

The Ethics of Genetic Testing: How Science Can Tear Families Apart

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On October 25, Zooming into Health Ethics held its first event of the year, entitled “Cases in Medical Ethics.” The purpose of the event was to find out the audience’s opinion on genetic cases dealing with two hereditary illnesses, Cystic Fibrosis (CF) and Huntington’s disease (HD). The audience was shown videos and asked questions at the end, to which they had to raise previously-provided green and red cards for “agree” and “disagree” respectively. Dr. Chantal Farra, assistant professor of pathology and lab medicine at the AUB Medical Center, was the featured guest speaker; she had previously “participated in...the Human Genome Project at Harvard School of Medicine.”

The first set of cases dealt with CF and involved a genetic counselor’s dilemma upon her discovery that a mother must have had an affair with another man: the husband, wife, and child were all tested for the disease, and the results provided overwhelming evidence of infidelity. Dr. Farra, who asserted that there is no “right or wrong” in cases of false paternity, found it “surprising” that most people believed that “the husband should be informed.” The “international guidelines on this issue,” she continued, “recommend that we inform the woman but not tell the man. Genetic testing should not be used to disrupt families. This is the system supported by Europe and the USA.” In Lebanon, however, the picture is much more ambiguous. Genetic tests are “cheap and widely available,” said Farra, “but there are no guidelines on the matter. It is, however, dangerous to disclose the truth to both parents, as this may lead to domestic violence, divorce, and even criminal acts—especially honor crimes—against the mother.” The audience’s views varied; some believed that these issues should be dealt with on a “case by case basis, not according to guidelines,” while others thought that counselors “should always tell the truth.”

The second set of cases involved HD, a fatal hereditary illness with late onset. The question here was whether the family should be notified if their father, now dead, tests positive for the disease. “International guidelines state that, for HD, no professional can inform the family,” said Farra. “Only the sick person himself can do it,” she added. The audience generally agreed, but insisted that the “all the children should be tested for it.” One audience member said that by “knowing that he/she will die young, the person can tie up loose ends and have enough time to make arrangements for his/her children’s futures.”

CF is recessive genetic trait that very often leads to death in infancy; life expectancy is about 37, depending on the source. The mutation leads to the accumulation of mucus in the lungs, thereby impairing breathing. Both parents have to be healthy carriers of the mutated gene for them to have a child with CF. HD, on the other hand, is a dominant hereditary trait in which one copy of the mutated gene alone will result in the illness. It is *always* fatal, but only manifests itself *after* the age of 40—it is *completely* hidden before that, thereby increasing the risk of passing the gene on to one’s children without the person’s knowledge. There is currently no cure for CF and HD.