

Get the Facts
Before You Decide!

The New York State Task Force on Life and the Law

Advisory Group on Assisted Reproductive Technologies

The New York State Task Force on Life and the Law was created in 1985 to develop public policy on issues arising from medical advances. The Task Force includes leaders in the fields of law, medicine, nursing, philosophy, consumer rights, religion and ethics.

In 1998, after extensive research and interviews with people involved in fertility treatment, the Task Force found that egg donors frequently are not adequately informed about the process. The Task Force received a grant from the Ford Foundation to create a model process and form for obtaining informed consent, and this guidebook for egg donors.

This guidebook was prepared by the Task Force's Advisory Group on Assisted Reproductive Technologies. The Group included infertility specialists, consumers, ethicists, Task Force members, and representatives of the American College of Obstetricians and Gynecologists and the Society for Assisted Reproductive Technology. In addition, egg donors shared their experiences with the Group and Task Force staff.

# TABLE OF CONTENTS

Introduction5
Who can become an egg donor?5
What does egg donation involve?6
What should I know about ads for egg donors?6
How are egg donors selected?
General medical screening
Infectious disease screening
Screening for inherited disease
Psychological screening
What if I am not accepted?12
Who will use my eggs?
Will the recipient know who I am?
How are donors matched with recipients?
What if someone asks me to donate?
What is the egg donation process?
Stopping your normal cycle
Stimulating egg production
Monitoring your progress
Removing the eggs
Follow-up care
Will donating eggs affect my everyday life?
What happens to the donated eggs?
What is informed consent?

# TABLE OF CONTENTS

Are there other legal and financial considerations?20
Contracts
Confidentiality
Parental rights and responsibilities
Payments
Expenses
Insurance
Can I donate more than once?
Glossary
Checklist: Before you give consent
to donate eggs
New York State Task Force on Life and the Law
Advisory Group on Assisted Reproductive Technologies

# INTRODUCTION

Many couples who want to have children find it difficult or impossible to conceive. Using special techniques, some couples can conceive using their own eggs and sperm. Others must use sperm donated from another man. More recently, egg donation has allowed some women, whose ovaries do not produce enough healthy eggs, to become pregnant using donated eggs.

You may be reading this guidebook because you answered an ad for egg donors or were asked by a friend or relative to consider becoming a donor. If so, you need to learn all you can about the process and think seriously about what it involves before you start. Becoming a donor is a very important decision.

This guidebook provides prospective egg donors with unbiased information. It suggests issues for you to consider and questions to ask before deciding whether or not to become a donor.

### WHO CAN BECOME AN EGG DONOR?

Not all women can donate eggs. Programs vary in the qualities they prefer, but some criteria are fairly standard. Certain rules are set for legal reasons. Other policies are designed to increase the chance that a pregnancy will result and that the process will be safe for both donor and recipient.

Commonly, egg donors must be a certain age, usually 21, and be no more than 35. The lower limit ensures that a woman can legally enter into a contract. The upper limit reflects the fact that older women respond less well to fertility drugs. There is also a chance that an older woman's eggs will be abnormal, making pregnancy less likely or increasing the risk of a birth defect.

Some programs prefer to use donors who have already given birth or successfully donated eggs. It is believed that they are more likely to be fertile and it is easier to anticipate their feelings about having genetic offspring born to someone else.

# WHAT DOES EGG DONATION INVOLVE?

If you apply to become an egg donor you may have several medical visits before you are accepted. These visits will include a physical and gynecological exam, a medical and family history, blood and urine tests, and a psychological evaluation. You will also discuss your rights and responsibilities with a program representative. A donation will not occur unless you are accepted, matched with a woman who will receive your eggs, and give your consent.

Using donated eggs to establish a pregnancy involves *in vitro fertilization* (IVF). First, you will take a series of fertility drugs (some of which must be injected) to stimulate your ovaries to produce many eggs at one time. While using the drugs, you will have frequent medical tests. Removing the eggs from your ovaries involves a minor surgical procedure. After you recover from egg retrieval, your part of the treatment cycle is finished.

Your eggs will then be mixed with sperm from the intended father in the clinic's laboratory. If embryos result, they will be grown in a lab dish before one or more are transferred into the uterus of the recipient. If she becomes pregnant and delivers a child, she will be the birth mother and legal mother of that child even though the child will be genetically related to you.

# WHAT SHOULD I KNOW ABOUT ADS FOR EGG DONORS?

When you answer an ad for egg donors, it is important to find out who placed it. Many infertility programs advertise for egg donors to help treat their patients. These programs provide all the screening, matching, and medical procedures required by the donation.

In some cases, ads are placed by egg brokers. These individuals or organizations recruit egg donors but do not provide medical services. If you contact a broker, be sure to find out who is responsible for each part of the egg donor process. Will you be screened by the broker? Will an infertility program want to repeat those tests? Who will pay your medical bills? What will happen if you develop complications? What will happen to information you provide?

Occasionally, advertisements – supposedly on behalf of a specific couple – will offer a large amount of money to the right egg donor. These ads seek donors with special qualities, such as above-average height, athletic or musical ability, or an Ivy League education. Be aware that, in some cases, there is actually no couple willing to pay the enticing fees. Instead, a broker is trying to attract a large number of applicants. Details about these applicants will be used in the broker's advertising or on its Web site to attract recipients. Some brokers will use the information you give in these ways unless you specifically refuse permission.

You may receive a phone call offering a much lower fee to serve as a donor to another couple. Even if you are never called, information from your application may become available on the Internet.

Remember, the purpose of an ad is to entice you to become an egg donor. Do not rely on an advertisement for details about the process. You will need to read any educational materials and consent forms carefully. Ask questions until you understand the process well enough to make a decision.

# **HOW ARE EGG DONORS SELECTED?**

If you answer an advertisement, you may be interviewed over the telephone, or be sent an application to fill out. Based on your responses, the program may decide that you are unlikely to be chosen, and you may not hear from them again.

If the program decides that you are likely to be chosen, you may be invited to proceed with the selection process. Before you are accepted as an egg donor, however, you will be required to undergo medical and psychological screening.

Before you are screened, program staff should thoroughly describe the procedures and risks involved in donation. That way, if you decide not to proceed, you can avoid the screening process. In any case, do not give your written agreement to become an egg donor before the screening process is complete. After you are screened, you should have access to the results of your medical tests — whether or not you become a donor.

**General medical screening:** You will have a physical examination, including a pelvic exam. Blood will be drawn to check your hormone levels. *Ultrasound* (which uses sound waves, not X rays) will be used to examine your uterus, ovaries and other pelvic organs. These tests might reveal an existing health problem. If anything is found, ask about your options for treatment (either from the program or another health professional).

You will complete a detailed medical and psychological history about yourself and close blood relatives. It will include questions about your use of cigarettes, alcohol, and both prescription and illegal drugs. Many programs conduct unannounced drug tests during the screening and donation process.

**Infectious disease screening:** When blood or tissue is transferred from one person to another, it can carry viruses or bacteria. To minimize the risk that a donor egg could cause illness in the recipient, donors are tested for a variety of infections.

During your pelvic exam, a small scrape from your cervix will be taken to test for gonorrhea and chlamydia. Blood will be drawn to test for syphilis, hepatitis B and C, and HTLV-1 (a very uncommon virus that is associated with some cancers).

You will have a blood test to see if you have been exposed to HIV. New York State Law requires that you consent to this test in writing, after you read about the pros and cons of the test and understand who can receive the results.

Although there has never been a report of this happening, a program should not accept any egg donor who is at increased risk for exposure to HIV or other infections. According to State regulations, you may not donate eggs if you have injected drugs or been engaged in prostitution within the last five years. You are not eligible to donate eggs if, within the last year, you have been diagnosed with syphilis or if you have received acupuncture, a tattoo or body piercing without being certain that sterile procedures were used. If you have had more than one sexual partner in the last six months, you are not eligible to donate eggs. The program may also require your sexual partner(s), if any, to be tested for HIV.

Before you are screened for infectious diseases, make sure you understand the tests, and whether and how you will be given the results. If you have an infection, seek medical treatment to protect your own health and fertility.

Screening for inherited disease: Most programs try to learn all they can about a donor's genetic make-up in order to minimize the chance that a baby will have a birth defect or serious inherited disease. You will be required to provide your complete medical history. You will be asked medical questions about your biological parents, grandparents, brothers and sisters. The program may tell you what information to collect, or they may have you work with a genetic counselor to identify:

- Any birth defects that required surgery or resulted in medical problems (such as a cleft lip, spina bifida or a heart defect).
- Certain genetic disorders (such as Huntington's disease, hemophilia, Tay Sachs disease or sickle cell anemia).
- Inherited diseases that are of special interest to a recipient because of her own family history.
- Any major medical problems, surgeries, mental retardation, or psychiatric problems.

For any close blood relatives who have died, you will need to know how old they were and the cause of death. Some common diseases (such as cancer or heart disease) that strike when people are middle-aged or younger are influenced, at least in part, by genetics.

If you do not have access to the necessary information, either because you are adopted or there is no informed person to ask, you should not become an egg donor.

Some programs do a large number of genetic tests on all donors. Others select specific tests for each donor. Some tests are required by state law. A program may check for disease genes that are common in the ethnic group of either the donor or recipient. You might be tested to address a genetic concern in the family of the recipient, or to answer questions raised by your family history.

Genetic tests usually involve a simple blood test. However, genetic testing may give you information for which you are not prepared or need help to understand. For example, what if you carry a gene that puts you at high risk for breast cancer, or a gene that might create a risk of serious disease in your children? Or, what if you are rejected for medical or life insurance because of your genetic test results? Before undergoing genetic testing, find out:

- Will you receive the results?
- Is a genetic counselor available? If not, will the program refer you to one?
- Will the program give anyone else the results, such as your doctor or insurance company?
- How might the results influence your ability to get insurance coverage in the future?

**Psychological screening:** Donating eggs requires you to confront complex ethical, emotional and social issues. The screening process should help you evaluate your desire to donate and to think through these issues.

You should have a chance to ask questions and express any concerns. In most programs, you will meet with a mental health professional to discuss your life circumstances, your support system, your feelings about the donation, and related issues. In addition, many programs ask donors to take psychological tests.

Another goal of psychological screening is to make sure that you will fulfill the complex requirements of egg donation. Failure to follow instructions can endanger your health and jeopardize the procedure. The program also wants to minimize the chance that you will have regrets or psychological problems, or find the procedures traumatic.

Before you decide to participate, you must try to foresee how you will feel about donating your eggs and the possibility that children will be created who are genetically related to you. You may want to discuss these issues with your spouse, a relative or a trusted friend.

The program should offer you psychological counseling and support throughout the decision making and donation process. Talking with an independent counselor can be helpful, too. If you need help finding one, the program should be able to refer you to an independent counselor who is familiar with infertility treatment issues. The goal of counseling is not to convince you, or help you "adjust" to the program's demands, but rather to better allow you to decide, of your own free will, whether you wish to donate your eggs.

No matter how motivated, most donors do not find the process easy. Take advantage of counseling services offered through the program, and think about who might serve as a good support person.

Organized religions hold various opinions about whether it is appropriate to use donor eggs and sperm in the creation of children. If these views are important to you, you may want to consult a religious advisor before you decide.

The American Society for Reproductive Medicine suggests that a woman should *not* donate eggs if she:

- Has a serious psychological disorder.
- Abuses drugs or alcohol or has several relatives who do.
- Currently uses psychoactive medications.
- Has significant stress in her life.
- Is in an unstable marriage or relationship.
- Has been physically or sexually abused and not received professional treatment.
- Is not mentally capable of understanding or participating in the process.

If any of your close, blood relatives have serious psychiatric disorders, the program needs to know, because some psychiatric disorders may be inherited.

# WHAT IF I AM NOT ACCEPTED?

It's natural to feel rejected if you are not chosen. Sometimes the decision is made to protect you from medical harm. Or, it might become apparent that you may find the process too time-consuming or emotionally difficult. In some cases, it simply means that the right match has not been found.

To prevent prospective donors from dwelling on the reason they were not accepted, some programs will not provide this information. If that is the policy where you are applying, make certain you are comfortable with that before going through the screening.

# WHO WILL USE MY EGGS?

Egg donation is a treatment option for women who do not produce enough normal eggs but are otherwise able to be pregnant. Some of these women have malfunctioning ovaries or entered menopause at an early age. Others are at an age when they produce eggs less readily, even with fertility drugs. Still others tried standard IVF but produced poor quality eggs or embryos.

Less commonly, women decide to use donor eggs because they are aware of an increased risk for inherited disease in their biological offspring. For example, the woman herself may be healthy, but she and her partner may both carry a gene for the same disease. This creates a risk in the child if it inherits the altered gene from both parents. Using an egg donor who does not carry the gene eliminates this risk.

Who will use your eggs depends on the policies of the program. Most often, donor eggs are used by women in their late 30s or 40s who are attempting to become pregnant. Very few women under the age of 36 use donor eggs. Programs have various upper age limits for recipients. Some programs will allow women over age 50 to be recipients.

Most programs will treat unmarried women who are trying to become pregnant without a male partner and who require donor *sperm* as well as donor eggs. Some programs match an egg donor with more than one recipient.

If you have concerns about who might receive your eggs, discuss them with the program before agreeing to become a donor. Some programs allow donors to place restrictions on the use of their eggs. However, no program can guarantee how your eggs will be used.

### WILL THE RECIPIENT KNOW WHO I AM?

Most programs keep the identity of donors confidential (often called "anonymous donation"). If you enter one of these programs, the recipient will have important information about you, but you will never meet or know each other's names. Other programs are more open. They may accept:

- Donors willing to be identified later: Some donors give permission to be contacted once the child reaches a given age.
- Donors willing to meet the recipients: In some programs, the donor and recipient meet to get to know each other and to ask questions.
- Donors who want ongoing relationships with recipients:
   Some programs help donors maintain contact with the recipients, through an occasional photo or card, or a closer role as a special family friend.
- Donors who already have relationships with recipients: A recipient
  may contact a fertility program after she has already asked a friend or
  relative to donate.

No single type of arrangement is right for everyone. Each presents unique challenges during and after the donation.

# HOW ARE DONORS MATCHED WITH RECIPIENTS?

In most infertility programs that use "anonymous" donors, program staff match a recipient with the donor who most closely resembles her, including ethnicity, height, body build, skin type, eye color, and hair color and texture. Once a possible match has been found, the recipient is given information about the donor and decides whether to proceed or wait for another donor.

In some programs, recipients are given information about several possible donors and select the match they would like to pursue. Donors may be asked to take intelligence tests or to provide other information (essays, childhood photos, school transcripts, lists of hobbies, etc.) that will be given to possible recipients. Other programs, however, do not provide this type of information because it implies, without good evidence, that these characteristics are largely determined by genetics.

### WHAT IF SOMEONE ASKS ME TO DONATE?

Some women donate eggs to help a relative or friend who has been unable to have a child. These are often called "known donors."

If someone asks you to donate, it does not automatically mean you can. In New York State, a "known" donor must undergo the same screening as an "anonymous" donor. In addition, the program will make certain that you are not feeling pressured to take part because of your emotional or financial ties to the recipient. For example, you may not be allowed to donate eggs to your boss or to your mother. Because of the risk of inherited disease, you will not be allowed to donate eggs if you are a close blood relative of the intended father.

As a known donor, you must be ready for problems that might emerge later. How will your relationship with the recipient change? What will the child and other family members be told? Will you feel comfortable being an "aunt" or "family friend" to your genetic child?

Even when pregnancy does not occur, egg donation can still have a longlasting impact on a donor's relationship with her relative or friend.

It is valuable (and often required) for a known donor and recipient, along with their spouses, to meet together with a counselor, as well as separately.

# WHAT IS THE EGG DONATION PROCESS?

These are the standard steps in the process and the risks:

**Stopping your normal cycle:** You may be prescribed a medication for one or more weeks to temporarily halt your ovaries' normal functioning.

This makes it easier to control your response to fertility drugs. A doctor or nurse will give you an injection or instruct you about how to inject the medication daily at home.

*The risks:* The medications can cause hot flashes, vaginal dryness, fatigue, sleep problems, body aches, mood swings, breast tenderness, headache, and/or vision problems.

Stimulating egg production: In a normal menstrual cycle, one egg matures and, at ovulation, is released from an egg-containing sac (called a *follicle*) on the ovary. In egg donation, the goal is to obtain several mature eggs. You will be prescribed medication to stimulate your ovaries to mature more eggs than normal (called "controlled hyperstimulation"). The medications are similar to the hormones that your body produces, but at much higher doses. These medications must be injected (either under your skin or into a muscle). Treatment will start on a specific day of your cycle and continue for about ten days. You will be shown how to inject the medications. If you are unable to inject yourself reliably, you will need someone else to do it for you.

The risks: You may develop soreness, redness or mild bruising around the injection site. You may experience mood swings, tender breasts, enlarged ovaries and mild fluid retention. Occasionally, the medications cause more hyperstimulation than intended (known as "ovarian hyperstimulation syndrome," or OHSS). This will cause fluid retention and swelling of the ovaries. In mild OHSS, you may have abdominal pain, pressure and swelling. This should go away after your next period. In moderate OHSS, you may require careful monitoring, bed rest and pain medication. Severe OHSS is rare but can cause serious medical complications, including blood clots, kidney failure, fluid build-up in the lungs, and shock. In rare cases, hospitalization is necessary and the condition can be life-threatening. One or both of your ovaries may have to be removed. The risk of OHSS decreases after the eggs are retrieved.

If you show signs of OHSS before the eggs are ready to be retrieved, the doctor may decide that it is too risky for you to keep taking the hormones. You must stop using the medication and the cycle will be canceled.

If you decide, for some reason, not to undergo egg retrieval after having completed fertility drugs, you increase your risk of OHSS.

Very rarely, an enlarged ovary will twist on its stalk and cut off its blood supply. This painful condition requires immediate surgery and the ovary may have to be removed. Also, very rarely, a woman has an allergic reaction to fertility drugs.

You can become pregnant during the cycle, if you have unprotected intercourse. This could occur if some of the eggs are released before retrieval, or if the doctor is unable to retrieve all of the mature eggs. There is a chance that you could become pregnant with twins, triplets or quadruplets. You must abstain from intercourse or use effective barrier contraception. Ask the doctor about restrictions on intercourse during the donation cycle.

The long-term risks of fertility drugs are unknown. A few studies suggest that fertility drugs might increase a woman's risk for developing ovarian cancer later in life. Others do not show this link. At this time, no one knows for sure.

Monitoring your progress: During the donation cycle, you must have frequent blood tests and ultrasound examinations to track the developing eggs and to see how you are responding to the hormones. Based on these tests, you will be told how to adjust the dose of medication. The ultrasound exams involve inserting an ultrasound probe (about the size of a tampon applicator) into your vagina so the doctor can see the growing follicles on your ovaries.

When the time is right, you will receive a final injection of another drug to prepare the eggs for retrieval. This injection is given shortly before egg retrieval.

The risks: Blood drawing can cause mild discomfort and there is a chance you will develop a bruise in the area where the needle was inserted.

Ultrasound examination may be slightly uncomfortable but has no known risks.

Removing the eggs: The eggs will be removed from your ovaries in a minor surgical procedure called *transvaginal ovarian aspiration*. An ultrasound probe will be inserted into your vagina. A thin needle attached to the probe will be inserted into each follicle. Using suction, the egg and liquid inside each follicle are removed. You may be given painkillers, sedatives or anesthesia during the retrieval, which lasts about 30 minutes. When all the eggs have been retrieved, you will recover for a few hours before going home. You must have someone drive you home. Afterwards, you will need to rest for the day. Often, it takes several days of restricted activity to recover.

The risks: After the needle is inserted into the ovary, there may be bleeding. Although rare, it is possible to damage or puncture the bowel, bladder or nearby blood vessels. In the unlikely possibility of severe internal bleeding or serious damage to the pelvic organs, major abdominal surgery may be needed.

To prevent infection, you may be given antibiotics. If infection occurs, it may affect your own future fertility. Ask the doctor about the risks of all medications used during retrieval.

**Follow-up care:** You should be given clear instructions about what to do if you need medical attention. In some programs, donors return for one or two check-ups. You may also be scheduled to meet with a counselor.

Many programs do not provide follow-up care, and it is normal for a donor to feel let down after her intense involvement in the process ends.

Many women are concerned that giving up some of their eggs may reduce their ability to later become pregnant. If there are no complications, being an egg donor should not affect your later fertility. However, if you develop serious complications, involving bleeding, infection, or loss of an ovary, it may jeopardize your ability to conceive.

# WILL DONATING EGGS AFFECT MY EVERYDAY LIFE?

Egg donation is time-consuming. During the donation cycle, you will be given medications for about three weeks, and you will make several visits to the program for blood tests and ultrasounds.

You will be responsible for arranging your work or school schedule to fit the demands of egg donation. Some donors find it difficult to continue their normal activities. They have trouble keeping up at school or on the job, and in fulfilling their family responsibilities.

You will be required to refrain from drinking alcohol, smoking cigarettes and using illegal drugs. You will not be able to use any prescription or non-prescription drugs without permission. If you are in a sexual relationship, you must abstain from unprotected intercourse during specific weeks of the treatment cycle.

# WHAT HAPPENS TO THE DONATED EGGS?

You must be aware that many things can happen to your eggs after they are removed from your ovaries:

- No embryos may be formed. This may be due to a sperm problem, the condition of the eggs, or a problem in the laboratory. Immature or unfertilized eggs can be discarded as medical waste or used in research.
- Pregnancy may not occur or may end in a *miscarriage*. More than half of egg donor cycles do not lead to successful pregnancies, even when embryos are formed and transferred.
- The recipient may become pregnant with more than one fetus. She and her doctor will decide how many embryos to transfer at one time. Pregnancies involving two or more fetuses are at higher risk of various complications, including miscarriage, premature birth and infant death. If the recipient becomes pregnant with a dangerously high number of fetuses, she may choose to undergo multifetal pregnancy reduction. In this procedure, a lethal chemical is injected into one or more fetuses to lower the number that continue to develop and decrease the risk that the entire pregnancy will be lost or end prematurely.

- More embryos may develop in the laboratory than can safely be transferred to the woman's uterus. The remaining embryos may be frozen and kept in storage for later use. You cannot be certain when a genetic child of yours may be born – it could be nine months or even years after your donation.
- The eggs may go to more than one recipient. One or more women may conceive, using your eggs, now or years from now. Or, no pregnancies may occur.
- The original recipient may never use the frozen embryos. The program may
  ask the recipient to: donate the embryos to another couple; donate the
  embryos to research; leave the embryos frozen indefinitely; or allow the
  embryos to be destroyed.

Once you donate your eggs, their fate is entirely up to the recipient. *You have no say about what happens.* 

# WHAT IS INFORMED CONSENT?

A doctor must obtain your informed consent before treating you. But informed consent is more than a form to be signed. It is the process of helping you fully understand and agree to the medical procedures. Before you give your consent, the doctor who will provide your care should meet with you and answer your questions. If you wish, you should also be able to discuss any concerns or doubts with a nurse, social worker or counselor.

Before giving your consent for the procedures involved in egg donation, you should understand:

- What is involved in each procedure.
- If each procedure is:
  - generally accepted as effective and safe by fertility specialists
     (although thorough research may or may not have been conducted); or
  - 2) new and innovative and not generally accepted among fertility specialists.

- How much experience the program has with each procedure, including the level of training of the professional staff.
- The risks of all medications and procedures, and what will be done if complications occur.

You can change your mind. You cannot be forced to undergo medical procedures against your will. Many programs acknowledge that a donor may withdraw her consent to participate at any time before retrieval of the eggs. Before consenting to donate eggs, make certain you understand and agree to the program's and/or the broker's policy on withdrawing consent.

# ARE THERE OTHER LEGAL AND FINANCIAL CONSIDERATIONS?

**Contracts:** You may be asked to sign one or more contracts with the program and/or the recipient. These contracts may detail your responsibilities and those of the recipient and the program. Contracts are different from consent forms, because they may be legally binding.

Do not sign any contract before you have completed the informed consent process. Do not sign any contract that you do not fully understand. Some programs may require you to meet with a program lawyer to discuss the provisions of the contract. These lawyers represent the program's interests, not yours. You may wish to get independent legal advice before signing.

**Confidentiality:** A program or broker will gather a great deal of information about you from your application and throughout the screening process. In order to donate, you must agree to let a program disclose certain information to potential recipients of your eggs. If you are donating anonymously, the recipient should not be given your name or any information that can be used to identify you.

Before giving any information to an agency or a broker, ask about all the ways it may be used. Do not apply unless you are comfortable with the answers.

If you donate eggs and it results in the birth of a baby, State regulations require the program to keep certain information about you on file. Some of this information may be available to the child. According to current State regulations, no information will be released (unless you give permission) that would allow a child to identify you as the donor. However, it is possible that confidentiality laws and regulations may change in the future. In addition, a program cannot guarantee that someone will not discover confidential information by unauthorized means.

You should also be told under what circumstances, if any, a program might contact you in the future. Do they ever call previous donors to ask them to participate in research? Would you be contacted if the child has an inherited disease or needs a bone marrow transplant?

Parental rights and responsibilities: Once your eggs are retrieved, you have no control over what happens to them. You bear no responsibility for the outcome of the pregnancy. Any documents you sign should make it clear that the recipient is legally and financially responsible for any children that result, no matter what their condition. Ask to see the documents that she will sign, as well.

Although the clear intent is for the recipient to become the legal parent, this is a fairly new area of law and one that most state laws do not address specifically. A program cannot guarantee that this legal understanding will hold up in court (if a dispute arises) or that current laws will stay the same. However, it is extremely unlikely that you would be able to establish yourself as the legal mother of any child born as a result of your donation.

**Payments:** Most fertility programs offer payment to egg donors for their time, effort and discomfort. It is not payment for the eggs themselves and should not depend on the outcome.

If a cycle must be canceled before eggs are retrieved, some (but not all) programs provide partial compensation (often based on the number of days of treatment completed). After egg retrieval, you should receive the full, agreed-upon amount no matter the number or quality of the eggs.

Before signing an agreement, make sure you understand how you will be paid — directly by the recipient, or by the program? Will the program have the money in hand before the cycle starts? Is there any payment for donors who are screened but not selected? What is the payment (if any) if a cycle is canceled prior to retrieval?

According to the Internal Revenue Service (IRS), you must pay taxes on any money you receive for donating your eggs. The program must report how much they pay you, and you should receive a Form 1099 to use in preparing your tax return. Find out if the program will do the necessary IRS reporting and if it will withhold taxes from your payment.

Usually, there is no financial compensation when a woman donates eggs to a relative or friend. If you arrange to be paid outside of the program, the program will not be able to protect you if things do not go as planned.

**Expenses:** Think about what it will cost you to participate. This may include days off from work, transportation to the program, baby-sitting, or other expenses. Find out what records you need to keep, and if you will be reimbursed by the program or recipient.

**Insurance:** In most cases, your medical bills for procedures involved in the donation will be paid, in full, by the program or the recipient. Make sure that this is clearly stated, in writing, before you sign up.

In some programs, donors are required to have their own medical insurance. Ask under what conditions any treatment will be billed to your insurance. In most cases, no planned expenses will be billed to your insurance. However, if complications develop, your insurance may be billed.

Some programs will not accept a donor who does not have insurance.

Others will arrange special, short-term insurance to cover you in the event of medical complications. If this is the case, you need to know:

- Who will pay the insurance premium?
- How long will the coverage last? What if you have long-lasting medical complications? What if a problem arises several months after you have completed your donation?

 How do you access care under the policy? Do you see your private doctor or must you first return to the program?

If no insurance is offered, you need a clear agreement, in writing, of how bills will be paid for complications. If there is a general statement, such as the program "covers all expenses," there are still likely to be restrictions and limitations. Is there a limit on the amount paid? If the recipient is supposed to pay, is it up to you or the program to collect the money? What about problems that appear later? What if you are unable to work or need special care?

Before starting a cycle, you may be asked to sign a statement that waives your right to sue the program for medical malpractice, pain and suffering, or any other expenses resulting from complications. You should consult with an attorney before you sign any such waiver. Even if you do sign, you can still sue to recover any medical expenses, pain and suffering, and other costs associated with injuries or complications caused by the negligence of the program. In the unlikely event that you are injured or have medical complications, and the program is unwilling to assist you, you should see an attorney.

# CAN I DONATE MORE THAN ONCE?

There are no firm rules about how many times a woman can donate her eggs, but there are several reasons why a program may limit repeat donations. For one thing, there are still unanswered questions about the possible long-term impact on a woman's health and fertility. Because of this, programs are often reluctant to expose a healthy woman to the process more than a few times.

Programs are required, by the American Society for Reproductive Medicine and the State Health Department, to limit the number of children created using the same donor.

This limit is necessary, because all children from a single donor will be genetic half-siblings. The small chance that they might meet later in life and be unaware of the relationship raises health concerns about their potential offspring.

Because of the costs involved in screening, some programs ask prospective donors to commit, in advance, to donate eggs several times. Think carefully before agreeing. You do not know how the medications will affect you, how difficult the procedure will be, or how you will react to the possibility of creating genetic offspring.

Do not sign a consent form for more than one cycle of egg donation. Even if you do sign, no one can force you to make multiple donations. On the other hand, it is reasonable for a program or donor egg recipient to want to know if you would consider donating eggs more than once. A recipient may see you as an ideal match and wonder whether, if there is not a successful pregnancy, you would be willing to try again. Or, if a child is born, she may wonder if you would help her conceive that child's little brother or sister.

# **GLOSSARY**

**ART (assisted reproductive technology)** – All treatments or procedures that involve surgically removing eggs from a woman's ovaries and combining the eggs with sperm to help a woman become pregnant.

**Canceled cycle** – An ART cycle in which ovarian stimulation was carried out but which was stopped before eggs were retrieved.

**Egg** – The female reproductive cell, also called an oocyte.

**Egg retrieval** – A procedure to collect the eggs contained in the ovarian follicles.

**Embryo transfer** – Placement of embryos into a woman's uterus through the cervix after in vitro fertilization.

**Fertilization** – The penetration of the egg by the sperm and the resulting combining of genetic material that develops into an embryo.

Follicle – A structure in the ovaries that contains a developing egg.

**Gestation** – The period of time from conception to birth.

**In vitro fertilization (IVF)** – An ART procedure that involves removing eggs from a woman's ovaries and fertilizing them outside her body. The resulting embryos are then transferred into the woman's uterus through the cervix.

**Miscarriage** – A pregnancy ending in the spontaneous loss of the embryo or fetus before 20 weeks of gestation.

**Multifetal pregnancy reduction** – A procedure used to decrease the number of fetuses a woman carries and improve the chances that the remaining fetuses will develop into healthy infants.

**Oocyte** – The female reproductive cell, also called an egg.

**Ovarian stimulation** – The use of drugs to stimulate the ovaries to develop follicles and eggs.

**Sperm** – The male reproductive cell.

**Ultrasound** – A technique used in ART for visualizing the follicles in the ovaries and the gestational sac or fetus in the uterus.

Source: CDC, National Center for Chronic Disease Prevention and Health Promotion, Division of Reproductive Health

# CHECKLIST: BEFORE YOU GIVE CONSENT TO DONATE EGGS

Be sure you carefully read the informed consent documents. Do not give your written consent to become an egg donor unless you have received acceptable answers to all of your questions:

What screening tests will be performed?
What are the pros and cons of genetic testing?
What procedures and medications will be part of your donation process?
Have they been thoroughly described?
What are the risks of any drugs, procedures and anesthesia?
What are the side effects?
What information about you will the program keep on file?
What are all the currently known ways that your eggs or resulting embryos might be used?
What information about you will the program give to the recipient?
What costs might you have to pay if you need treatment for complications?
At what point can you no longer change your mind about the donation?
What financial compensation will you receive for a completed cycle or one canceled before egg retrieval (for various possible reasons)?
Do you fully understand and agree with all conditions?

# NEW YORK STATE TASK FORCE ON LIFE AND THE LAW

# ADVISORY GROUP ON ASSISTED REPRODUCTIVE TECHNOLOGIES

#### Rev. Msgr. John A. Alesandro, J.C.D., J.D.

Episcopal Vicar Western Vicariate Diocese of Rockville Centre

#### Rabbi J. David Bleich, Ph.D.

Professor of Talmud, Yeshiva University Professor of Jewish Law and Ethics Benjamin Cardozo School of Law

#### Owen K. Davis, M.D., F.A.C.O.G.

Associate Professor, Obstetrics and Gynecology Associate Director, In Vitro Fertilization Program Center for Reproductive Medicine and Infertility Weill Medical College of Cornell University Chair of Practice and Membership Committees Society for Assisted Reproductive Technology

#### Nancy N. Dubler, LL.B.

Director, Division of Bioethics
Department of Epidemiology and Social Medicine
Montefiore Medical Center/Albert Einstein College of Medicine

#### Alan Fleischman, M.D.

Senior Vice President
The New York Academy of Medicine

#### Cassandra E. Henderson, M.D.

Medical Director, MIC-Women's Health Services New York, NY Associate Professor of Obstetrics and Gynecology Albert Einstein College of Medicine

#### Margaret R. Hollister, J.D.

Director of HelpLine and Educational Services National RESOLVE

#### Gordon B. Kuttner, M.D., FACOG, FACS

Assistant Professor & Director
Division of Reproductive Endocrinology, Surgery & Fertility
Department of Obstetric and Gynecology
University of Miami School of Medicine
Member, Work Group on Assisted Reproductive Technologies, American College of Obstetricians and Gynecologists

#### Vivian Lewis, M.D.

Director, Reproductive Endocrinology Unit Associate Professor, Obstetrics-Gynecology University of Rochester Medical Center Rochester, NY

#### Ruth Macklin, Ph.D.

Head, Division of Philosophy and History of Medicine Department of Epidemiology and Social Medicine Albert Einstein College of Medicine

#### Kathryn Meyer, J.D.

Chair of the Advisory Group
Senior Vice President and General Counsel
Continuum Health Partners, Inc.
Senior Vice President for Legal Affairs and General Counsel
Beth Israel Medical Center
New York, NY

#### Mark V. Sauer, M.D.

Chief, Division of Reproductive Endocrinology Department of Obstetrics and Gynecology New York Presbyterian Hospital Professor of Obstetrics and Gynecology Columbia University New York, NY

#### Bonnie Steinbock, Ph.D.

Professor of Philosophy
Chair, Department of Philosophy
University at Albany, State University of New York

#### Judith Steinberg Turiel, Ed.D.

Author, <u>Beyond Second Opinions</u> (Berkeley: University of California Press, 1998) Berkeley, CA

#### Staff

#### Dwayne C. Turner, Ph.D., J.D., M.P.H.

Executive Director

New York State Task Force on Life and the Law

#### John Renehan, J.D.

Counsel

New York State Task Force on Life and the Law

#### Dana H.C. Lee, J.D.

Former Project Attorney
New York State Task Force on Life and the Law

#### Carl H. Coleman, J.D.

Associate Professor of Law Seton Hall University School of Law Former Executive Director New York State Task Force on Life and the Law

### Susan E. Ince, M.S.

Consultant

#### Judy Doesschate, J.D.

Division of Legal Affairs New York State Department of Health

#### Jeanne V. Linden, M.D., M.P.H.

Director, Blood and Tissue Resources Program New York State Department of Health



State of New York Department of Health

1127 5/09