

# **Governing the Pre-Demented: Genetic Testing for Alzheimer's Disease in Germany, the United Kingdom and the United States**

Margaret Curnutte

Postdoctoral Associate

Baylor College of Medicine, Center for Medical Ethics and Health Policy

## **Abstract**

The ethical debate over genetic testing for Alzheimer's disease continues with the test's migration into the market and across the Atlantic. In this case study, drawing on methodology from Science and Technology Studies (STS), I trace the availability of genetic testing for Alzheimer's disease in Germany, the United Kingdom (UK), and the United States (US) to explore the availability of self-directed genetic testing in these different national contexts.

An increasing number of private companies are harnessing the power of the Internet and the promise of the Human Genome Project to innovate genetic testing and whole genome services for consumers who are interested in "empowered" healthcare without the mediation of traditional health care professionals. To understand how the emergence of direct-to-consumer genetic testing is playing out internationally, this case study focuses on the availability of genetic testing for Alzheimer's disease, as such genetic testing raises particular concerns about its utility given the disease has no cure. Physicians, genetic counselors, and bioethicists have questioned whether providing information about one's probability of developing the disease is at all beneficial, if not potentially harmful, to pre-symptomatic adults. Proponents have argued that the test is valuable for identifying research participants and is useful for planning end of life care.

In this paper, I focus my attention on discourses of utility for treatment and research. Utility proves a useful lens for analyzing the way national contexts shape imagined benefits. I use Foucaultian theory to explore how different ideas of the genetic test's utility legitimize the ways each state governs the technology and reveals how different institutions envision the governable subject. I argue that the German paternalistic approach emphasizes containment; the British interest-balancing approach focuses on the greatest utility; and the US market-driven approach supports liberal consumerism. These varying national approaches have important implications for how genetic testing is understood, deployed, and integrated into each society.