Interests, obligations, and rights of the donor in gamete donation

Ethics Committee of the American Society for Reproductive Medicine

Birmingham, Alabama

This Ethics Committee report outlines the interests, obligations, and rights of both male and female donors who choose to provide gametes for use by others. (Fertil Steril® 2009;91:22–7. ©2009 by American Society for Reproductive Medicine.)

INTERESTS, OBLIGATIONS, AND RIGHTS OF THE DONOR IN GAMETE DONATION

1. Programs must respect the rights of donors to be fully informed about legal, medical, and emotional issues involved in gamete donation.
2. Donors must be given clear notice that they can obtain independent legal counsel at any point during the donation process.
3. Programs should strongly encourage donors to provide medical updates if they learn about serious genetic or other conditions that are pertinent to the offspring's health. Programs should clearly inform donors about policies and plans with respect to such medical information.
4. Programs should give consideration to the fact that donors may have interests in learning the outcome of their donation, especially when information sharing or contact between donor and offspring are possible in the future. Programs should clearly inform donors what, if any, information about outcomes will be shared.
5. Programs should fully inform donors of the clinic's policies about information sharing and contact, but they should caution that policies cannot be guaranteed if laws or individual circumstances change.
6. Although data are sparse about the outcomes of contact between donor and offspring, programs and agencies should inform donors that the possibility of contact from offspring in the future cannot be foreclosed. Donors should also be fully informed about the current policies of programs and agencies regarding future contact from offspring.
7. Programs and agencies should maintain accurate records related to tissue donation and are encouraged to set up systems to maintain the donor's psychosocial information and to enable information sharing in the future with any offspring if such information sharing is acceptable to the donor and offspring.

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The use of sperm and egg donors to form families is now well established, and the number of children born each year to parents using egg or sperm donation is growing. With this growth have come inquiries about the interests of offspring and recipient parents. Far less attention, however, has been given to the interests of the donors themselves, such as privacy, selection of recipients, knowledge of outcome from pregnancies resulting from their donated gametes, and contact or noncontact with resulting offspring.

Egg and sperm donation of course differ in important respects: for example, sperm donation involves no physical risks and, because of the relative ease and frequency with which it can be accomplished, may lead to more offspring and increased frequency of donation, including donation at several programs. This statement focuses on issues that affect both egg and sperm donors, such as updates about medical history and the possibility of later donor–offspring contact. Differences will be taken into account where relevant in the discussion.

The affected parties in gamete donation are recipients, offspring, and donors. These parties have distinct but, at times, competing interests. *Recipients* have interests in having healthy offspring and in having an uncomplicated rearing situation. This means that they will want some degree of choice in the gametes they use, and thus the information that they have available about the donor. They will also want to be protected from later involvement from the donor (unless, of course, they wish it). They also may or may not want their child to have information about the donor and the chance to have some kind of future contact. *Offspring* have interests in being healthy and knowing what their health risks are so that preventive or protective steps might be taken. They also may have interests in knowing or not knowing who their genetic parents are and in being able to act on that information. *Donors* have interests in being able to donate, being protected in the process, being treated fairly if injuries occur, and in not having obligations imposed on them without their consent. They may also have an interest in having or not having contact with offspring.

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Contact between donors and offspring has become an issue of special importance, with many Web sites offering assistance to offspring and half-siblings in tracing their origins. This development raises the possibility of unexpected contacts between donors and offspring, as well as among half-siblings. Moreover, heightened sensitivity to the interests of offspring in knowing their genetic histories suggests that donors may bear some responsibilities in the donation process to facilitate the provision of information about their genetic makeup and family health history. The interest of offspring in knowing their genetic origins, however, does not require knowledge of the specific identity of the donor or extend to contact with the donor. Nor is it clear how far donors must go in providing updates about their health information for the benefit of recipients or offspring. But increased attention to this issue suggests the presence of new situations and responsibilities for persons to consider before donating gametes to enable others to have children.

Before donation, informed consent to recipients requires donors to be honest about their family and personal health histories and their behaviors so that genetic and health factors that could affect the health or well-being of offspring are known in advance. Of course, infectious disease and genetic screening should also occur, so that the main burden of protecting the health of recipients and offspring is placed on programs. Less clear is the extent to which, after donation, donors have ongoing responsibilities to keep programs or recipients informed of their health status or new findings that might be of interest to parents to protect the health of offspring.

Still another area of uncertainty is the independent interests that donors may have in the donor process and its outcomes. Whereas some donors may be content with simply providing their gametes, others may be interested in knowing who the recipients are or what the outcome of the donation was (1). In addition, donors may or may not wish some information on or other contact with offspring. These interests may conflict with the interests of programs, recipients, and offspring in privacy, autonomy, or in having information about the genetic and social characteristics of the donor (2).

At present, there is little consensus about how best to balance these competing factors. As with so many transactions in the health area, much will depend on initial expectations and disclosures and on the terms that donors, recipients, and programs set for the relationship. Consequently, programs must be explicit about expectations as to whether there will be no or any future information sharing, as well as about policies regarding contact between donors and offspring. Any guarantees that programs give, however, may be affected by future legal change. So too may the donor's personal circumstances change in a way that affects their willingness to provide information at a future time. In addition, programs often go out of business or change hands, leaving unclear how donors will be able to provide updated information or where donors and offspring can arrange for future information exchange or even contact to occur.

In short, the greater acceptance and use of gamete donation has led to a more fluid and continuous set of relationships than existed when the world of sperm and even egg donation was much simpler. Instead of a one-time event substituting the donor's gametes for that of a spouse or partner, the process has moved toward a more continuous and on-going set of relationships of still uncertain scope. The relationship is changing from one with absolute anonymity into more fluid conceptualizations of information exchange and relative anonymity. With these changes comes a need to examine the ethical issues that arise for gamete donors in the donation process (3). In this statement, we begin to identify some of the medical, ethical, and social interests and conflicts that can arise, indicating, where possible, guidelines or resolutions.

DONATION AND DISCLOSURE

Persons choose to provide gametes to other persons for noncoital reproduction for a variety of reasons, ranging from compensation, to altruism, to wanting children without the responsibilities of rearing them. Some may want a time- and relation-limited transaction that hands control over to others and maximally protects their privacy, whereas others may want a varying mix of input over recipients, knowledge of outcome, and information or other relational contact with offspring.

Gamete donation makes possible the birth of a new person and affects many people in the process, including the recipients and offspring. As a result, it should be clear that donors have certain responsibilities in these arrangements about which they should be informed at the outset and corresponding limitation on their ability to set the terms of the transactions.

Honesty and Full Disclosure of Health History and Status

It is the duty of programs and others facilitating these arrangements to screen donors for infectious disease and genetic risk factors. Because the medical and genetic status of a person will affect the willingness of recipients to accept a donation and affect the well-being of any potential offspring, it is essential that donors be honest about their medical and social history so that factors that might exclude them will become known. These requirements should be fully disclosed to donors as part of the process of informed consent.

Duty to Update Health Status

An emerging issue is the extent to which donors have a duty to keep the program, recipient, or offspring informed of health events that may be relevant to the status and health of offspring. A model that is time-bound and cuts off all relations at the donation would imply that there is no such duty, whereas one that sees the donor–offspring relationship as an ongoing one, with mutual duties and responsibilities, would imply that there is a responsibility to provide health updates to the program or another locus that could then pass them on to the parent or offspring. This, however, may be more of an intrusion than many donors would choose. Moreover, growing sophistication in whole-genome screening could lead to

TABLE 1

Levels of gamete donor information sharing.

Level 1	Non-identifying information	Donor provides non-identifying medical or biographical information
Level 2	Non-identifying contact for medical updates	Donor agrees to be contacted with anonymity intact by the program for medical updates and further information if requested
Level 3	Non-identifying personal contact	Donor agrees to have non-identifying contact when the child reaches a certain age and both agree to the disclosure
Level 4	Identifying personal contact	Donor agrees to have identifying information shared with the offspring when the child reaches the age of maturity and both agree to the disclosure

ASRM Ethics Committee. Interests of the gamete donor. Fertil Steril 2008.

more efficient ways to obtain genetic information relative to offspring health.

LEVELS OF INFORMATION SHARING

Four levels of donor information sharing can be identified, ranging from basic to comprehensive (Table 1): [1] non-identifying information, [2] non-identifying contact for medical updates, [3] non-identifying personal contact, and [4] identifying information.

Non-identifying information is the donor's provision of medical or biographical information, such as a statement or letter to be given early to recipient couples. This practice is available in most programs.

Non-identifying contact for medical updates is the donor's willingness be contacted with anonymity maintained by the program to provide medical updates and further information if requested by parents seeking to learn more about the child's health conditions. This category also covers the donor's initiative in contacting the program with news about serious genetic or other conditions pertinent to the offspring's health.

Non-identifying personal contact is the willingness to have non-identifying contact with the donor when the child reaches a certain age and both agree to the disclosure.

Identifying information is a willingness to have identifying information shared with the offspring when the child reaches the age of maturity and both agree to the disclosure.

Gamete donation has traditionally followed a model of anonymity and either non-identifying information or non-identifying contact for medical information, with the gamete donor having little or no involvement with the recipient family over time. In anonymous donation, potential recipients look through profiles in catalogues or Web sites to learn about the background, personalities, and medical histories of potential donors and their families. Studies indicate that donors are generally satisfied with this level of involvement* (4–6); yet anecdotal cases and some studies indicate that donors may have different feelings about their donation years after the fact (7). Changing norms about the wisdom of anonymity in gamete donation, moreover, make it timely to ask whether this model of gamete donation is too narrow in the way it situates the donor as a mere provider rather than a participant in a complex process, with responsibilities as well as rights (8, 9).

DONOR INTERESTS AND RIGHTS

Gamete donors have a right to be fully informed of the risks of the process, including, but not limited to, the medical risks. The medical risks are, of course, quite different for egg than for sperm donation. Programs also have an ethical obligation to ensure that donors have adequate insurance coverage for medical complications, either requiring purchase by the recipient of a health insurance policy or confirming coverage. Donors also should be informed as to whether genetic tests will be carried out and be told of the clinic's policy in apprising them of test results, which may include unexpected information.

Donors also should be informed that donation will ordinarily sever all legal rights and duties to rear or have contact with any resulting children (or even to know if they exist). Donors have the right to be informed that they can obtain independent legal counsel. Donors also should be informed about details relating to their compensation. They should be counseled about the emotional benefits and risks of donation, and they should be aware that data are lacking about the long-term emotional and psychological aspects of gamete donation.

It is also advisable to discuss with donors the broader context in which they are participating in a donation program. Donors should be made aware that they are not necessarily acting alone. If they have children or plan to have children in the future, their children will, if donation is successful, have genetic half-siblings, some of whom may be together in the same family. Thus, donors should be counseled to consider the potential impact on their own children and to think about whether their own children should be told about the donation. Donors should be advised to think about their

children's interests if the latter learn they may or do have genetic half-siblings but are unable to find out more about them. Donors also should be advised that their present or future spouse(s) or partner(s) may have an interest in the consequences of the donation.

Considering the impact of donation on the donor's own family may become more important in years to come. Inadvertent disclosure has occurred in some cases in which offspring have identified their donors using mechanisms available through the Internet. From this and other methods, identity disclosure can take place regardless of clinic policies about anonymity and the understanding reached between clinic and donor at the time of donation. In addition, the legal basis for anonymity also could be challenged in the future by courts or legislatures that weigh the offspring's interest in knowing his or her genetic origins more strongly than the donor's interest in privacy. Some countries, such as the United Kingdom, Sweden, and states in Australia, mandate that donors' anonymity be lifted when the child reaches the age of majority. Because children born through donated gametes were not party to the decision making, in these mandates, the needs of the children to learn of their origins supersede those of the adults who voluntarily participate in the process. Some programs in the United States also are changing their policies to allow the release of the donor's identifying information to offspring when mutually sought by both parties. In short, the possibility of inadvertent or mandated disclosure points to the wisdom of weighing the implications of this issue during the consent process.

DONOR RESPONSIBILITIES

Donors need to be truthful and honest with all information they provide. We have also suggested previously that donors be encouraged to consider the impact of their donation on their own family members, particularly in the event of future inadvertent disclosure. It also is advisable for donors to consider the interests of the recipients or offspring in being notified about medical information later learned by the donor that may have an impact on the health of the offspring, such as the discovery that the donor carries a gene making him or her particularly susceptible to a form of cancer.

The donor contributes a supreme benefit to the recipients—the opportunity to have a child. Notwithstanding certain legal responsibilities (depending upon applicable law in a given jurisdiction), the donor may have an ethical obligation to consider authorizing some kind of disclosure to the offspring. This is not to say the donor is obligated to agree to identifying personal contact—among other concerns, a policy of mandatory disclosure might severely reduce the number of eligible donors. It is to say, however, that respect for the recipient's or offspring's interests might require that the donor consider how release of non-identifying information (or the lack of it) may affect the potential child.

The Ethics Committee of the American Society for Reproductive Medicine (ASRM) has previously reviewed issues relating to disclosure to the child by the recipient parent(s) of the fact of gamete donation in her or his conception. The Committee recommended that disclosure is "ultimately the choice of recipient parents" but that "disclosure to offspring of the use of donor gametes is encouraged" (10). If the parents do tell the child of his or her origins, the question of disclosure becomes more important because some children will want more information. Moreover, in an age of genetic medicine, there is a risk of inadvertent discovery as children and parents have genetic testing for a variety of reasons. If parents tell the child of his or her conception but the child cannot learn more about the donor, this could be emotionally difficult for some children. Thus, the donor may consider the emotional interests of the potential child when selecting an assisted reproductive technology program and the choices the program permits for different levels of disclosure.

At a minimum, donors should be encouraged to provide the first and second levels of disclosure, including medical updates when appropriate. This is a logical extension of a donor's intentions to help another couple procreate. It is reasonable to suppose that a person who goes so far as to donate would also be willing to take a step related to the offspring's future health. However, this responsibility does not extent to an ethical obligation to help that child by, for example, agreeing to be a living donor for organ transplantation. It is also recognized that a donor may have a change of circumstances or attitude that would make contact undesirable.

Although arguably not as compelling as the case for transferring medical information, there are also strong ethical reasons for respecting the non-identifying contact of the third level of disclosure. Giving children the opportunity to find out more about their genetic parents is a way of respecting the child's interest in knowing his or her origins. It also gives some measure of autonomy to the offspring.

There are also arguments for the fourth level of disclosure, permitting identifying contact, but here the donor's interests in anonymity may prevail. A donor who agrees with identifying contact can help ward off inadvertent contact—which may be damaging for all involved—in the event donors cannot fully protect their anonymity and other factors. Planned disclosure of a gamete donor's identity, if all agree, allows accurate information to be given, and it has the potential of satisfying the intellectual and/or emotional needs of a child who enters young adulthood. On the other hand, the impact of identifying contact on the willingness of people to serve as gamete donors is unknown. Although some offspring are likely to desire contact with donors, a positive outcome cannot be guaranteed. Disclosure and subsequent contact may not yield the results the offspring and his or her parent(s) anticipate or desire. Nor will contact necessarily be positive for the donor if his or her wishes regarding future contact are not respected or if unwanted demands are made. Because of the potential disadvantages of required contact, it should be strongly encouraged but not mandated.

However, informed consent discussions with donors should include their consideration of allowing contact in the future if their circumstances at that time allow it. The recommendation that children should be told the circumstances of their conception is accompanied by the supposition that openness is better for the offspring, which has not been substantiated by reliable data. It is incumbent on professionals, programs, and agencies to counsel all participants about the possibility for contact. In the consent process, the donor should be asked whether she or he is willing to have contact with any offspring born, because it is the donor who bears much of the emotional and psychological burden of managing this contact.

However, complicated and competing interests go into decisions about future contact. Asking donors or recipients to project 18 years into the future is fraught with uncertainty. Consequently, all participants must be counseled and be willing to accept that circumstances may change an original agreement to permit openness. The donor, recipients, and offspring all have the right to withdraw any agreement for openness.

DONOR PREFERENCES TO LEARN THE OUTCOME OF THE DONATION

The donor may have other interests not necessarily covered in the consent process, such as the request to be informed of the outcome of the cycle. This could include news about whether a pregnancy resulted and a birth occurred, and whether the baby was born healthy. Arguably, programs are not ethically bound to reveal the outcome because [1] donation is equivalent to the blood donation model, whereby the donation is made without regard to the outcome, [2] news of a successful cycle may unexpectedly cause distress to the donor, [3] news of an unsuccessful cycle may cause the donor to develop unwarranted fertility concerns that affect her or his own family planning, and [4] the donor's eggs may result in frozen embryos that may be utilized in a cycle at a time very distant from the original cycle, and the donor may be unprepared to receive this information or the contact may place an undue burden on the clinic. Moreover, as a practical matter, some parts of the outcome would violate the privacy rights of the mother if disclosed involuntarily, such as whether she experienced medical complications during the pregnancy. However, donors are entitled, upon request, to be provided with available genetic or appropriate medical information that comes to light from the donation or any resulting offspring that may affect their health or the health of their own family.

On the other hand, it can be argued that the outcome should be disclosed because [1] in matters as important as reproduction, donors may deserve to know whether their gametes resulted in a pregnancy, [2] knowledge of the outcome could be helpful in the event of planned or unplanned contact from the offspring, [3] knowledge would give donors the opportunity to tell their children about genetic half-siblings, and [4] knowledge of the outcome may help donors put psychological closure on their participation. We encourage programs and clinics in the consent process to give donors the option of learning about whether a child was born. This information can offer psychological closure to the donor, caution the donor that contact may later occur, and give donors who already have children the opportunity to consider the impact of future contacts on their children and/or partner.

Nevertheless, because there are no data from studies to support either side of the argument regarding the disclosure or nondisclosure of the outcome of the cycle, it is ethically acceptable for programs not to inform donors of the outcome.

Programs that plan to disclose delivery outcomes, if requested, also should inform donors as to whether supernumerary frozen embryos remain. At the very least, donors should be informed that their gametes may result in embryos that may be frozen unused but preserved for future use. Donors also should be informed about what those future uses may be. Cryopreserved embryos may later result in more offspring and may go to more than one recipient, thereby raising the potential for unanticipated contact. The emotional impact of contact from multiple offspring remains unknown and, consequently, the choice for the donor to be prepared for multiple contacts should be offered. In addition, a donor's psychological need to know the outcome or to be prepared for future contact supports the principle that the donor's decision to know or not know the outcome should prevail over that of the recipient. Moreover, donors should be told whether spare embryos might possibly be donated for research, which may affect their willingness to donate. Donors should be informed that they do not have any claim to any spare embryos in the future.

Donors also may ask to specify the categories of people to whom the gametes will be given. For example, a donor may want to donate only to couples in their 20s or 30s or to married or gay couples. Requests could conceivably be made for age, marital status, health status, sexual orientation, race, religion, or education. Programs may refuse to allow donors to participate if such restrictions are demanded by the donor. The principal argument for directed donation is that it is autonomous and the donor has the right to specify the type of person to receive this gift, but clinics can find this ethically unacceptable. Donations to specific individuals are acceptable, but a program may decline to participate for good faith reasons. Internet sites also can be set up to arrange this kind of matching; if this occurs anyway, it might make sense for clinics to enable privately arranged matches. On the other hand, directed egg donation may not be practicable owing to the shortage of egg donors. Moreover, in some situations the direction could be contrary to clinic policy. If, for example, the clinic will not discriminate against patients with HIV and a donor expressly asks for the gametes not to be given to patients with HIV, acquiescence to the request would lead the clinic to violate its own policy. Moreover, the traditional model of anonymous organ donation suggests that selection of categories of recipients undercuts the altruistic principle of donation. Consequently, directed donation is not part of the anonymous organ donation process. This suggests that

it is ethically acceptable to select recipients in anonymous gamete donation without regard to the donor's preferences, and donors should be counseled to this effect.

REPEATED DONATIONS

Donors may request to donate repeatedly. As a condition for accepting the donor, it is ethical for a program to require donors to disclose the extent of their donation in other programs. The general practice of agencies, sperm banks, and assisted reproductive technology programs is to limit the number of offspring per donor; in egg donation the number of cycles is limited for medical considerations (11). If the donor agrees to have contact with offspring, the psychological and emotional burden has the potential to be too great as numerous encounters result. Limiting the number also takes into account the potential emotional impact on the offspring of learning they have multiple genetic half-siblings and the potential emotional impact on the donor's children of learning they have multiple genetic half-siblings.

SUMMARY

Traditional practices of anonymity in gamete donation are slowly changing. The ASRM Ethics Committee and other advisory groups and researchers have encouraged recipient parent(s) to disclose the fact of gamete donation to offspring, and a growing number of clinics provide for some form of future contact between donor and offspring if the participants agree. As gamete donation continues to grow and change, new questions of ethics arise. Gamete donation is more than a transfer of gametes from one party to another. It is part of a method of family building that involves a complex interchange of emotions and psychological needs of donor, recipient, offspring, and, potentially, the donor's family. This calls for a re-examination of the consent process and new attention to the landscape of ethical responsibilities as well as the rights of involved parties to one another.

This statement focused on the interests of gamete donors. It highlighted donors' possible need for information in the consent process, and it addressed preferences expressed by donors over who should receive their gametes, what they should be told about the outcome of donation, and the number of times they donate. It also considered the responsibilities donors have to their own families, to recipient families, and to offspring conceived with their gametes. As a minimum, donors have an obligation to authorize the disclosure of non-identifying medical information where appropriate. Donors also should be encouraged to consider allowing non-identifying and/or personal contact in the future if the offspring and donor agree. By implication, programs and agencies should include discussions in their consent process about the donor's role in agreeing to, or in not agreeing to, requests in the future for medical or other information. At the time of the donation process, programs also should make clear that law and circumstances may change and that promises of anonymity or future contact cannot be assured.

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