

Informing offspring of their conception by gamete or embryo donation: an Ethics Committee opinion

Ethics Committee of the American Society for Reproductive Medicine

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This document discusses the ethical implications of informing offspring about their conception using gamete or embryo donation. It replaces the 2013 ASRM Ethics Committee document of the same name (*Fertil Steril* 2013;100:45-9). (*Fertil Steril*® 2018;109:601-5. ©2018 by American Society for Reproductive Medicine.)

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KEY POINTS

- Disclosure to donor-conceived persons of the use of donor gametes or embryos in their conception is strongly encouraged, while ultimately the choice of recipient parents.
- Counseling and informed consent about disclosure and information sharing are essential for donors and recipients.
- Assisted reproductive technology (ART) programs; sperm, oocyte, and embryo banks; and oocyte and embryo-donation programs should expect inquiries from donor-conceived persons about their genetic background and should develop written policies to respond to these inquiries.
- ART programs; sperm, oocyte and embryo banks; and oocyte and embryo-donation programs should gather, maintain, and permanently store medical and genetic information about donors.

- Donors and recipient parents should be informed in advance about how and when ART programs; sperm, oocyte, and embryo banks; and oocyte and embryo donation programs will release donor information to recipients and offspring. Donors and recipients also should be counseled that later changes in the law may affect any agreements.

THE NATURE OF THE DILEMMA

An important question in gamete and embryo donation is whether donor-conceived persons should be informed about 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. Assisted reproductive technology (ART) programs; sperm, oocyte, and embryo banks; and oocyte and embryo-donation programs vary in

the amount and kind of information they collect from donors, the amount and kind of information they share with recipients and offspring, and the circumstances under which they release it to recipients and offspring. Legal requirements concerning recordkeeping and release of donor information are changing; these changes may be expected to continue, and they may vary from state to state.

Although whether to reveal the fact of donor conception to donor-conceived persons has long been the subject of debate, more recently a strong trend in favor of encouraging disclosure has emerged (1-3). The ASRM Ethics Committee finds that disclosure to offspring about the fact of donor conception and, if available, characteristics of the donor(s), may serve the offspring's best interests. The Committee also recognizes that the decision is a highly personal one about which the parties may have differing values (1-3). The overall benefits of disclosure for parents, donors, and, most significantly, donor-conceived persons are under continued study. Support has grown for disclosing the fact of donation and allowing offspring access to

Received December 28, 2017; accepted January 3, 2018; published online March 28, 2018.

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Fertility and Sterility® Vol. 109, No. 4, April 2018 0015-0282/\$36.00

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<https://doi.org/10.1016/j.fertnstert.2018.01.001>

non-identifying information about donors, as evidenced by research showing an increase in the number of parents who intend to disclose (2). ART programs; sperm, oocyte, and embryo banks; and oocyte and embryo donation programs should conduct gamete and embryo donation in ways that promote the interests of offspring in learning facts about their conception, while respecting the privacy and autonomy interests of donors and recipient parents.

CONSIDERATIONS IN FAVOR OF DISCLOSING DONOR CONCEPTION TO OFFSPRING

Many arguments are offered in favor of disclosure. Some commentators argue that not telling the child of his or her origins violates that child's autonomy (4). Human beings, it is argued, have a fundamental interest in knowing their biological origins (5–7). Supporting this interest can, proponents claim, facilitate the donor-conceived person's understanding of his or her identity and provide information relevant to future decisions. Proponents also argue that the United Nations Convention on the Rights of the Child provision regarding identity should be interpreted to encompass disclosure of the use of donated gametes or embryos (5).

Parents who disclose donor conception cite a number of values and beliefs that contribute to their decision. These include “the child's right to know,” the importance of honesty in the parent-child relationship, possible harm to the child in not knowing, a desire to avoid accidental or traumatic disclosure, or simply, that “there is no reason not to tell.” Proponents believe that disclosure is an important part of open communication within families and that secrecy can compromise family functioning (2, 7, 8). Research on families who have disclosed indicates that disclosure does not appear to injure the child, and some research suggests a positive effect on parent-child relationships in disclosing families (9–12). Research also indicates that among parents who disclose, few express regret, most report positive feelings and report no negative effect on their relationship with their child (13–17).

Other proponents of disclosure emphasize the medical interests of the donor-conceived child independent of any fundamental human right. Disclosure can protect the offspring's interest in knowing their genetic heritage, in securing accurate information about potential health problems, and in making future medical decisions (4, 18, 19). Both recipient parents and those who provide the gametes and embryos gamete and embryo should be counseled that the possibility of unplanned disclosure has increased with the growing frequency of genetic testing in contemporary medicine and the growing existence of DNA databases (20).

Other concerns about disclosure relate to the timing of disclosure. Some social scientists, mental health professionals, parents, and donor-conceived persons suggest that there is an advantage in disclosing during the preschool and school-age years, before puberty, so the child can absorb that information over time and the child “always knows” (21). While there is no research that identifies a specific ideal age for disclosure, the literature suggests that children who are

told when they are young respond neutrally, with curiosity, or pleasure, rather than distress (9, 13, 14, 21). Late disclosure, during adolescence or adulthood, has been associated with negative feelings of confusion, betrayal, distrust, and anger among offspring (17, 22). However, research has not consistently found an association between the age of disclosure and family or offspring functioning, suggesting that factors other than age at disclosure contribute to positive disclosure outcomes (8, 22, 23).

RELEVANCE OF ADOPTION HISTORY TO DISCLOSURE

While comparisons between adoption and donor conception remain controversial, proponents of disclosure have looked 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 (24). Historically, adoption professionals, like professionals in ART, advocated secrecy and closed records in a perceived effort to protect children from stigma, prevent a relationship between the birth parents and offspring, and protect the adoptive parents from later disruption. More recently, adoption and mental health professionals have shifted toward favoring disclosure of adoption, providing information about birth parents, and support of open adoption, in which birth parents and adopting parents may meet and know each other. Historically, adopted persons who searched for information about their birth parents were viewed as a discontented minority of adoptees. As more adoptees have searched and birth records have become legally available, the search is now seen as a normal part of identity development for adoptees (25–27).

CONSIDERATIONS AGAINST DISCLOSING DONOR CONCEPTION TO OFFSPRING

An increasing number of parents in all family types report intention to disclose, especially so among same-sex couples and single parents. Research from 2002 also indicates that a significant majority of heterosexual couples do not inform offspring about their donor conception, even if they have told others (12). Those who argue against disclosure, including parents who do not disclose, express concerns about the negative effect on the child, on the parents' privacy, fear of the effect on the non-genetic parent and his/her relationship with the child, avoidance of stigma, protecting the family from disruption, and concern that the child will want to find the donor (1, 7, 19). Above all, parents wish to normalize their families, minimize the role of the donor, and be seen as “real” parents. Studies of children who have not been informed show they are doing well developmentally and psychologically and have not been harmed by nondisclosure (12, 28).

DECIDING WHAT DONOR INFORMATION TO SHARE

For offspring informed of their donor conception, making sense of their identity can lead to questions about the donor(s). Parents who intend to tell their children they were

conceived by donor also face questions about how much donor information to share with their children or how to respond to their offspring's wish for more information. While parents who disclose usually plan to share non-identifying information, the parents and/or the donor-conceived offspring may find themselves at a loss, either because the parents originally received little information about the donor(s), no longer have it, or wish an update.

Disclosing Non-identifying Donor Information

When choosing a donor, recipients typically seek extensive information about donor characteristics and medical history (18, 29). Parents who plan to tell their offspring about their donor conception should 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 donation. 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. Disclosure in the case of embryo donation might include the existence of full genetic siblings who are being raised by the donors.

Fertility programs; sperm, oocyte, and embryo banks; and oocyte and embryo donation programs differ in policies about archiving and sharing information about donors. Given this variation, it is important to inform donors before donation about the possibility of parents' disclosure of donor conception and sharing of donor information, including pictures, when the donor has made them available. Donors should also be informed that adolescent or adult donor-conceived persons might make contact with providers to request more information or contact with the donor. Donors should be informed that the availability of personal information on the internet and technological advances in DNA tracing have made it easier for donor-conceived offspring to locate donors with only non-identifying information, and therefore, providers can no longer guarantee their anonymity. Recognizing that parents and/or the offspring may contact providers for donor information, providers should maintain permanent records on donors and develop a policy for the release of the non-identifying information that also protects the donor's confidentiality.

Those who advocate access to a comparatively full range of non-identifying information about the donor point out that this supports recipient autonomy and choice in selecting donors. Advocates also report that this approach is increasingly preferred by recipients, reassures recipients, supports recipients' disclosure decisions, and allows the parents to support the offspring's interest in information (29).

Fertility programs; sperm, oocyte, and embryo banks; and oocyte and embryo donation programs also should develop policies now to prepare for the possibility that offspring will contact them in the future to seek information about their conception and donor. In developing these policies, programs may consider sharing with inquiring offspring who have

reached 18 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 also may consider more active responses, such as contacting a donor to see if he or she is willing to share more information, provide a photograph, participate in mediated contact without disclosing his/her identity, or share identifying information. If the inquiring offspring is not yet a legal adult, it is recommended for the program or sperm, oocyte, or embryo bank to seek consent for discussion with the child from recipient parents.

Disclosing Identifying Donor Information

Although most gamete donation recipients, especially heterosexual couples, choose anonymous donors, a preference for open-identity donors is on the rise. In the preceding 20 years in the United States and other countries, commentators have argued for the right of donor-conceived persons to access identifying information about their donor. Changes in legal policy and clinical practice have led several countries, as well as some gamete providers in the United States, to practice open-identity gamete donation in which adult donor offspring are given access to the donor's identity upon request (30). While the practice of releasing identifying information about donors remains controversial and the research on its effects only beginning, such release is permissible if all parties consent (30).

Sperm, oocyte, and embryo banks; fertility programs; and oocyte and embryo donation programs in the United States vary widely in their policies about releasing identifying donor information and/or facilitating mutual consent contact between the donor and intended parents and between donor and donor-conceived offspring. Just as there has been an increased rate of parent disclosure of donor conception, there is also evidence of increased desire for or acceptance of open-identity donors by both donors and recipients (31–35). In the United States, a growing number of sperm banks, oocyte and embryo donation programs, and ART programs make gametes or embryos available from donors who agree to be identified or contacted now or in the future (35, 36).

Recipients and donors should have shared expectations about the release of information. It is advisable for ART programs; sperm, oocyte, and embryo banks; and oocyte and embryo donation programs to store non-identifying information in the event recipients later want more information released, and to store and update identifying information in case all parties later agree to some form of identifying disclosure. Counseling recipient parents about disclosure and sharing of information is important even for prospective parents who do not intend to disclose the donor conception to their offspring because the parents may change their plans in the future.

RECORDKEEPING

Professional associations increasingly recognize the need to maintain records and release information under certain circumstances. For example, the ASRM's 2013 Practice Committee document titled "Recommendations for Gamete and Embryo Donation a Committee Opinion" recommends that

clinics maintain permanent records of donor screening and selection data, donor examinations, and clinical outcomes as a future medical source for offspring. Providers are expected to create a mechanism to maintain these records (37). The American Medical Association Code of Medical Ethics calls for maintaining permanent records with identifying and non-identifying health and genetic screening information on sperm donors (38). The American Association of Tissue Banks has published data collection and record-keeping standards for sperm banks (39). Some mental health and legal experts have proposed the creation of a national donor registry, which would collect medical and genetic histories on gamete donors and disclose the information to adult donor offspring upon request (40).

SUMMARY

In the United States and throughout the developed world, legal policy and clinical practice have led to more openness in the practice of gamete and embryo donation, both in support of disclosure of donor conception and in sharing information about gamete donors. Providers, mental health professionals, academics, and donor-conceived persons have called for more openness in donor conception in order to protect the interests of offspring. Because of each person's 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 their donor conception to offspring. It also supports the gathering and storage of medical and genetic history information that can be provided to offspring if they request. It recognizes, however, that decisions about disclosure are highly personal and it is the recipient parents' choice whether to disclose the fact of donor conception to their offspring. The Committee encourages ART programs; sperm, oocyte, and embryo banks; and oocyte and embryo donation programs to develop flexible policies to accommodate the varying information-sharing preferences of donors, recipients, and donor-conceived offspring.

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. 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 of the American Society for Reproductive Medicine and the Board of Directors of the American Society for Reproductive Medicine.

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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J.D.; Elena Gates, M.D.; Susan Gitlin, Ph.D.; Elizabeth Ginsburg, M.D.; Sigal Klipstein, M.D.; Laurence McCullough, Ph.D.; Richard Reindollar, M.D.; Ginny Ryan, M.D.; Mark Sauer, M.D.; Sean Tipton, M.A.; Lynn Westphal, M.D.

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