UPDATE: GENETIC TESTING: ETHICS, REGULATION, AND ONLINE ACCESSIBILITY

BY COURTNEY THIELE, LEGAL INTERN (2010-2011)

People are often uncomfortable with the unknown. This is even more the case with our health, where people want to know as much as possible about potential diseases. With the rapid advances in medical science and technologies, notably the completion of the Human Genome Project in 2003, people are turning to their genetic make-up to fill in some of the answers. Yet, caught up in the desire to find out all we can about ourselves, we may unwittingly create more unknowns in the process.

During May 2010 a national drug store chain planned to begin selling over-the-counter, direct-to-consumer (DTC) genetic testing kits. The kits ranged from $20 - $30 in addition to the report fee costs, which ranged from $79 - $249.1 When the FDA began investigating DTC genetic testing companies, the drug store chain reversed course, postponing the availability of the kits.2 Postnatal genetic testing, or adult genetic testing, is frequently employed for the purpose of screening whether or not an individual is the carrier of a disease that could either be passed down to his or her children or that could be expressed in him or herself.3 Genetic testing has the potential to become accessible to the masses with the production and marketing of DTC genetic testing kits. These kits were on the market for a short period of time at the beginning of last summer (2010) when intervention is possible is clearly a great benefit to the disease themselves. Other times the results of genetic testing are used in making reproductive decisions. Clearly in these scenarios major life concerns are being addressed. The potential effects from the results of genetic testing can be significant in a person’s life. Concern is particularly amplified with DTC genetic testing kits. Issues of inaccuracy, interpretation, and risk-benefit analysis require careful consideration. The average consumer often does not have the knowledge base or the access to obtain the appropriate information for properly understanding the results of DTC genetic tests.

We must note that genetic testing is not inherently negative. There is potential for significant good to come from the increase of information available through genetic testing. Identifying genetic diseases and conditions at an early stage when intervention is possible is clearly a great benefit to the patient. As Leon Kass recognizes, the foreknowledge of treatable genetic propensities would greatly be beneficial.4 We must consider, however, if the proposed benefits outweigh the present concerns.

DTC kits, however, can still be purchased through websites such as 23andMe.9 With the claim, "all it takes is a little spit," the company homepage, www.23andme.com (accessed May 11, 2011). 10(2010): 965–968.

2 Ibid.
6 Ibid.

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Although our conference speakers represented three streams in Christendom—Orthodox, Roman Catholic and evangelical—they were united in theme and purpose.

So, the scandal of bioethics is not, as Noll put it, the absence of the evangelical mind, but the disappearance of theologians or explicitly Christian discourse from the newly minted field of bioethics. (The conference gave us reason to be more hopeful.)

Mark Noll’s book appeared fifteen years later, the same year as the first CBHD summer conference. The Center for Bioethics & Human Dignity was born in 1993. John Kilner, Nigel Cameron, Harold O.J. Brown and a small group of visionaries helped launch a “kingdom project” to engage bioethics from a Christian perspective, to reclaim that land so carelessly yielded. (And the Center has never given up on that vision.)

Nearly twenty years later, what can we say? Did they succeed? Have we succeeded? Has our “rigorous research, theological and conceptual analysis, charitable critique, and thoughtful engagement” made any difference? Is there a Christian influence in technology, science, and medicine to be reclaimed? (We strongly assert, Yes!)

How would you answer? Whether or not you attended the conference, these are important questions. These are the problems that drive us to keep at it. We are not content to generate activity, but are committed to push harder, see farther, reflect more deeply, and network more broadly.

2 As quoted in Jonsen, 57-58.