

# Updated terminology for gamete and embryo donors: directed (identified) to replace “known” and nonidentified to replace “anonymous”: a committee opinion

Ethics and Practice Committees of the American Society for Reproductive Medicine

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Technology and the regulatory framework in which we practice and live are continually evolving. Shifting mores and the ease with which individuals can identify one another with the assistance of social media and deoxyribonucleic acid (DNA) testing has necessitated the current change in medical terminology. For decades, gamete and embryo donors were referred to as “known” if they had a relationship with the intended parent(s) and “anonymous” if they were unknown to one another at the time of the donation. The American Society for Reproductive Medicine encourages all stakeholders with an interest in gamete and embryo donation to adopt *directed (identified)* in lieu of “known” and *nonidentified* in lieu of “anonymous” to more accurately describe the relationships between donors and recipients in this new era of social media and genetic information sharing. (Fertil Steril® 2022; ■ : ■ - ■. ©2022 by American Society for Reproductive Medicine.)

**Key Words:** Sperm donation, oocyte donation, gamete donation, assisted reproduction



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**G**amete and embryo donation have historically been characterized as known or anonymous. The terminology reflected what was true at one time; donors and recipients either knew one another or did not at the time of the donation. For those who were unknown to each other at the time of the donation, the expectation was that this anonymity would continue indefinitely. The identity of anonymous donors was protected by both clinical protocols and, to varying degrees, legislation intended to address legal parentage of recipients and non-parentage of donors.

Social media, changing mores, and more recently significantly broader access to direct-to-consumer deoxyribo-

nucleic acid (DNA) testing (DTC DNA) have all contributed to a new reality that expectations of donor anonymity can no longer be assured. It is estimated that at the present time, tens of millions of Americans have their genetic information stored in privately owned and largely unregulated databases (1).

Other modalities such as facial recognition have also recently become refined and more accurate (2). These technologies have introduced a means by which donor-conceived offspring and those to whom they have genetic ties may identify, locate, and contact one another. It should be noted that individuals who donated gametes or embryos, or who are donor conceived, may be traceable even if they never enroll in

any DNA testing program themselves. This may occur if others with genetic ties to them participate in DTC DNA programs that allow for the identification of those to whom they are genetically linked (3). The era of perpetual donor anonymity has ended. This loss of anonymity has the potential to affect both current and past donations, including donors, recipients, donor-conceived offspring, and those who are genetically linked to them. While donor identity can still be withheld at the time of a donation, the discovery of genetic relationships leading to gamete and embryo donor identification may occur both outside the control of medical professionals and indefinitely into the future.

These emerging genetic and technological realities have changed the landscape of gamete and embryo donation, necessitating a concomitant change in the language used to describe these donations and in the counseling of those who participate in them.

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As such, the American Society for Reproductive Medicine has changed the nomenclature of gamete and embryo donation. Donors who were previously described as known will now be referred to as *directed (identified) donors*, and those previously described as anonymous will be referred to as *non-identified donors*.

## DIRECTED DONORS

The choice of the term *directed (identified) donor*, previously called known donor, was selected to align with the Food and Drug Administration (FDA) regulations (4). The gametes from a *directed (identified) donor* who is deemed “ineligible” based on FDA guidance for tissue donation may in some cases be used if both parties are aware of the theoretical infectious or genetic risks to the recipient(s) and offspring and consent to move forward with the donation (5). The categorization of an individual as a *directed (identified) donor* affords recipients the option of waiving some exclusion criteria when they value the benefits of the known donor (e.g., sister to sister egg donation) so strongly that they are willing to accept the presumably low risk of infectious disease transmission. The use of the term *directed (identified)* mirrors the FDA language that specifies exclusions and exceptions for gamete and embryo donation based on whether the parties are known to one another. The new terminology should assist physicians and administrators as they interpret and apply the FDA regulations to clinical practice.

## NONIDENTIFIED DONORS

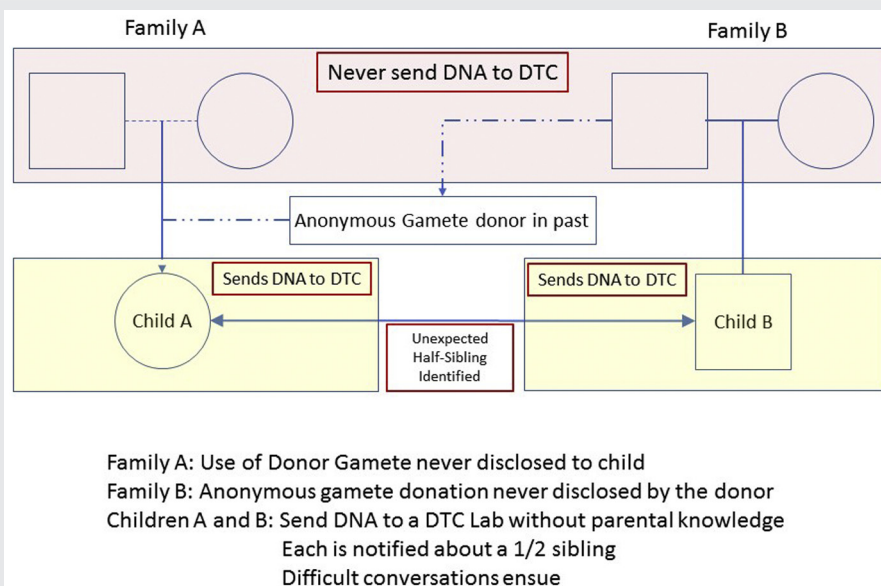
The choice of the term *nonidentified* for those who were previously called anonymous donors acknowledges the

intention of all involved in the donation process, including donors and recipients, as well as any medical, professional, or coordinating entities or professionals, not to share identifying information of the donor or recipient with one another. The intention at the time a nonidentified donation contract is entered into, or the donation undertaken, is that the identities of the donor, recipient, and any resulting offspring will remain unknown to one another to the extent permitted under law or to an explicit and limited degree, such as when a contract or consent document may allow for arranging contact between the donor-conceived offspring and the donor upon the offspring reaching a specific age, often the age of majority. These latter types of arrangements are sometimes referred to as open-identity arrangements, and the donors who agree to them are referred to as open-identity donors.

Example of unplanned identification (Figure 1): Family A: Use of donor gamete never disclosed to child. Family B: “Anonymous” gamete donation never disclosed by the donor. Children A and B: Independently send DNA to a DTC DNA Laboratory without parental knowledge. Each is notified about a 1/2 sibling. Difficult conversations ensue.

This scenario applies equally to egg, sperm, and embryo donation. Furthermore, it need not be the donor-conceived offspring who participate; it could be other genetically related individuals. Finally, in cases of directed gamete donation, where the donor and recipient are known to one another, the parties involved will want to consider who are the other genetic relatives that should be made privy to the information, as they may inadvertently find out about the donation at some future date if they participate in genetic testing.

FIGURE 1



Unplanned identification. DNA = deoxyribonucleic acid; DTC = direct-to-consumer.

Ethics and Practice Committees of the American Society for Reproductive Medicine. Updated terminology for gamete donors. *Fertil Steril* 2022.

## CONCLUSION

In conclusion, given a multitude of global social media platforms, increasingly accessible and used DTC DNA services, and facial recognition technology, true anonymity between donors and recipients can no longer be guaranteed. All parties involved in gamete and embryo donation should be aware that identities may be discovered by the resulting offspring and other genetically linked individuals at any future time. This holds for both directed (identified) and nonidentified donations. Complicating matters is the fact that past donors, whether they donated with the intention of anonymity or not, are now potentially discoverable at any future date. The extent to which such revelations will occur is unknown. A 2019 estimate suggested that approximately 8% of the US population had already sent DNA to a DTC DNA vendor with speculation that the number could more than triple over the next several years, thus greatly expanding the population of people who can identify one another based on their genetic links (6). A related, but somewhat different, scenario is the active pursuit of connection among offspring who know they were conceived from donor gametes or embryos (7).

The impact that this will have on those being discovered and whether this current reality will change the willingness of individuals to serve as gamete or embryo donors remain to be seen. The collateral effects on genetically linked individuals much removed from the donation process are also unknown but will become clearer over time. Critical to the donation process is the informed consent of donors and recipients regarding the possibility that genetically linked individuals may identify one another, both intentionally and otherwise, at any future date.

Physicians and those who arrange gamete and embryo donation should provide maximum transparency regarding the limits of anonymity to all known stakeholders at the time of the donation, beginning with the change in nomenclature when referring to *directed (identified)* and *nonidentified* gamete and embryo donors.

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