# **CHAPTER 9: Anonymity**

Traditionally, throughout much of the world, gamete donation has been treated with anonymity to protect the donor, physician, and parents. The importance attached to genetics has now led some countries to review the ethics of their statutes on anonymity. The laws have been changed in Sweden, the Netherlands, Austria, Australia, the United Kingdom (1), and Canada. As early as 1985, Sweden enacted legislation that requires semen donors to provide information on themselves when the offspring reach maturity. New Zealand, too, has had a so-called open system of information sharing for some time. The Netherlands introduced a law in 2004 giving offspring conceived by donated semen or oocyte the right to know the identity of the donor when they reach the age of 16 years. The United Kingdom enacted an anonymity law protecting donors in 1990. This was reversed in 2006, and gamete donors now are required to provide information to offspring when they reach the age of 18 years. The changes in that law include limiting donor compensation. In the United States, where there is a lack of such legislation and anonymity has always been assumed, a few cases now have been settled through the court legal system in favor of the offspring requiring donor identification. This is now causing a reluctance to participate among some potential donors. Anonymity is protected by law in France. There, through their Bioethics Law of 1994, donation is voluntary, nonremunerated, anonymous, and confidential (2).

The lack of anonymity has become a major stumbling block to oocyte and sperm recruitment in some countries. In the United Kingdom, where a wait for an oocyte donor of 1–2 years is not unusual, there is concern that these delays may be further lengthened as donors become more reticent (3). Along with anonymity or the lack of it, there are the moral, ethical, and legal issues that present themselves in every country regarding appropriate compensation of the donors. In Canada, where the government passed legislation in 2004 prohibiting all purchase or sale of gametes, there is serious concern over future donor gamete availability. Furthermore, that federal government will record all donor and donor offspring information.

### ANALYSIS OF SURVEY

As shown in Tables 9.1 and 9.2, guidelines dealing with anonymity are changing in many countries. The data from this survey indicate that there are now 18 countries, one third of the 54 surveyed, where information on the donor must be or customarily is provided to the offspring when requested, usually after the age of 18 years. In only 3 of these countries, Canada, Greece, and Slovenia, can this be limited to nonidentifying information. In the case of 16 other countries, the respondents indicated that their statutes or guidelines did not address this issue, and those from 6 other countries did not know whether providing offspring with nonidentifying information about the donor was customary. In Latvia, where donors remain anonymous, they must be willing specifically to provide genetic and anthropologic information. In New Zealand, by statute, donors may request information on their offspring's identity, but the children can decline. With respect to oocyte donation, Hungary has adopted legislation requiring the donor to be a relative of the couple.

#### DISCUSSION

When anonymity of donors has been traditional, any changes in anonymity rules can create new issues. Systems whereby offspring can obtain information on the donor are generally well received by the public and by those on the psychological and theoretical side of patient care. However, as a result, some gamete donors themselves may become reticent to participate, and there is associated difficulty recruiting sufficient numbers of donors. This potential for decreased availability of gametes is a source of concern to infertility physicians. For example, the number of egg donation cycles in the United Kingdom and Europe has lagged behind that of the United States in the past 2 decades, which largely is attributed to governmental restrictions in these countries, as compared with the lack of regulation in the United States (4). Furthermore, there are important ethical and legal issues regarding appropriate compensation for donors. In most countries where federal legislation prohibits anonymity, there are significant legal restraints on compensation of donors. This may further restrict availability of donor gametes. In countries without these legal restraints, donor compensation is variable, and self-regulation remains a challenge.

#### **SUMMARY**

Traditionally, anonymity has protected gamete donors through guidelines, statutes, or generally accepted practice. A greater understanding and awareness of the importance of genetics and hereditary issues has caused an increasing number of countries to enact laws that provide offspring access to identifying information on the donor. Many of these statutes also significantly limit compensation to donors. In these countries, potential donors often become reticent and chose not to become involved. The lack of anonymity and restricted compensation is making the recruiting of sufficient numbers of donors more difficult in many countries.

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TABLE 9.1										
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		or gu of do	Has le ideline	Has legislation or guidelines on anonymity of donors been modified?	Non ah	Nonidentifying information about donor provided on request	ation	<u>Ide</u>	Identifying information about donor provided on request	_
How ART is governed	Country	Yes <sup>a</sup>	Š	Not mentioned or don't know	Allowed/ customary	Not allowed/ not customary	Not mentioned/ don't know	Allowed/ customary	Not allowed/ not customary	Not mentioned/ don't know
Covered by statutes	Austria		+				+	+		
	Belgium		+				+			+
	Bulgaria		+				+			+
	Canada		+		+				+	
	Czech Republic		+				+		+	
	Denmark		+			+			+	
	France		+			+			+	
	Germany		+		+			+		
	Greece		+		+				+	
	Hong Kong		+		+					+
	Hungary	+			+					+
	Israel		+			+			+	
	Italy		+			+				
	Korea		+				+			+
	Latvia	+				+			+	
	Netherlands	+			+			+		
	New Zealand	+			+			+		
	Norway	+			+			+		
	Russia	+					+			+
	Saudi Arabia			+			8			No
							response			response
	Slovenia		+		+ (Medical				+	
	Spain		4		reasons)			HF life		
	Opalli		F		F			\(\rac{1}{2} \cdot \cdo		
	dopowo				+			threatening)		
	Sweder		+ -		+	-		+ &		
	SWITZERIAND		+			+		+ (Once		
	Taiwan		+			+			+	
	Tunisia			+			+			+
Kempers. Anonymity. Fertil Steril 2007.	Fertil Steril 2007.									

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