Interests, obligations, and rights in gamete and embryo donation: an Ethics Committee opinion

Ethics Committee of the American Society for Reproductive Medicine
American Society for Reproductive Medicine, Birmingham, Alabama

This Ethics Committee report outlines the interests, obligations, and rights of all parties involved in gamete and embryo donation: both males and females who choose to provide gametes or embryos for use by others, recipients of donated gametes and embryos, individuals born as a result of gamete or embryo donation, and the programs that provide donated gametes and embryos to patients. This document replaces the document “Interests, obligations, and rights of the donor in gamete donation,” last published in 2014. (Fertil Steril® 2019;111:664–70. ©2019 by American Society for Reproductive Medicine.)

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KEY POINTS

- Programs should inform gamete donors and individuals donating embryos, as well as recipients of donor gametes and donated embryos, about potential legal, medical, and psychosocial issues involved in their donation.
- Programs should inform donors and recipients that they may be screened for specific infectious diseases and other health-related risk factors, including genetic testing, and provide them with the results of such testing, inform them of the significance of any medical conditions that are discovered, and offer donors and recipients referral if further counseling or medical care is warranted.
- Donors should be given clear notice that although they may withdraw from the donation process at any point, they no longer have dispositional control over their donated gametes or embryos once procured unless a valid contract between the parties provides otherwise.
- Individuals should be informed that donating gametes or embryos does not give them legal rights or duties to rear any resulting children. Recipients should be informed that upon procurement of gametes or embryos, they assume legal rights and duties over the gametes, embryos, and any resulting children produced from the donation.
- Programs should consider that donors may have interests in learning the outcome of their donation, including whether any children have resulted from their participation. Programs should clearly inform donors and recipients before initiating care, what, if any, information will be shared; this preference should be documented.
- Programs should caution participants that policies related to information sharing are not guaranteed since laws or individual circumstances change and that there is a possibility they may be contacted by offspring in the future. Similarly, maintaining anonymity of parties cannot be guaranteed since commercially available genetic testing and agencies that allow dissemination of identifying information through social media increases the risk of inadvertent disclosure of participants.
- Programs should strongly encourage donors and recipients to provide the program with medical updates if they learn of serious genetic or other conditions that are pertinent to the health of individuals sharing genetic relationships or might be significant to the health of a donor’s future children.
- Programs are strongly encouraged to develop and make available written policies setting out the mechanisms for collecting medical updates from donors and recipients, and, if applicable, for making available or distributing newly acquired medical information to individuals whose health may be impacted by this information.
- Donors, recipients, and programs must recognize that they have a
These individuals also may have an interest in knowing about steps that might be taken to safeguard their future well-being. What their health risks are so that preventive or protective measures can be taken. Donors have an interest in being healthy and knowing about the opportunity for future contact. Individuals born as a result of donation have an interest in being healthy and knowing about the donor(s) and any information that is available about them.

The use of sperm and egg donors in reproductive medicine, as well as the donation of embryos from individuals who themselves were enrolled in assisted reproduction, is now firmly established practice. As a result, concerns regarding the ability to share information related to the genetic, health, and ancestral past history of the donors have arisen. Less attention, however, has been given to the interests of the donors themselves, such as privacy, information about medical or genetic conditions discovered through screening or subsequent medical care if injuries occur as a result of donation, selection of recipients, knowledge of outcome from pregnancies resulting from their donated gametes and embryos, disclosure of adverse pregnancy outcome events, and contact or noncontact with individuals born as a result of their participation.

The term “donor” has been used conventionally for decades to describe an individual who provides gametes (eggs or sperm) that have been manipulated outside the human body with the intent of producing a pregnancy in a recipient. Typically, gamete donors do not intend to establish a legal relationship (that is, no parental rights or responsibilities) with any resulting child. The present statement focuses on matters that affect both egg and sperm donors, as well as individuals who donate embryos to programs for reproductive purposes. Important issues include updates about medical history and the possibility of later contact between participants. Differences will be taken into account where relevant in the discussion.

The involved parties in gamete donation and embryo donation are the donors, the recipients or intended parents, and the individuals born as a result of the donation. These parties have distinct but, at times, competing interests. These interests may give rise to rights and corresponding obligations. At present, there is little consensus about how to balance conflicting interests or define the rights and responsibilities of donors, recipients, and programs. For this reason, it is especially important that programs are explicit about expectations regarding future information sharing and contact between donors and individuals born as a result of donation.

Recipients have interests in bearing healthy children. This means that they will want some degree of choice in the gametes or embryos they use and therefore will seek personal information that is available about the donor(s). They may also want to have a say in the extent of their future involvement, if any, with the donor(s). Intended parents also may or may not want their child to have information about the donor(s) and the opportunity for future contact. Individuals born as a result of donation have an interest in being healthy and knowing what their health risks are so that preventive or protective steps might be taken to safeguard their future well-being. These individuals also may have an interest in knowing about their genetic and ancestral origins and in being able to act on that information. Donors have an interest in being able to donate, being protected in the process, being treated fairly if injuries occur, and not having obligations imposed on them without their consent. They also may have an interest in having contact with individuals born as a result of their donation.

Contact between donors and individuals born as a result of their donation has become an issue of special importance, with many websites offering assistance to donor-conceived people wishing to trace their genetic origins. This development raises the possibility of unexpected contact between donors and persons conceived from donated gametes or embryos, as well as between other unknown genetically related parties that may be unaware of a donor’s participation (for example, children of gamete and embryo donors who share a genetic link). Moreover, heightened sensitivity to the interests of individuals born as a result of donation in knowing their genetic and ancestral histories suggests that donors may bear some responsibility in the donation process to facilitate the provision of accurate information about pedigree and their family health history. The interest of individuals knowing their origins, however, neither requires knowledge of the specific identity of the donor nor extends to contact with the donor. It is also unclear to what extent donors must go in providing updates about their health information for the benefit of recipients or genetically related individuals. However, increased public attention to this issue suggests the presence of evolving responsibilities for persons to consider before donating gametes or embryos to enable others to have children.

Before gamete or embryo donation occurs, informed consent requires donors to be honest about their family and personal health histories, and their personal behaviors, to ascertain genetic and health risks that could affect the well-being of genetically related individuals. Less clear is the extent to which, after donation, donors have ongoing responsibilities to keep programs or recipients informed of their health status or disclose any new medical findings that might be of interest to parents to protect the health of children born from donation.

Another area of uncertainty relates to the independent interests that donors may have in the treatment process and its outcomes. Whereas some donors may be content with simply providing their gametes or embryos, others may be interested in knowing more personal information about the recipients or the outcome of their donation, including any complications that may arise (1). These interests may conflict with the interests of programs providing clinical services, recipients, and individuals born from donation regarding privacy, autonomy, or information sharing (2).

At present, there is little consensus about how best to balance these competing interests. As with many transactions involving health care, much will depend on initial expectations, disclosures, and agreed terms that donors, recipients, and programs set for the relationship. Consequently, programs must be explicit about expectations, best documented by written policies, as to whether there will be any or no future information sharing, as well as about policies regarding contact between the various parties.
Because the law in this area is evolving, and because it is becoming increasingly easy to conduct searches for individuals on the Internet or through social media, programs should make it clear to donors that they cannot guarantee immunity from future contact by recipients or offspring. Recipients also should be aware that changes in donors’ personal circumstances could affect their willingness to provide information at a future time. In addition, programs and agencies may close or change ownership, leaving it unclear how participants would be able to provide updated information or arrange future information exchange or contact to occur. Also, past records may not be available.

In short, the greater acceptance and use of gamete and embryo donation has led to changing expectations about relationships among recipients, children born from donation, and donors. For example, the expectation of absolute anonymity has evolved into an expectation that recipients will have more information about donors, and vice versa, and even a possibility of future contact between parties. With these changes comes a need to examine the ethical issues that arise for gamete and embryo donors in the donation process (1). In the present statement, we identify some of the medical, ethical, and social interests and conflicts that can arise, indicating, where possible, guidelines or resolutions.

INTERESTS, RIGHTS, AND DUTIES OF RECIPIENTS

Recipients have an interest in having healthy children and defining a relationship with the donor that best fits their values and conception of family. For many, this will mean no contact with the gamete or embryo donor, while others may prefer some degree of contact among donor, recipient, and resulting children. Recipients typically want the autonomy to exercise some degree of choice in the gametes they use, and toward that end, they desire information about the donor’s physical, psychological, and cognitive characteristics. They often have an interest in the family and personal health histories of donors, as well as an interest in knowing about behaviors that could impact the health and well-being of individuals conceived through donation. They may hope to have updates from donors about changes in their health status that could be relevant to the health of children born as the result of donation.

Recipient interests may conflict with the interests of donors who may be concerned about protecting their personal privacy and being free from burdensome reporting requirements. Although donors and recipients may disagree about how to balance competing and conflicting interests, at a minimum, recipients and programs have a right that donors be honest and forthcoming about their health histories and behaviors relevant to offspring health. Because the medical and genetic status of a person will affect the willingness of recipients to accept a donation and may affect the well-being of potential offspring, it is essential that donors be truthful about their medical and social history so that factors that might exclude them become known. These safeguards should be fully disclosed to donors as part of the process of informed consent.

INTERESTS AND RIGHTS OF OFFSPRING

Individuals born as a result of donation presumably share with the recipients of donor gametes and embryos—who, in most cases, are their rearing parents—an interest in being healthy and knowing their health risks so that preventive or protective measures might be taken. To promote this interest, they may have a right to non-identifying medical information about donors that is relevant to their own health status and risks. Some individuals also may have an interest in having non-medical information about their genetic origins and personal attributes. Whether they have a right to this information is less clear, because their interest in this information may be at odds with their parents’ judgments about whether providing them with this information is in their best interest and the interest of the family. That said, nothing prohibits donor-conceived persons from searching out information about their donor when they are capable and interested in so doing.

More controversial is whether individuals born as a result of donation have a right to identifying information, and the possibility of contact with the gamete or embryo donor, because these interests may diverge from the interests of donors who wish to remain anonymous, as well as from the interests of the rearing parents, if they do not want contact between the donor(s) and child. One argument for providing identifying information to individuals when they reach the age of majority is the comparison with adoption, where it has become increasingly accepted that children have a right at least to medically relevant non-identifying information, and perhaps to identifying information of and the opportunity to contact with genetic relatives. Others argue that there are important differences between adoption and gamete donation. In cases of adoption, the woman who relinquishes her rearing rights and responsibilities gives birth to the child; she is appropriately considered the “birth mother.” In contrast, those who donate gametes or embryos do not have a legal parental role. The appropriateness of the adoption analogy to gamete and embryo donation will undoubtedly continue to be debated, as well as whether individuals born following donation have a right to identifying information about the gamete and embryo donors.

INTERESTS, RIGHTS, AND DUTIES OF DONORS

People choose to provide gametes or embryos for a variety of reasons, including a desire to help others have children and, in the case of gamete donors, compensation. These reasons are not mutually exclusive. Thus, donors share with recipients an interest in being able to donate and in not encountering unreasonable obstacles placed in the way of donation. Donors also have an interest in their own health and ability to make fully informed decisions, and in the case of egg donors, about undergoing medical treatments and procedures, especially when these tasks are primarily for the benefit of others. Gamete donors have a right to be fully informed of the risks
of participating, starting with the medical risks. Donors should also be counseled about the emotional and psychological benefits and risks of donation, and they should be aware that data are lacking about the long-term emotional and psychological impact of participating in gamete donation.

Programs or agencies should specify the amount of payment that the gamete donor is to receive and the terms for which payment will be rendered. Regarding egg donation, it should be stated that payment is for service and effort and not dependent upon the number or quality of eggs retrieved. Therefore, a payment schedule may be reasonably invoked in which a donor is given full payment for the screening, ovarian stimulation, monitoring, and egg retrieval. There should be a written advance directive related to the partial payment of donor services in cases in which donors or treating physicians halt treatment before egg retrieval, because occasionally egg donors will discontinue participation for personal or medical reasons. Payments for sperm donation are usually made on a per-specimen basis for samples that meet clinical criteria. Written directives related to behavioral requirements (for example, abstinence intervals, avoidance of hot tubs, and high-risk sexual behaviors) and a schedule for their payments also should be defined.

It is also advisable to discuss with donors the broader context in which they are participating. Donors of gametes and embryos should be aware that they are not necessarily acting alone. 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 their donation.

The risks of complications from egg donation are low, but real and potentially severe (3, 4). Egg donors have not only a donation.

The conventional model of anonymity has been questioned, in part because of a conviction of some that people have a right to information about their genetic origins that goes beyond non-identifying medical information, but also because some donors want to know the result of their donation, and some would like information about children who were created and perhaps even develop a relationship with them. Some maintain that the anonymity model makes the donor a mere provider of genetic material, instead of a participant who has both rights and moral responsibilities (9–11), including a right to information about the result of donation, an ongoing and lifelong responsibility to provide information relevant to protecting the health of the child, and a right to some level of participation in the recipient family, including contact with individuals born from their donation.

Some countries, such as the United Kingdom and Sweden, mandate that gamete donors’ anonymity be lifted when the child reaches the age of majority. In the United States, some programs are changing their policies to allow disclosure of the gamete donor’s identifying information to offspring when mutually sought by both parties. In addition, anonymity could be challenged in the future by courts or legislatures that weigh the offspring’s interest in knowing his or her genetic origins as greater than the donor’s interest in privacy or the recipients’ interests in having an uncomplicated family.

LEVELS OF INFORMATION SHARING

Three levels of donor information sharing can be identified, ranging from basic to comprehensive: 1) non-identifying information; 2) non-identifying contact information for medical updates; and 3) identifying information. Non-identifying information is the donor’s provision of medical or biographic information, such as a statement or letter to be given early to recipient couples. This approach is available in many programs.

The provision of non-identifying contact information demonstrates the donor’s willingness to be contacted by the program to provide medical updates and further information if requested by parents seeking to learn more about the child’s health conditions. The provision of non-identifying contact information is consistent with the obligation of the program to protect the donor’s anonymity, if this is desired by the donor, while also meeting the moral obligation to disclose information that may protect the child from harm.

Identifying information allows children the possibility of contacting donors at a future date, usually when the child reaches the age of majority. It should be pointed out, however, that in the absence of identifying information, individuals may be able to identify and locate donors through websites offering such assistance or by using newer
technologies, such as computer-based face-recognition programs. Even if a program adopts a policy of providing only non-identifying information, it cannot guarantee donor anonymity and can only provide de-identified information as well as possible.

**DUTY TO UPDATE HEALTH STATUS**

An emerging issue is the extent to which gamete and embryo donors have a duty to keep the program, recipient, or individual born as a result of donation informed of health events that may be relevant to their well-being (12). A model that severs all relationships at the time of donation implies that there is no such duty, whereas one that sees the donor-child connection as ongoing and lifelong, with mutual duties and responsibilities, implies that there is a responsibility to provide health updates to the program or another locus that could then pass information on to the recipient or child. However, this may be more of an intrusion than many donors would choose and, though recommended, cannot be enforced. Moreover, growing sophistication in genetic technology ultimately may lead to more direct and efficient ways to obtain genetic information related to the child’s health.

Occasionally, a child may be diagnosed with a medical condition that is known to place the donor at risk for similar abnormalities in their own future offspring. In such cases, recipients should report these results to the program so that physicians may alert the donor and other families in which children were born from the use of gametes or embryos from the affected donor regarding the heightened health risk and possible need for prenatal surveillance or specific genetic testing. Ethical conduct requires open disclosure of medically relevant information to minimize the risk of serious adverse outcomes to all parties. Programs are strongly encouraged to develop and make available written policies setting out the mechanisms for collecting medical updates from donors and recipients, and, if applicable, for making available or distributing newly acquired medical information to individuals whose health may be impacted by this information.

**DISCLOSURE AND FUTURE CONTACT**

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 that gamete donation was used in her or his conception. The Committee recommended that, “While ultimately the choice of recipient parents, disclosure to donor-conceived persons of the use of donor gametes or embryos in their conception is strongly encouraged” (13). The recommendation that children should be told the circumstances of their conception is accompanied by the supposition that openness may be better for the child. If the parents tell the child of his or her origins, the question of disclosure becomes more important because some children will want even more information. Moreover, in an age of genetic medicine and the widespread availability of commercial genetic tests to determine ancestry, there is a risk of inadvertent discovery as children and parents have genetic testing for a variety of reasons. Telling the child of his or her conception when the child cannot learn more about the donor could be emotionally difficult for some children. Therefore, the recipient should consider the emotional interests of the potential child when selecting a program and the choices the program permits for different levels of disclosure.

At a minimum, donors should be encouraged to provide non-identifying information for medical updates when appropriate. However, this responsibility does not extend to an ethical obligation to help that child by, for example, agreeing to be a living donor for organ transplantation. It also is recognized that a donor may have a change of circumstances or attitude that would make contact undesirable.

**Potential Benefits of Identity Disclosure**

There are arguments for permitting the release of identifying information, but here the donor’s interests in anonymity may prevail. A donor who agrees with the release of identifying information can deter 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 developmental needs of a child who enters young adulthood.

**Concerns regarding Identity Disclosure**

The impact of contact from offspring on the willingness of people to serve as gamete and embryo donors is unknown. Although some individuals born from donation are likely to desire contact with donors, a positive outcome cannot be guaranteed. Disclosure and subsequent contact may not yield the results that the individual and his or her parent(s) anticipate or desire. Nor would contact 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 and differing interests of the parties, the possibility of contact between the donor and offspring should be offered but not mandated. However, informed consent discussions with donors should include their consideration of allowing contact in the future if, at that time, they desire it. It is incumbent on professionals, programs, and agencies to counsel all participants about the possibility for contact during the consent process. Asking donors or recipients to project 18 years or more into the future is challenging. Consequently, all participants must be counseled, and be willing to accept, that circumstances may change and that the parties may, in the future, opt to nullify the original agreement to permit openness, or choose not to agree to have contact.

**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 about the outcome of the participation. 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) in
other kinds of anonymous tissue donation, the donation is made without regard to the outcome; 2) news of a successful pregnancy may unexpectedly cause distress to the donor; 3) news of an unsuccessful pregnancy may cause distress or cause the donor to develop unwarranted fertility concerns that affect her or his own family planning; and 4) the donor’s gametes may result in frozen embryos or gametes that may be utilized in a cycle at a time very distant from the original procurement, and the donor may be unprepared to receive this information at a later date 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 have a legitimate interest in being provided with available genetic or appropriate medical information that comes to light from the donation or any resulting children that may affect their health or the health of their own family.

Alternatively, 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 and embryos resulted in a pregnancy; 2) knowledge of the outcome could be helpful in the event of planned or unplanned contact from the genetically related individuals; 3) knowledge would give donors the opportunity to tell their children about genetic relatives; 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 is born, for the reasons noted above. 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 whether a pregnancy occurs.

Programs that plan to disclose delivery outcomes, if requested, should inform donors also whether supernumerary frozen embryos remain. At the very least, donors should know that their gametes may result in embryos that may be unused but preserved for future use. Donors also should be informed about and consent to what those future uses may be. Cryopreserved embryos and gametes may later result in more children and may go to more than one recipient, thereby raising the potential for unanticipated contact. The emotional impact of contact from multiple children remains unknown. 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 unused gametes or embryos might possibly be donated for research, which may affect their willingness to donate. Donors should specifically consent to the use of embryos created with their gametes for purposes of stem-cell or other medical research (14). Donors should be informed that they do not have any claim to any cryopreserved embryos or stored gametes in the future unless specified in advance by contract.

Donors may ask to specify the categories of people to whom their gametes or embryos will be given. For example, a donor may want to donate only to younger-aged couples or to married or same-sex couples. Programs may agree to accommodate requests related to age, marital status, health status, sexual orientation, race, religion, or education. However, programs may also refuse to allow donors to participate if restrictions are demanded. The principal argument for directed donation is that it respects the donor’s autonomy and recognizes that the donor has the right to specify the type of person to receive this gift. Donations to designated individuals are acceptable, but a program may decline to participate for good-faith reasons. In some situations, the direction could be contrary to clinic policy. If, for example, the clinic will not discriminate against patients with human immunodeficiency virus (HIV) and a donor expressly asks for the gametes or embryos not to be given to patients with HIV, acquiescence to the request would cause 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

Egg donors may request to participate repeatedly. Sperm donors often make repeated donations. As a condition for accepting the donor, it is permissible for a program to require donors to disclose the extent of their donation to other programs. The general practice of agencies, sperm banks, egg banks, and assisted reproductive technology programs is to limit the number of offspring per donor to avoid potential consanguinity issues in the offspring; in egg donation, the number of cycles should be limited also because of possible health risks associated with repetitive ovarian stimulations and egg retrievals (15).

If the donor agrees to provide identifying contact information to offspring, the psychological and emotional burden could be great if there are numerous requests for contact. Limiting the number of donations also takes into account potential impact on both the offspring and the donor’s children of learning they may have multiple genetic relatives.

SUMMARY

Traditional practices of anonymity in gamete and embryo donation are slowly changing as views about the interests and rights of children to know the identity of their genetic origins evolve. Views about the interests and rights of individuals to know the identity of their gamete and embryo donors are becoming more prevalent, and in any event, individuals born as a result of donation now may have the ability to discover the identity of genetic donors through social media, the Internet, and access to commercial genetic-testing platforms that identify DNA matches. The ASRM Ethics Committee and other advisory groups and researchers have encouraged recipient parent(s) to disclose the fact of gamete donation to children, and a number of clinics provide for some form of future contact between donor and child if the
participants agree. As gamete donation continues to grow in popularity and evolve in practice, new ethical challenges arise. Gamete and embryo donation is more than a transfer of gametes/embryos 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, children, and, potentially, the participants’ extended 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 and obligations of involved parties to one another.

The present statement highlights the need for shared information in the consent process, and it addresses preferences expressed by donors over who should receive their gametes and embryos, what they should be told about the outcome of donation, and the number of times they donate. It also considers the responsibilities that donors have to their own families, to recipient families, and to children conceived with their gametes and embryos. As a minimum, donors and recipients have an obligation to authorize the disclosure of non-identifying medical information where appropriate. Donors should also be encouraged to consider allowing non-identifying and/or personal contact in the future if all parties agree. By implication, programs 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 should also make it clear that law and circumstances may change and that promises of anonymity or future contact cannot be assured.

Acknowledgments: This report was developed by the Ethics Committee of the American Society for Reproductive Medicine as a service to its members and other practicing clinicians. Although this document reflects the views of members of that Committee, it is not intended to be the only approved standard of practice or to dictate an exclusive course of treatment in all cases. This report was approved by the Ethics Committee of the American Society for Reproductive Medicine and the Board of Directors of the American Society for Reproductive Medicine.

This document was reviewed by ASRM members, and their input was considered in the preparation of the final document. The following members of the ASRM Ethics Committee participated in the development of this document. All Committee members disclosed commercial and financial relationships with manufacturers or distributors of goods or services used to treat patients. Members of the Committee who were found to have conflicts of interest based on the relationships disclosed did not participate in the discussion or development of this document.

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