

## **THE (GENETIC) TIES THAT BIND US AND THE DUTY TO DISCLOSE GENETIC RISK: A COMPARATIVE STUDY**

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Family bonds raise sensitive and challenging questions relating to the disclosure of genetic information. Genetic information of one individual, for example, may reveal a genetic risk inherent in other blood relatives of this individual. Questions arising in this regard are, for example, whether a family member may be compelled to undergo genetic testing; and whether a person has a duty to share his or her genetic information, which may include information regarding a genetic risk, with other relatives. Does a woman have to share the genetic information that she is the carrier of one mutation of the breast cancer gene with her blood sisters? Some forms of genetic testing involve linkage studies which require blood relatives to provide tissue samples to ascertain whether a mutant gene can be traced in one family. Identifying one specific form of gene mutation can assist in the diagnosis of one specific person belonging to a specific family. Children, moreover, may want to be informed of familial genetic disorders in order to make responsible reproductive choices. Parents, on the other hand, may require genetic information relating to their young children in order to make financial and medical decisions for the future of their off-spring. Spouses, or persons involved in permanent relationships or contemplating marriage may also be entitled to know whether the persons they are spending their lives with, are the carriers of some genetic disorder.

The few examples above clearly illustrate the intricacy and sensitivity relating to the disclosure of genetic risks. The logical question arising is whether there is a duty, legal or otherwise, to disclose genetic risks to blood relatives and partners in intimate relationships. The purpose of this paper is to compare how this question is addressed in the following three jurisdictions: the United States, Germany and South Africa. In South Africa, the disclosure of a person's HIV-status to his or her intimate partner has received close attention and provides an interesting analogy to the question at hand and will hence also be explored