Selling Personalized Genetics

Several companies on the Internet sell genetic tests directly to consumers including 23andMe, Navigenics, decode Genetics, DNA Tribes, Genelex, ScientificMatch, Consumer Genetics, Salugen, DNAprint Genomics, Genova Diagnostics, Suracell, and many more. The companies ask customers to collect a sample of their genes with a cheek swab and send it to them for testing. Most test by putting the customer's gene sample on a small flat "DNA microarray chip" that already contains pieces of DNA matching known genes (or gene mutations). If one of the customer's genes matches one of the pieces of DNA on the chip, it binds to the DNA fragment which creates a tiny fluorescent glow showing that the gene indicated by the DNA fragment is in the sample. A computer then analyzes the pattern of glowing spots on the chip and prints out a list of the genes (or gene mutations) in the customer's sample. Scientists have discovered a few genes that are associated with specific diseases or personal characteristics. Studies found, for example, genes that are linked to cystic fibrosis, Tay Sachs disease, and Lou Gehrig's disease, genes that increase the risk of certain breast, colon, and thyroid cancers, and genes associated with sensation seeking, eye color, obesity, and lactose intolerance. They also found that some genes are more often found in people whose ancestors came from certain regions of the world. The companies say that based on these studies and their own gene tests, they can give customers valuable personalized information (for a price, of course). One company, Sciona, (no longer operating) said on its web site: "Sciona is a leader in nutrigenomics, the science of personalizing your nutrition and lifestyle choices to match your genes"; Sciona gave customers "a personalized preventative dietary regime" that was supposed to prevent the diseases their genes put them at risk for. Another site promises: "Based upon the ... [genetic] analysis, Suracell recommends to each client a personalized regimen of nutraceuticals [vitamin supplements]." Another states: "DNA Tribes ... uses genetic material ... to measure your genetic connections to individual ethnic groups and major world regions." Another company claims to do it all: "With a simple saliva sample we'll help you gain insight into your traits, from baldness to muscle performance. Discover risk factors for 95 diseases. Know your predicted response to drugs, from blood thinners to coffee. And uncover your ancestral origins." Critics claim, however, that with a few exceptions, most studies have shown only weak connections between genes and specific traits, disease risks, drug responses, nutritional or vitamin needs, or ancestral origins. Many studies that link specific genes to a disease are only preliminary and the full picture has not yet been worked out. Moreover, critics say, it is wrong to tell customers their genes put them at risk of a deadly disease without proper counseling, especially when the scientific studies are weak and many other environmental, demographic, and lifestyle factors determine actual onset of a disease. Ordinary consumers, they conclude, are being sold a product that they do not have the expertise to interpret. But defenders of the tests say consumers have a right to know what genes they carry and what science has learned about those genes. The companies charge from $140 to test for two or three genes, up to $999 to test for a full suite of genes.

1. Evaluate the ethics of selling gene tests directly to consumers like these companies are doing. What would each of the three theories of a business's duties to consumers say about what the companies are doing? Under what conditions do you think selling the tests would be ethically legitimate?
2. Check out the video of GAO interviews of gene-test company sales people at *http://www.gao.gov/products/gao-10-847t*. Evaluate the selling practices shown on the video.