



# DONOR IDENTITY DISCLOSURE: IMPACT AND CONSEQUENCES

by Alfonso P. Del Valle, M.D., FRCS(C)  
and Tamer M. Said, M.D., Ph.D.

The use of donor gametes – donated sperm and eggs – in assisted reproduction is a rapidly evolving practice. As a result, several regulations and best practice guidelines have been developed to ensure the safety and best interest of all parties involved, especially those of the donor offspring. Perhaps one of the most significant changes in Canada was the enactment of the *Assisted Human Reproduction Act* (AHRA) in 2004. At that time, the long-anticipated Act was considered a milestone which would establish a solid platform for assisted human reproduction regulations in the country. Yet, to date, most of its objectives have not been met and only regulations pertaining to donors' consent have been

issued. In addition, several sections of the Act have generated a nationwide debate including a constitutional challenge currently under review by the Supreme Court of Canada.

The mandatory disclosure of gamete donors' identity has been a subject of controversy. As it stands, Section 15 of the *Assisted Human Reproduction Act* upholds the right of gamete donors to remain anonymous unless clear written consent to the contrary is provided. It is important to note that although both anonymous and known donations were always offered, the majority of donations used in assisted reproduction have originated from anonymous donors. However,

full-disclosure donations have been steadily increasing.<sup>1</sup> This recent development is associated with an increase in the number of programs offering this more open type of donation.<sup>2</sup>

In Canada, sperm banks and importers of donor semen currently offer samples from both anonymous and open-identity donors; the latter having consented to the release of their identity information once the offspring reaches the age of 18 years. Nevertheless, the absolute majority of open-identity donor samples are today imported from the United States and Denmark. Interestingly, neither country has regulations that ban donor anonymity. Several other jurisdictions worldwide

---

## The provision of donated sperm and eggs in sufficient numbers and of diverse enough ethnic origins to meet patients' needs is the ultimate objective of a successful donor recruitment program.

---

have enacted legislation effectively removing donor anonymity, such as Australia, Austria, Finland, Netherlands, New Zealand, Norway, Switzerland, Sweden, and the U.K. The impact of such legislations on reproduction involving a third party and its contributing role in donor gamete shortages has been the subject of many contradictory research studies. The most recent data published by the European Society of Human Reproduction and Embryology (ESHRE) indicates that the greatest number of donor insemination treatments were conducted in Denmark, France and Spain, all countries where donor anonymity is permissible.<sup>3</sup> This may indicate that such treatment is more accessible and that donated sperm and eggs are more readily available in these countries.

Gamete donation is a complex method of alternative reproduction that has many medical and social ramifications. Interestingly, the process is overwhelmingly equated by both donors and recipients to blood donation rather than adoption.<sup>4</sup> Some donors choose to offer their reproductive cells anonymously as an altruistic gift. Others choose to participate in donation programs that result in the release of their identity either at the time of donation or when the offspring turns 18. Similarly, some gamete recipients willingly choose anonymous donor samples; they are normally counseled by a healthcare professional and then give their consent accordingly. Others prefer to use samples

from an open-identity donor. Regardless of the type of donor used, a consensus exists as to the need to provide the recipients and offspring with pertinent non-identifying information about the donor that includes medical and genetic history, as well as health updates.

It has been suggested that legislation to abolish donor anonymity fosters the basic well-being of recipient families. However, the impact this would have on the availability of donor gametes remains to be seen.<sup>5</sup> Some published reports indicated that the legislation enforcing donor identity disclosure had little impact on donor gamete shortages. Careful examination of these studies is necessary to ensure the provision of adequate health care services.

One such study aimed to identify the views of 32 previous semen donors regarding the sharing of donor information with the offspring.<sup>6</sup> Their questionnaire answers would indicate that around 50% would still have donated if they had been required to disclose their identity to the offspring. Based on these results, it was concluded that recruiting identifiable donors is feasible and very plausible. Yet, despite these positive findings, it is important to acknowledge an obvious selection bias in this study's general design, in that it was conducted on previous semen donors and not potential semen donors. Therefore, the questions posed were hypothetical in nature, such as, "Would you still have donated if required to be

identified by the offspring?"

Consequently, one cannot extrapolate that donors who are being recruited will have the same attitudes as donors who have donated in the past. The latter donors are no longer faced with the need to make such a decision.

Similarly, a recent US study reported that an impressive 97.4% of oocyte (egg) donors were open to contact with the offspring.<sup>7</sup> This is another example of a study hampered by selection biases. To name a few, 1) as only individuals who responded to the survey questions were included, it is possible that those who did not respond hold very different views; and 2) the study was retrospectively conducted on previous donors; again, it was not conducted on potential donors who are being recruited and are therefore faced with the need to make a decision regarding identification. It is also of interest to note that donors in the United States are compensated, which may very well encourage them to support regulations they wouldn't support otherwise. One cannot automatically preclude their preference regarding identification one way or another.

Notably, it has been consistently observed that abolishing donor anonymity translates into a reduction of available donated gametes. It was shown that a staggering 51% of potential donors in Western Australia will not participate if identity disclosure is enforced.<sup>8</sup> When asked directly if they would still consider becoming a donor if their identity were revealed to future offspring, only 48.9% of potential semen donors responded positively. Then, there are other challenges associated with donor recruitment such as disease screening results, sample quality, donor commitment, representation from different ethnic groups, etc. All these factors pooled

together will outline the extent and reasons for a donor gamete shortage.

In support of the association between abolishing donor anonymity and a shortage of donated sperm and eggs, a German study showed that only 43% of semen donors are willing to be contacted by mature offspring.<sup>9</sup> This indicates that there is a risk of losing even more than 50% of semen donors if anonymity is abolished. Since current recruitment rates in Canada are around 1%,<sup>10</sup> a 50% or more reduction of potential Canadian donors will have a severe detrimental impact on donor recruitment and availability of donor samples. Further evidence is provided in a recent systematic review regarding oocyte (egg) donations. Many studies included in this review documented that up to 80% of donors are not in favor of disclosure. In addition, only a significant minority of the most relevant study group, i.e. potential donors, continue to report willingness to donate as identifiable donors.<sup>11</sup>

For helpful clues regarding the impact of enforcing a ban on donor anonymity, one could also take a look at countries that have imposed such a ban. Recently published data by the Human Fertilization and Embryology Authority (HFEA), the U.K.'s regulator, initially suggested a positive impact of abolishing donor anonymity. The HFEA reports an increase in new donor number registrations over time following a decrease in donor numbers that was noted after the enactment of identity disclosure regulations. However, in-depth review of the published data reveals that the actual number of donor insemination treatments is declining: ([www.hfea.gov.uk/donor-conception-treatments](http://www.hfea.gov.uk/donor-conception-treatments)); moreover, the number of imported donor registrations is on the rise: ([www.hfea.gov.uk/3413](http://www.hfea.gov.uk/3413)). Both trends are



## Many other studies document that enforcing donor identity disclosure leads to a shortage in donor gametes.

clear indications that U.K. based donors are not providing enough samples to meet the needs of patients.

In this respect, HFEA has recently declared that it welcomes current public input as to how to tackle the shortage of sperm and eggs donated for IVF treatment in the U.K. HFEA has recently decided to include full, public consultation in its donation policies, which will be revisited in light of what has been learned over the past years: ([www.hfea.gov.uk/6055](http://www.hfea.gov.uk/6055)). These statements by the HFEA are somewhat alarming; one might wonder what would the consequences be in Canada of enforcing an altruistic, non-anonymous model without proper analysis of its impact on donor practices. The provision of donated sperm and eggs in sufficient numbers and of diverse enough ethnic origins to meet patients' needs is the ultimate objective of a successful donor recruitment program. Therefore, the availability of donor gametes is the critical indicator that

should be evaluated, not new donor numbers or registrations. The reason is that many donors do not pass the mandatory screening tests. In the end, the availability of donor gametes is the result of a long process that includes donor recruitment, registration, collection of samples, screening, quarantine and repeat screening. Making any of these steps more complex and demanding may result in a shortage in donor semen.

One of the concerns regarding donors' anonymity is the lack of information about medical and family histories. However, AHRA aimed at establishing the Personal Health Information Registry. The Registry was meant to provide gamete recipients and donor offspring with anonymous health-related information such as personal characteristics, genetic information and medical history ([www.ahrc-pac.gc.ca/v2/faq/accessFAQ-accesFAQ-eng.php#1](http://www.ahrc-pac.gc.ca/v2/faq/accessFAQ-accesFAQ-eng.php#1)). Unfortunately, the Assisted Human Reproduction Agency of

Canada has yet to establish this Personal Health Information Registry. Such delay raises concerns regarding the safekeeping of critical donor medical records. Currently, sperm banks follow best practice guidelines that recommend the maintenance of donor semen records indefinitely.

## CONCLUSION

Several studies have attempted to show that abolishing donor anonymity does not seriously undermine donor recruitment rates and therefore does not induce donor gamete shortage. However, most of these studies are either characterized by sparse study population numbers, design flaws or over-interpreted data. On the other hand, many other studies document that enforcing donor identity disclosure leads to a shortage in donor gametes. One concludes that it is entirely speculative at present to assume that similar legislations in Canada would not have a negative impact on donor semen availability here.

None of the published studies were aimed at designing adequate donor recruitment strategies in Canada or explored attitudes of potential donors regarding identity disclosure. Based on previously published research, when studies are appropriately conducted in Canada, results could be entirely different compared to others conducted in different countries. Therefore, it is imperative to design and conduct a national study that aims at investigating these issues before imposing any further restrictions on, or introducing any changes to, the existing donor semen regulations.

The inability to provide adequate numbers of donor semen samples from different ethnic groups will lead to conse-

quences such as depriving some minority groups from suitable fertility treatment, increased treatment waiting lists, increased importation of gametes and reproductive tourism, a well recognized consequence of restrictive legislations.<sup>12</sup> Since both anonymous and identity disclosure donors are currently available in Canada, it is important that gamete recipients be properly counseled regarding both options and empowered to make the decision that best fits in the context of their individual families.

All references are listed on the IAAC website at [iaac.ca/content/library](http://iaac.ca/content/library)

## About the author

Dr. Alfonso Del Valle is Medical Director at ReproMed – The Toronto Institute for Reproductive Medicine. In addition to assisting patients with infertility evaluation and corresponding treatment protocols, Dr. Del Valle is the founder of the sperm bank at the institute. For over 20 years, ReproMed has been the Canadian leader in sperm banking services helping to create families through the use of donor semen specimens and via advancements in cryopreservation techniques. You can learn more by visiting [www.repromed.ca](http://www.repromed.ca).

## ADVERTISEMENT

### REVIEW

### Best Before Date: Struggles with Childlessness and Infertility

*A documentary intended to help friends and families of infertile couples*

Directed by Reena Kukreja  
49 mins / 2010 / DVD / Canada

*Best Before Date* is a densely textured documentary that creates a compelling and moving portrait of people at various stages of their infertility and childlessness. It chronicles the feelings, anguish, and hopes of women and men as they speak out with searing openness about their attempts to conceive, in vain.

The documentary began when filmmaker Reena Kukreja and her husband, Paritosh Kumar, found their family and friends unable to understand

the toll that infertility was taking on them. Trying to make sense of what they were going through, they set the camera on themselves and others like them to offer an intimate glimpse of infertility and childlessness. With honesty, intelligence and, sometimes, humour they take the viewer through their experience of hope and grieving, self-reflection and social awareness.

*Best Before Date* is as therapeutic as it is instructive. People struggling with infertility will find their experience validated; family, friends and health-care workers will be a little better-informed and, hopefully, more sensitive after viewing this must-see documentary.

### Contact Tamarind Tree Films Production

[info@tamarindtreefilms.com](mailto:info@tamarindtreefilms.com) for copies of the film

Reviewed by Susan Anderson,  
Queen's University, Kingston, Canada