



IDP

Patient Information

Introduction:

Some embryo recipients choose to tell friends and family about conceiving a child through embryo donation while others prefer to keep the information private. Recently, there has also been a trend towards telling the donor-conceived offspring (DCO) their origin.

In deciding to donate your embryos, you may also have struggled with deciding if you should disclose your decision to donate your remaining cryopreserved embryos to your friends and family, including your existing children who may be directly related to any future embryo donor-conceived offspring (DCO). Your decision to disclose and whom to disclose to is a very personal matter.

Below are some common questions that embryo donors may ask themselves in deciding if they would like to somehow connect with the recipient family and especially the DCO:

- What do the children look like?
- Would they like to meet my family?
- Would I like to connect with the recipient family years from now?
- If I were the child, would I want to know my genetic family?
- Would the child like to meet their siblings?
- What would I want if I were a donor-conceived offspring? How would I feel about the donor family?

Some embryo donors feel it would be most appropriate and perhaps even ideal to eventually be contacted by the DCO. The reasons for considering this option for you, your family, the embryo recipients as well as the DCO, will be outlined in these materials.

To give embryo donors, embryo recipients and the DCO's a choice, Embryo Donation International, P.L., (EDI) developed the Identity Disclosure Program (IDP). ***This program also allows for current anonymity to be maintained until you, the embryo donors, decide when and how it is appropriate that anonymity be discontinued.***

[On a side note, we offer apologies to the single men and women who are donating their embryos. Writing the information below using “I/we” as well as making the sentences in both singular and plural makes the material very difficult to read. As most embryo donors are couples and to simplify the writing style, we wrote this patient information using “we” keeping the sentences in the plural form.]

What is normally told to the DCO by the embryo recipients?

As previously stated, there has been a general trend towards disclosing the embryo donation process to the DCO. Currently, embryo recipients are faced with two different decisions regarding disclosure to the DCO:

1. Disclosure that the embryo donation procedure took place
2. Disclosure that the embryo donation procedure took place plus providing the donor’s medical/social/educational/genetic histories which you provided in your embryo donor application form

All embryo recipients will have the ability to disclose items 1 and 2 above to the DCO using the detailed information available you originally provided in your embryo donor profile. With the IDP, there is now the potential for a third option:

3. Disclosure that the embryo donation procedure took place, providing the donor’s medical/social/educational/genetic histories *plus identifying information about the donors*

It is this third disclosure option involving the release of embryo donor identifying information that is the focus of this supplemental program.

Is the IDP available to all embryo donation procedures performed at EDI?

Remember there are three main embryo donation alternatives here at EDI. As the embryo donor, you decide if the embryos are to be donated anonymously, in an approved fashion or in an open embryo donation procedure.

Anonymous Embryo Donation

Anonymous donations occur when the donors want closure, but do not necessarily desire contact with the embryo recipients at this point in time.

Approved Embryo Donation

Approved procedures are similar to anonymous donations with the addition of a Mental Health Professional (MHP) evaluation of the recipients. The donors then approve of the recipients based on the MHP’s written report describing the recipient’s history, lifestyle and life goals

absent any identifying information about the recipients or the MHP who performed the session.

Open Embryo Donation

Open embryo donation procedures are similar to open adoption proceedings with the parties knowing the identity of the other with legal representation granted to both. In an open embryo donation procedure, an attorney represents each party, and it is common practice to outline identity disclosure issues in the contracts.

Therefore, the embryo donor IDP is available in the anonymous and approved embryo donation procedures.

Why would we want to participate in the IDP?

Below are some of the common reasons why embryo donors may want to participate in the IDP:

1. You feel it is the right of the DCO to know their genetic and family background
2. You may be curious about the DCO and the family in which they were raised
3. Your offspring may be interested in connecting with the DCO, their potential genetic siblings
4. You understand that the DCO may be very curious and want to somehow connect with you

Always remember that you are not the DCO's parents - the embryo recipients are. Research suggests that the DCO's desire to connect with the donors does not in any way compromise the existing relationships between the DCO and their parents. Studies suggest that their love for the parents that raise them doesn't change even after connecting with you and your family.

Learning more about you, the embryo donors, may help the DCO better understand themselves.

Why would embryo recipients want to disclose the genetic origins to their DCO?

There are numerous reasons an embryo recipient might want to disclose the genetic origin to the DCO:

1. Some embryo recipients feel it is the moral right of the DCO to know their origin
2. Many MHP's feel that secrets within the family are difficult to keep and can be destructive
3. Some DCO's discovered their origins later in life (i.e., death of a parent, divorce or inadvertent disclosure by family/friend) leaving them feeling betrayed, angry and isolated

At what age will the DCO be able to contact us?

You first decide if you want to participate in the IDP. Next, you decide what age the DCO should reach before you will allow first contact.

Identifying information about you may be provided only when the DCO reaches the following:

- When the DCO is any age ("DCO any age option")

- When the DCO is six or more years of age (“DCO 6 or older option”)
- When the DCO is 12 or more years of age (“DCO 12 or older option”)
- When the DCO is 18 or more years of age (“DCO legal adult option”)

Some MHP’s recommend that disclosure regarding the origin of the DCO be initiated as early as the child is able to comprehend. If left beyond age ten, the children may experience feelings of mistrust and alienation. Providing identifying information is entirely separate from the basic disclosure that the DCO was conceived using donated embryos. If you agree to participate in the IDP, your identifying information will only be provided when the DCO reaches the age that you feel is most appropriate.

Yet another important facet of the IDP is the decision by EDI to have contact possible before the DCO reaches age 18. Some sperm and egg donation programs encourage contact after age 18 but, if we are really creating the IDP for the good of the child, it seems quite clear that allowing contact earlier than age 18 may be ideal for the health and wellbeing of the DCO. The choice is yours.

May we receive help in making this important decision?

Skilled MHP’s will be available to you upon request to guide you through this decision. The MHP may ask you questions that you may not have thought of. Telemedicine by phone or video may be needed if the MHP is not located close to home. MHP assistance is strongly encouraged although it is not absolutely required by EDI.

If we agree to the IDP, are we certain to be contacted by the embryo recipients or the DCO?

If you agree to the IDP, the embryo recipients, the parents of the DCO, will still have to decide IF to disclose and then precisely WHAT to disclose to the DCO. By agreeing to the IDP, you have the potential for being contacted but contact is not a certainty. Recent publications suggest that about half of the embryo recipients will disclose the genetic origins to the DCO although we don’t know what percentage of that group will actually contact the embryo donors through the IDP if given the opportunity.

We do feel that by creating the IDP, it is likely that full disclosure by the embryo recipients to the DCO will become more common since the potential benefit to the DCO may also increase by connecting with you and your family.

How will the embryo recipients or the adult DCO contact us?

The following must take place before you will be asked to connect with the embryo recipients or the adult DCO:

1. You must have agreed to participate in the IDP.

2. The embryo recipients must provide full disclosure to the DCO including the fact that contact is possible.
3. The DCO must reach the age at which you agreed to contact.
4. The embryo recipients/adult DCO must then contact EDI requesting contact be initiated between the DCO and you, the embryo donors.

Assuming the above takes place, the following will next occur:

1. EDI will contact you and ask what is to be your preferred method of contact. For example, some embryo donors may suggest a letter while others prefer an email or a phone call. We ask that you respond to us within 90 days and hope you will do so quickly.
2. Once the preferred method of contact is provided to EDI, this will be passed on to the embryo recipients or the adult DCO.
3. Once they contact you, we again ask that you respond and connect with them within 90 days although we expect most responses occur quite quickly.

Exactly what contact information will be provided to the embryo recipients or the adult DCO?

When you completed the embryo donation application, a great deal of information was already provided including medical, social, ancestral, family and educational histories. The potential information about the donors provided via the IDP may include, but not necessarily be limited to, the following:

- Donors names
- Last known address
- Telephone numbers
- Email addresses
- Dates of births

Florida state laws, where EDI is located, require that our medical records be kept for at least seven years. The Federal Drug Administration requires that medical records involving donated material be kept for 10 years. EDI commits to keeping the records longer than 10 years but not indefinitely.

Remember that no record collection system is not without risk for loss. Paper records can be destroyed in flood or fire and electronic records can also be destroyed by natural and even unnatural disasters. Therefore, an *absolute guarantee* of providing the identifying information to the embryo recipients or adult DCO cannot be given. Still, EDI does commit to providing the embryo recipients/adult DCO our most up-to-date identifying information about you, the embryo donors.

Will our contact with the embryo recipients or the adult DCO be sustained over time?

As stated in the IDP contract (link), you are agreeing to at least a single contact with the embryo recipients/adult DCO. Any future contact will be decided by mutual consent of all parties.

May we change our minds regarding our participation in the IDP?

The simple answer is “no.” Once you agree to participate in the IDP, you are committing to a potential level of contact by the embryo recipients/adult DCO.

If you do not respond to EDI within 90 days when we ask for the preferred method of contact, your latest contact and identifying information will be provided to the embryo recipients/adult DCO when requested per your stipulations. Also, if you do not respond to the embryo recipients/adult DCO request for contact within 90 days, your latest contact and identifying information will again be provided to the embryo recipients/adult DCO. Lastly, if the contact is made but you did not provide identifying information to the DCO, the DCO will potentially have access to this information when they are 18 years of age or older.

Your decision to participate in the IDP is a true commitment. As part of this agreement, the embryo recipients and/or the adult DCO may eventually be given your identifying information as long as the DCO has reached the age at which you requested or they are 18 years of age or older.

What disclosure issues will we have to consider?

When you decide to donate your cryopreserved embryos, you will have the option to disclose this decision to your own family, friends or even coworkers. Family could also include your children who may very well be the genetic siblings of the DCO.

Many make the decision to donate their embryos very privately and may not disclose their decisions to others for fear of being judged, receiving criticism or even the potential for excommunication, such as in the Catholic religion. For these reasons and others, some patients who donate may not disclose their decisions to others.

If you agree to participate in the IDP, it makes sense that you will eventually disclose your decision to donate your embryos to your current offspring in preparation for the potential contact by the DCO.

May we change our mind regarding the age at which the embryo recipients/adult DCO may contact us?

If you would like to potentially be contacted by the embryo recipients at an *earlier* date than you originally agreed upon, new contracts or addendums will be signed and the embryo recipients notified

of your requested change. You will NOT be allowed to move the age of potential contact to a later DCO age bracket as the embryo recipients agreed to receive your embryos with a potential contact age in mind.

Can the embryo recipients request contact before the age of the DCO we agreed to?

The simple answer is “no.” EDI will adhere to the consent/contract as previously agreed to and will NOT ask you to agree to earlier contact simply because the embryo recipients and/or DCO request it. We feel asking you to make contact earlier would place inappropriate pressure on you.

There are a few potential emergency exceptions regarding a request for earlier contact, which we will take under consideration. These might include, but not necessarily be limited to, the following:

1. In the case where the DCO is in dire need of donated organs (e.g., bone marrow, kidney and/or liver)
2. The life of the DCO may be in true danger and future contact is truly uncertain
3. If EDI is required by court order to divulge contact information
4. If legislation retroactively requires, wherever EDI primary facility is located, that contact information be provided by law

In the examples above, EDI will contact you, explain the circumstances and urge that contact be considered earlier than expected. We are unable to foresee all of the rare possibilities wherein an exception to the consent/contract would be considered. Even with these important exceptions, EDI does not ever guarantee to the embryo recipients or the adult DCO that you will agree to an earlier emergency contact. The choice will be yours.

Are there extra fees associated with the IDP?

Administrative costs are significantly higher with the IDP. EDI must maintain contact with you for extended periods of time, well beyond the original donation. Additional time is also required of the staff to educate all parties and to help set up the initial contact years after the original donation.

Embryo donors will NOT receive any financial reimbursement for participation in the IDP as the decision must be made purely on a voluntary basis without any form of enticement. The embryo recipients pay for any administrative fees involved in the IDP process.

Will we ever be provided the embryo recipient or DCO contact information?

Identifying information about the embryo recipients and/or any DCO created through your donation will NOT be provided unless they provide it themselves at the time of contact.

Will we have any legal rights or responsibilities towards the DCO?

In cases of open embryo donation procedures where the parties know each other from the start, the donors clearly release their legal obligations to the recipients as is outlined in the contracts.

We feel that in the anonymous and approved embryo donation procedures, the Florida Statute 742.14 (shortened ink: <http://bit.ly/1icKd71>) clearly protect the anonymous embryo donors and recipients.

Embryo donors participating in the IDP will have absolutely no legal relationship, rights, responsibilities or obligations to any offspring born using their donated embryos as is already discussed in the embryo donor and embryo recipient EDI consents and is further based upon Florida law. The lack of a legal relationship between the embryo donors and the DCO is also further emphasized in the IDP consent/contract.

Are there potential disadvantages to participating in the IDP?

As with any medical decision, there are always advantages and disadvantages. Here are some of the potential disadvantages:

- By participating in the IDP, you will really need to disclose your decision to donate your remaining embryos to your current children. At some point in time, the DCO may want to contact you and delaying the discussion could be quite difficult.
- Please understand that agreeing to the IDP does not make it a certainty that the recipients or adult DCO will contact you at a later date.
- If you agree to the IDP, it is possible that the embryo recipients and/or DCO will contact you years from now wherein your family situation may be very different than it is today.
- You are asked to update your contact information each year with EDI so that if the embryo recipients and/or the adult DCO contact us, we will be able to provide the most up-to-date contact information.
- There are simply not enough studies available to give you information as to the probable outcome of the potential interactions between the embryo recipients, the DCO and your family. If the adoption world is a potential guide, the potential interactions may be fulfilling for many but not necessarily for all.

What happens if Embryo Donation International closes?

Since many medical practices close or merge with other practices, it is *possible* that EDI will do the same in the years ahead. This is essentially true of all medical practices. If this does occur, EDI will transfer the records to a specific facility and attempt to notify both embryo donors and recipient families of the transfer of records. Please rest assured that your records will be handled with the utmost of confidentiality and care.

IDP, Patient Information (cont.)

I/We have read and understand the above and have had an opportunity to ask questions and have had them answered to my/our satisfaction.

_____ Woman's Signature	_____ Woman's Name (print)	____/____/____ Date
_____ Partner's Signature	_____ Partner's Name (print)	____/____/____ Date
_____ EDI Coordinator's Signature	_____ EDI Coordinator's Name (print)	____/____/____ Date
_____ Physician's Signature	_____ Physician's Name (print)	____/____/____ Date

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