

Embryonic screening as a European human right

On 28 August 2012, the Council of Europe's Human Rights Court concluded that the Italian ban on embryonic screening violated Article 8 of the European Convention on Human Rights, which provides a right to respect for one's private and family life.¹ Since Italy is one of the few countries prohibiting pre-implantation diagnostics (PID) for medically-assisted procreation, this ruling may force Italy to lift this ban in the near future.

The applicants, Rosetta Costa and Walter Pavan, are an Italian couple. In 2006, after they had a daughter born with cystic fibrosis (CF) they found out they were both carriers of the disease. During a second pregnancy Mrs Costa opted for an abortion because upon prenatal screening the fetus was diagnosed with CF.

This time the couple wanted to have a child by *in vitro* fertilisation (IVF), and to genetically screen the embryo *prior* to implantation (PID). However, Italian law prohibits PID. Conversely, it allows IVF for infertile couples and those situations in which the man has a sexually transmitted infection such as HIV or hepatitis B

or C, to avoid transmitting the infection.² The couple claimed that the only way to have a healthy baby would be by starting a pregnancy in a natural way, have the fetus' genetic profile monitored throughout pregnancy, and then decide to terminate the pregnancy every time the fetus was tested positively for CF. Such a stressful procedure is the direct result of the ban on PID, which interfered with their right to start a family.

In this case, the Court considered the Convention's right to private and family life applicable (Article 8). Traditionally, the focus was on privacy of health information. Nowadays, however, the concept of private life is interpreted more broadly including "a person's physical and psychological integrity, and may even include a right to establish and develop relationships".³ Apart from abstaining from arbitrary intervention in the private sphere, Article 8 incorporates so-called 'positive obligations' of member states to realise the fulfilment of a private life. These positive obligations may cover: facilitating access to fertility treatment, access to donor insemination, and the implantation of a de-frozen embryo.⁴ Since assisted procreation is a controversial issue in the member states, the Court allows member states a wide margin of appreciation in terms of deciding on the nature and extent of these obligations. Furthermore, the Court allows member states to formulate restrictions on family life for specific reasons (e.g. protection of health and morals) and in accordance with the law.

The Italian government defended the ban as an interference "to protect the health of the mother and child, and to avoid the risk of eugenic abuses". In its review, the Court criticised this justification since Italian law accepts a therapeutic abortion in case of genetic defects such as CF, but simultaneously prohibiting a less invasive and less stressful selection method like PID. This inconsistency in legislation, causing harm to the couple, was reason for the Court to conclude that the ban on PID was a disproportionate (ineffective and unnecessary) interference of the couple's private life and therefore violated their right to private and family life.

This outcome can be considered as a victory for fertile couples genetically afflicted with CF. Apart from this conclusion the Court made another interesting observation, namely that more than 32 Council of Europe member states already allowed PID as a means for medically

assisted procreation. The Court therefore concluded that there is consensus on this ethical delicate issue. In addition, the Biomedicine Convention, although not ratified by Italy, also legitimises predictive and genetic screening test for health purposes.⁵ What the Court is saying is that, in case there was no consensus, the Court may have accepted Italy's wide margin of appreciation in banning PID. This was the case in *SH v Austria*, in which a same-sex couple requested donor insemination (heterologous IVF).⁶

Although the Court accepted a right to access to embryonic screening, Article 8 must not be interpreted as providing claimants with a right to a genetic healthy child. Such a claim would be illusory since one cannot claim health as a legal right. Instead, one can claim access to health care services as a means to achieve good health. Secondly, PID and other genetic screening technologies cannot fully exclude all genetic risks.

André den Exter, LLM, PhD

Lecturer in Health Law, Institute of Health Policy and Management, Erasmus University Rotterdam, Rotterdam, The Netherlands; denexter@bmg.eur.nl

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- 3 Niemietz v Germany (Application No. 13710/88) 16 December 1992 (§29).
- 4 Dickson v The United Kingdom (Application No. 44362/04) 4 December 2007; *SH v Austria* (Application No. 57813/00) 3 November 2011; *Evans v The United Kingdom* (Application No. 6339/05) 10 April 2007.
- 5 Article 12 Convention on Human Rights and Biomedicine (Biomedicine Convention), 1997.
- 6 *SH v Austria* judgment in the case of *SH and others v Austria* (Application No. 57813/00).