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Informing offspring of their conception by gamete donation

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American Society for Reproductive Medicine, Birmingham, Alabama

The Ethics Committee supports disclosure from parents to offspring about the use of donor gametes in their conception. The merits of further disclosure are discussed, and suggestions are made for policies for programs and sperm banks. (Fertil Steril® 2004;81:527–31. ©2004 by American Society for Reproductive Medicine.)

1. **While ultimately the choice of recipient parents, disclosure to offspring of the use of donor gametes is encouraged.**
2. **Parties should agree in advance on how and when ART programs and sperm banks will release donor information to the recipients.**
3. **Programs and sperm banks should gather and store medical and genetic information concerning donors.**
4. **Counseling and informed consent about disclosure are essential for the donor and recipients.**
5. **Programs and sperm banks should expect inquiries from donor offspring and consider developing a written policy to respond to these inquiries.**

An important but long unresolved question in gamete donation is whether offspring should be informed of the facts of their conception and, if so, how much information about donors should be revealed. Parents, donors, and offspring may have different interests and views on these issues. ART programs and sperm banks also vary in the information they collect from donors and the circumstances under which they release it to recipients and offspring.

Prospective parents face two types of disclosure questions: first, whether to disclose the facts of conception to their offspring and, second, if they do disclose it, how much information about the donor to reveal. While the first question is within their control, the second, particularly whether to disclose the donor's identity, depends in part on how much information the donor has agreed to share and how much information ART programs and sperm banks collect. Because parents, donors, and ART programs and sperm banks may have different expectations about the nature of disclosures to be made, it is important for recipients and donors to agree about the scope of information given to recipients or adult offspring.

The relative benefits of disclosure for parents, donors and, most significantly, children are under continued study. Nevertheless, support has grown in recent years for disclosing the fact of donation to children and allowing access to non-identifying information to offspring who request it. There is less agreement about the relative merits of releasing identifying information about donors, but it is widely agreed that such release is acceptable if all parties agree.

The purpose of this statement is to give guidance to ART programs, sperm banks, practitioners, patients, and donors about the issues and concerns that arise with disclosure in gamete donation. The Ethics Committee finds that disclosure to the child of the fact of donor conception and, if available, characteristics of the donor may serve the best interests of offspring. In addition, in cases in which all parties agree, disclosing the donor's identity may also be warranted. ART programs and sperm banks should conduct gamete donation in ways that promote interests of offspring in learning the facts of their conception while respecting the privacy interests of donors and recipient parents.

Disclosing the Fact of Gamete Donation to Offspring

Whether to reveal the fact of donor conception to offspring has long been the subject of debate. In recent years, however, a strong trend

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in favor of disclosure to offspring has emerged. While the Ethics Committee supports this trend, it recognizes that the decision is highly personal and it is one for parents to make. Recognizing that parents have the ultimate authority, the Committee discusses considerations for and against disclosure.

Considerations for Disclosure

Proponents of disclosure argue that human beings have a fundamental interest and perhaps even legal right to know their biological origins (1–5). Some argue that not telling the child of his or her origins violates that child's autonomy (1). Proponents look to the trend in openness in adoption as an indication of changing social mores that underscore the child's interests in knowing his or her origins. Studies of adopted children also indicate that the need to know one's biological origins is central to the development of identity and that secrecy can cause confusion and low self-esteem (6, 7).

Proponents also argue that disclosure is an important part of open and honest communication with children. Among other things, disclosure helps avoid secrets in the family that can strain family relationships and create possibly life-long tension and anxieties between those who know of the conception and those who do not (4, 5, 8). These tensions may be exacerbated in the event of divorce and remarriage. Openness, on the other hand, does not appear to injure the child, as some studies have shown that children told of their conception through sperm donation are well-adjusted (9). Other studies indicate that disclosure of conception may have a positive effect on the parent/child relationship (5, 10).

In contrast to studies revealing the positive dimensions of planned disclosure, some studies speculate that the information can be disruptive if it is disclosed in adolescence or later (3, 8, 11). Other studies indicate that people who do not learn the details of their conception until they are adults may feel mistrust, frustration, and hostility toward their family (3, 11, 12). Although the timing of disclosure is still a matter for discussion, investigators are beginning to shed light on when disclosure to children is most appropriate. There appears to be an advantage in telling children earlier rather than later so they can absorb that information over time (8, 13). The timing, however, also depends on the psychological readiness of the child and the parents' belief that the children are old enough to understand their stories.

Proponents also argue that planned disclosure will protect the child from accidentally finding out about his or her origins, which would be more damaging than an intentional structured disclosure (1, 11, 13, 14). Studies indicate that many parents who have used donor sperm do not intend to tell their children even though they have disclosed the fact to others (10, 15–21). In addition, even though couples who have used donor eggs are more inclined to tell their children about their conception than those who have used donor sperm (4, 21–23), some couples using donated eggs are nevertheless uncertain whether to tell their children, even though they have told others (23). The possibility of an accidental disclosure also rises with the growing frequency of genetic testing in contemporary medicine.

Other arguments have been given in support of disclosure. For one thing, it may benefit children by protecting their interests in knowing their genetic heritage and in securing accurate information about potential health problems. For another, it may benefit parents by enabling them to seek support from other parents in the same situation and from professionals caring for the families. In addition, some have suggested that informing children of their genetic origins will protect them against later inadvertent consanguinity (9).

A trend in favor of disclosure to offspring is even more pronounced in Europe and Australia, where the practice of facilitating, if not mandating, disclosure is not uncommon. Several countries have enacted laws (2, 24) or are considering policies to enable children to gain access to information. Switzerland's constitution recognizes a child's right to know his or her biological lineage, including identifying donor information (25). Austria; the Netherlands; Sweden; and Victoria, Australia, require identifying information to be available upon request, and New Zealand, Western Australia, and Southern Australia are considering similar laws (24, 25). The United Kingdom's Department of Health announced a planned change in the law to enable offspring conceived from donor gametes or embryos to learn the identity of their donor(s) when they turn 18 years of age (26). This will apply only to children conceived after April 2005.

Considerations Against Disclosure

Those who argue against disclosure express concerns that telling the child of his or her conception by gamete donation will subject the child to social and psychological turmoil, which will be especially disruptive if the child wants to learn more about the donor but cannot (4, 27). Preliminary studies of children not informed show they are doing well developmentally and psychologically and have not been harmed by nondisclosure (14, 15, 21, 28), although the children may be too young for researchers to draw valid conclusions. In addition, nondisclosure allows parents to keep the matter of infertility private, which may be important to them for a variety of reasons. For example, they may be concerned the child will reject the non-genetic parent, or they may wish to conceal the fact of donation from disapproving family members, especially those from cultures less accepting of gamete donation (13, 29).

While proponents of disclosure look to the adoption model to support greater openness, those arguing against disclosure distinguish gamete donation from adoption (30). They argue that in gamete donation one parent is usually genetically related to the child, whereas in adoption it is usually the case that neither parent is. In gamete donation,

the rearing mother is usually also the gestational mother, which furthers the ability of parents to keep the donation quiet, if they so choose. Thus, the goal of keeping donation private is arguably easier to achieve in gamete donation than in adoption.

Deciding What to Disclose to Offspring

Couples who intend to tell their children they were conceived with the help of sperm or egg donation also face questions about how much donor information to share with their children. Whether to share non-identifying information only or also to share identifying information is influenced by the practices of programs and sperm banks as well as the parents' preferences. Programs and sperm banks are developing new ways of providing identifying information, and perspectives of professionals indicate a growing acceptance of identity disclosure, providing all parties agree.

Consideration of Disclosure Issues Before Conception and Later

Programs and sperm banks differ in their policies about disclosure. Most make available detailed non-identifying information about the donor's characteristics and medical history and some may provide a photograph. A growing number of sperm banks and programs make gametes available from donors who agree to be identified now or in the future (31, 32). In some of these programs, anonymous donors sign agreements allowing the program to contact them to release information if a child requests (32). At least one sperm bank has created a registry to aid children who want to meet siblings genetically related to them through gamete donation (32). The practice of using known donors, some of whom are related, is more common in egg than sperm donation. Characteristics of some gamete donors are available on the Internet. Some donors create their own websites and state their willingness to meet the recipients and future offspring. With known donors, the recipient parents, offspring, and donor may maintain an ongoing relationship acknowledging the donation.

Although most recipients in gamete donation currently prefer donor anonymity, when choosing a donor they also typically seek extensive information about donor characteristics and medical history (23, 31). It is important for parents who plan to tell their offspring the circumstances of their conception to consider early in the ART process how much information they want to give their children so their expectations will conform with the practices of the facility they use for donated gametes. Some recipients may elect to give only minimal genetic and medical information to their offspring, others may intend to disclose detailed background information about traits and features of the donor and extended family, and still others may favor full identity disclosure if their child requests it. In open donation involving known donors, the donor's identity is known at the outset, although not all recipients using known donors intend to tell the facts of conception to their offspring. Consideration of disclosure options is important even for prospective parents who do not intend to tell their offspring about gamete donation because the parents may change their plans in the years to come.

Those who advocate access to a fairly full range of information about the donor point out that this gives parents and children important options and that the mere presence of these options, whether utilized or not, is a source of security for the child. Proponents also argue that access to information facilitates the disclosure process because available information may satisfy the child's desire to learn about the donor. They argue that more extensive disclosure will not reduce the number of donors as long as donors are asked at donation or later whether they agree to release the information to parents or children (33). Some donors have expressed a willingness to share information or meet the child once the child reaches a certain age (34). The important thing is to notify donors before donation about potential disclosure to offspring and any risk this poses to their privacy.

Recipients and donors need to have shared expectations about the release of information. It is advisable for ART programs and sperm banks to store non-identifying information in the event recipients later want more information released and to store identifying information in case all parties later agree to some form of identifying disclosure. While donor privacy must be protected, the donor should be advised that privacy cannot absolutely be guaranteed due to the possibility of new laws or the need to open medical records.

It is also advisable for programs and sperm banks to consider developing policies now to prepare for the possibility that offspring will contact them in the future to seek information about their conception and donor. Programs may consider sharing with inquiring offspring who have reached l8 years of age the information that would be available to the recipient parents, such as details about the gamete donation process and non-identifying information on file about the donor. Programs may also consider more active responses, such as contacting a donor to see if he or she is willing to share more information, to provide a photograph, to participate in mediated contact without disclosing his or her identity, or to share identifying information. If the inquiring offspring is not yet a legal adult, it is appropriate for the program or sperm bank to seek consent for discussion with the child from recipient parents.

Perspectives of Professionals

Professional associations increasingly recognize the need to maintain records and release information under certain circumstances. For example, the ASRM's 2002 Guidelines for Gamete and Embryo Donation require clinics to maintain permanent records of donor screening and selection data, donor examinations, and clinical outcomes as a future medical source for offspring (35). The American Medical Association calls for maintaining permanent records with identi-

fying and non-identifying health and genetic screening information on sperm donors (36). The American Association of Tissue Banks has published data collection and record keeping standards for sperm banks (37). In addition, a number of legal scholars recommend collection of medical and genetic histories of gamete donors and disclosure to offspring (38, 39).

There are also signs of a growing acceptance among medical professionals of identity disclosure to children. For example, in 1993 the ASRM guidelines on gamete donation encouraged anonymous sperm donation but by 2002 indicated an acceptance of directed, known donation if all parties agree (35, 40). The ASRM guidelines also regard known oocyte donation as acceptable (35, 40, 41).

Parallels to Adoption

A growing acceptance of identity disclosure in gamete donation may stem from a trend toward openness in adoption. Professionals involved in adoption at one time advocated sealed records. This was thought, among other things, to protect children from the stigma of illegitimacy, prevent a relationship between the birth parents and offspring, and protect the adoptive parents from later disruption. Professionals have, however, increasingly shifted toward favoring disclosure. Studies have shown the importance of knowing one's biological origins, and the option of identity disclosure for adopted children has proven to be less disruptive than feared. For example, one study from the United Kingdom revealed that children sought information more to satisfy their curiosity about who shared their looks and mannerisms than to establish an extended relationship (42).

The trend to openness in adoption has been reflected in state laws in the U.S. Several states have enacted laws allowing adopted children to learn the identity of their birth parents even without the consent of the birth parents (43); however, in some states the birth parents may file a form refusing contact (44, 45). Some states require disclosure of the medical and genetic histories of biological parents during the adoption process (46) and some have created registries or set up a procedure for intermediaries to facilitate contact between adopted children and their genetic parents (43, 47). Other states release non-identifying information to children upon request, and they will open sealed adoption records for legally justifiable reasons.

Summary

It is the recipient parents' choice whether to disclose the fact of donor gamete conception to their offspring. Clinicians, mental health professionals, academics, and children themselves have in recent years called for more openness in donor conception in order to protect the interests of offspring (11, 13, 29, 48, 49). Because of persons' fundamental interest in knowing their genetic heritage and the importance of their ability to make informed health care decisions in the future, the Ethics Committee supports disclosure about the fact of donation to children. It also supports the gathering and storage of medical and genetic information that can be provided to offspring if they ask. It recognizes, however, that disclosure is a personal matter to be decided by the participants, and the decisions will vary in particular situations. The Committee encourages ART programs and sperm banks to consider developing flexible policies to accommodate the varying disclosure preferences of both donors and recipients. To facilitate sound disclosure policies in gamete donation, it is the Committee's opinion that:

1. ART programs and sperm banks should discuss the issues of disclosure to offspring with both gamete donors (egg and sperm) and recipients prior to attempting pregnancy.
2. All prospective recipients and donors should receive counseling with a qualified mental health professional about the psychological implications of donation and disclosure for the recipients, donors, and children.
3. All gamete donors should undergo a complete medical history, physical examination, family genetic history, and laboratory screen, following ASRM guidelines.
4. The donor's medical and genetic information should be retained in a secure location by the program or sperm bank.
5. Gamete donors should be encouraged to inform the program or sperm bank of major health changes or of information that might have genetic implications for offspring.
6. The level of desired disclosure (anonymous, known or identified, identifiable later) should be clearly addressed in counseling and consent forms for both donors and recipients.
7. Non-identifying medical and genetic information regarding the gamete donor should be provided to recipients when they are in the process of choosing a donor and consenting to gamete donation.
8. Programs and sperm banks should consider how to accommodate the different disclosure options preferred by donors and recipients.
9. Programs and sperm banks should consider how to preserve medical records if the programs close or physicians retire.
10. The following should apply after successful anonymous donation:
    a. Programs or sperm banks should honor the original agreements with donor and recipients unless the donor and recipients agree to disclose more (or less) than originally agreed upon or the donor and adult child agree to additional disclosure.
    b. Donors and recipients need to be aware that the program or sperm bank could be compelled to disclose or protect the identity of the donor by court order or future legislation.
    c. Programs or sperm banks should expect to receive inquiries regarding donor medical and genetic information, donor identity, and/or other aspects of the donation process from the offspring; the practice should consider developing a written policy to respond to these inquiries.

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bers and other practicing clinicians. While 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 and the Board of Directors of the American Society of Reproductive Medicine.

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