, "Since we didn't know who this child was going to be, we loved watching her develop into the person she's become. We love her dearly, for herself."

At the same time, you may seek genetic donors with specific characteristics. While most recipients are content with any embryos they get, reported one donation agency director, some people do have preferences.
Agencies often will do their best to find the match that suits your requirements and those of the donors by vetting applicants and facilitating an exchange of information. It is also possible to pursue donation privately without the help of an agency or clinic. In that case, you will have to investigate the donors on your own to see if they meet your criteria.

Be forewarned. Even if you get the donor match of your dreams and the transfer is successful, there are still risks. Even with control over the prenatal environment, there’s the possibility of problems that screening and testing don't pick up. Problems that even the most careful pregnancy cannot prevent. These may be gestational, congenital, or genetic problems that can range from mild to severe. If you are lucky enough to carry a full-term pregnancy to delivery, you become a parent for life, like all other mothers and fathers. You must anticipate how you will react to a child who may be less than perfect - one that requires special attention and care - before you attempt pregnancy so that you can stay grounded whatever happens.

In this unique process, the objective is to maximize the chances of a positive outcome. Depending on the quality and number of embryos from a single donor, some centers will transfer embryos from more than one couple. If your program is one that does mix embryos, will you be comfortable not knowing which twosome is the genetic source? Another point to ponder is the broad spectrum of emotions and responses donor couples might experience. These people will have a genetic child out in the world. Their children, if they have any, will have a full sibling. They may wonder about the child that came from their gift to you. They may feel an emotional bond with that offspring. Consider how they might respond so that you are protected psychologically and legally before anything happens, if it ever does. Furthermore, even though most embryo donations are anonymous, laws protecting anonymity are not immutable. How would you deal with your child finding and making contact with them? How would you handle the sudden appearance of the genetic parents? What would you say to them, your family, your child?

"Open" donations made between couples known or related to each other require something slightly different. In that case, the four adults
involved in the transaction should discuss the extent and limits of the relationship of the donating couple to the child, their obligations to the child and you, and your obligations to them. You must all delineate and set boundaries. You must respect their needs as they must respect yours.

Last, but certainly not least, what is today an abstraction, a dream, may one day pass through babyhood and childhood to adulthood, full of questions and curiosity. You must determine how much you're going to reveal to your son or daughter about the circumstances of his or her conception. You should think not just about what you'll say, but how and when you'll say it.

Birth stories have tremendous weight in everyone's psychological and emotional development and sense of self, according to experts. This piece of your child's history should be handled with consistency and confidence whether or not you elect to discuss the donation. Most psychologists advocate openness with your child so there are no secrets or any of the discomfort and worry that secrets inevitably generate. You can pretty much bet that eventually your child will find out about his or her genetic roots and demand as much detail as he or she can get. You should be ready with answers that you and your partner (as well as anyone else you've brought into your confidence) have discussed and agreed to share.

WHEN IT DOESN'T
Because the assisted reproductive technologies that were used to help produce, freeze, and thaw the embryos yields a live birth in only one of five transfers, this process may not work. That 20% may be worth going for. But it means that embryo donation is the potential for a baby, not an ironclad promise. If you've already gone through the mill of infertility treatments, will you be able to accept a negative outcome?

Then there's the other uncontrollable: donor ambivalence. It comes in many, and often surprising forms. Sometimes one member may support the donation wholeheartedly, while the other is just going along with it. Sometimes, despite their stated and earnest commitment, when donors come face to face with the reality of relinquishing their genetic material to another couple, they get cold feet. That could happen at any point
prior to transfer, and you have to be willing to accept this possibility. This thicket of daunting issues is one that all would-be recipients must be ready to face, and absolute candor is the best tool for getting through. This decision affects a great many people. Fertility patient support organizations, medical professionals (including the American Society for Reproductive Medicine and the Society for Assisted Reproductive Technology) and legal experts urge all people contemplating donor embryos to get psychological counseling. A trained professional can help you disentangle the idealized notion of embryo donation from a potentially messy reality. The goal is to help you cope with whatever happens. It's not just you who needs preparation. Most programs recommend and often provide separate counseling for the donor couple, too.

**BODY WORK: THE MEDICAL ISSUES**

When you become an embryo recipient couple, brace yourself for the complex medical procedures your female half will undergo. First, you need to be certain that you (and the contributing donor couple) are healthy. Once you confirm that, you enter-or re-enter-the realm of Assisted Reproductive Technologies (ART). A detailed medical history and a thorough physical exam are the beginning. The doctor will check your uterus to make sure you can carry a pregnancy.

Then come the hormones, taken orally or by injection or both. Those hormones shut off, then mimic, a normal menstrual cycle enabling your doctor to calculate the best possible time for the transfer to take place. A few weeks prior to the procedure, you'll also start taking prenatal vitamins.

The point of transfer: Here's where one of those donor-dependent issues arises. The number of embryos transferred depends on the age of the female donor. Generally, the younger the woman, the better the quality of the embryos, the fewer will be transferred. The fewer the number of embryos transferred, the lower the risk of a multiple pregnancy. On the other hand, some programs transfer a set number of embryos as a matter of policy.

**ALTHOUGH YOU'RE PROBABLY FOCUSED ON SIMPLY GETTING PREGNANT, YOU MUST CONSIDER THE POSSIBILITY OF MULTIPLES.**
Although you're probably focused on simply getting pregnant, you must consider the possibility of multiples. Give serious thought to how you would feel about giving birth to twins or triplets or more, as well as how you feel about the possibility of needing multi-fetal reduction. Discuss these feelings with a mental health professional and with your physician so you can work together to decide the number of embryos you want to transfer.

After the transfer takes place, the clinic will continue to monitor you until blood and urine tests confirm a pregnancy. Then your care will shift to an obstetrical practice.

Of course, there are certain risks. Once again, the first involves the donor - the risk of miscarriage rises with age of donor. The older the eggs the more likely there will be chromosomal anomalies that compromise an embryo's viability.

Then there are those risks that come with any assisted conception. There's a small chance (1-3%) of a pregnancy that begins outside the uterus. Since an ectopic pregnancy is dangerous to the mother, the recipient will be followed closely until the doctors determine that everything is fine. There is also the possibility of a multiple pregnancy (twins or triplets). If more than one embryo implants, your doctor will discuss the potential consequences for you and the fetuses and your case will be treated as a high-risk pregnancy.

The chances of success are improved but not assured if:
• The donating mother is younger, in her 20s or early 30s
• The embryos were preserved within the last decade. Their viability has been enhanced by recent refinements in freezing and thawing techniques.
• The embryos available are of higher quality, in the subjective medical judgment of the program. Remember that the donor family has in all likelihood already used the highest quality embryos they produced in their own family building efforts.

It’s preferable for the actual transfer to be done at the clinic where the embryos are stored. Some recipients do have the embryos shipped close
to their homes. The program working with you will know the state's requirements.

Previously, the Food and Drug Administration regulations exempted sexually intimate partners engaged in reproductive treatment, from infectious disease testing prior to the creation of their embryos, which were intended for the couple's own use. Recently, the FDA expanded this exemption, which now permits couples who were not originally screened for infectious diseases, to donate their cryopreserved embryos to other couples. The regulations do suggest that attempts to test these donor couples should be made before the embryos are transferred to the recipient, but, when testing is not possible, the recipient should at least be advised of the potential communicable disease risks. Given that FDA regulations may change, you should be sure to understand what screening and testing requirements are in effect at the time of your donation.

Some agencies will include the testing issue in their donor contracts. One agency contract requires that donors be tested for infectious diseases six months after making the decision to donate; in the meantime the embryos are quarantined.

Although it might seem trivial, donors frequently are shocked by the profound emotional turmoil these testing and screening procedures stir. Often it is the first time that the implications of the decision move from the abstract to the tangible, when they come face-to-face with the real possibility that someone else could raise their genetic offspring. According to program administrators interviewed over the last two years, it is a pivotal moment that leaves many potential donors reconsidering the move. You must brace yourself for that eventuality. Be persistent about finding out the results-or even if the tests took place-to ensure the healthiest possible outcome for you and your baby.

**THE BEST DEFENSE: THE LEGAL ISSUES**

The legalities surrounding the creation of a family by embryo donation are unclear and vary greatly from state to state. If you decide to pursue embryo donation, you should consult a lawyer of your own - not one representing the clinic - as you move through the process.
Donation programs will make sure you understand what you are doing. 
"(Our) contract states in almost every other paragraph that the donors are giving up all parental rights," emphasized one egg donation agency's executive director. According to the spokeswoman for another private agency, the donor contract they've devised states embryos are relinquished before being shipped to new clinic. In addition, there's a separate, renewable "relinquishment" document that allows donor families to stay involved with embryos that were donated but not used. 
"Let's say the recipient family got 20 embryos from the genetic family and all of a sudden the recipients say 'we have triplets' and there are 10 embryos remaining, the responsibility for the decision about what to do goes back to the (donors)," she said.

AT A MINIMUM, MOST CLINIC-BASED PROGRAMS AND INDEPENDENT AGENCIES INSURE BOTH THE DONOR AND THE RECIPIENT SIGN CONTRACTS THAT STIPULATE THEIR RESPECTIVE RIGHTS, COMMITMENTS, RESTRICTIONS AND LIABILITIES.

If, however, your first attempts don't yield a pregnancy and there are embryos remaining, they remain your property to use. Since there is no standard, each agency or program will have their own guidelines about handling embryos you do not use for whatever reason. Some have special rules banning you from donating embryos you've received from another couple. Others do not. It is crucial that you find out about the policy of each program or agency.

At a minimum, most clinic-based programs and independent agencies insure both the donor and the recipient sign contracts that stipulate their respective rights, commitments, restrictions and liabilities. You and the donor couple will each be asked to sign detailed, specially tailored informed consent documents. However, donating or recipient couples can change their minds right up until the time of transfer. A donating couple could have a change of heart sometime during gestation and challenge the donation agreement. Such a contest would ultimately be adjudicated by the court, but it's impossible to speculate what the outcome would be. Such a dispute may result in highly publicized media attention.

In these untested waters, the legal status of a fetus that grows from a
donated embryo is unclear. As of mid-2005, only a handful of states have laws dealing with embryo donation, which the courts have likened to tissue donation, a gift, and an adoption, (Florida, Oklahoma, Texas, Virginia and North Dakota among them.) Yet embryo donation, precisely because if successful will result in a new person, occupies its own singular place. As a result, the law in this area is extremely unsettled.

A CHILD CANNOT BE ADOPTED BEFORE ITS BIRTH. AT A MINIMUM, LEGAL EXPERTS RECOMMEND THAT DONORS AND RECIPIENTS ENTER INTO A LEGAL AGREEMENT DETAILING THE TERMS AND CONDITIONS OF THE DONATION.

A child cannot be adopted before its birth. At a minimum, legal experts recommend that donors and recipients enter into a legal agreement detailing the terms and conditions of the donation.

You may want some extra insurance in the form of a contract designed to your particular desires and needs. You may want to stipulate and clarify protections against any possible claims by the donors or the siblings beyond what is typical. If you're receiving embryos from someone you know or it's an "open" donation, you may want an attorney to draft a legal document that sets forth the potential relationships you've agreed to with the donor family.

PICKING UP THE TAB
Recipient couples will bear all of the costs relating to the transfer. This will include donor screening and blood work, and the costs of thawing, culture, and transfer of the embryos. Many programs require you to bear (or pick up) the counseling fees for the donors as well. These costs, in 2005, should range from about $2500-$4000. In addition, you may incur other medical costs, as well as legal, psychological counseling and travel expenses.

DOWN THE ROAD
There is very little information on the long-term outcomes of embryo donations because this family building option is so new. Will the impact on donor and recipient families as well as the children be akin to adoption? Will it more resemble gamete donation? Or is it in a class by itself, with emotional and psychological ramifications no one yet
understands?

You and the donors are pioneers in this arena. Both sides are embarking on a unique process in which the givens are few and the outcomes uncertain. But it is a process with enormous potential to help you have the family you want. At the same time, it could provide donors with closure in their own ART journey. That is a gift, too.

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