**UC BERKELEY ADOPTS CONTROVERSIAL GENETIC TESTING PROGRAM**

By Jeremy Gruber

Instead of the usual summer reading, the University of California, Berkeley recently announced that it will be sending incoming freshman a cotton swab with which to send in a DNA sample. These DNA samples will be tested for three genes that help regulate the ability to metabolize alcohol, lactose and folates as part of a program for the class of 2014 that will focus on genetics and personalized medicine.

Berkeley’s program is the first mass genetic testing by a university and quickly brought national attention and an outcry from professors and public interest groups, including the Council for Responsible Genetics. The program’s proponents, including Dean of Biological Sciences at the University Mark Schissel, have claimed that the testing will be voluntary and anonymous, that sufficient safeguards are in place to protect the privacy of the information, and that subsequent forums would be available to students to build an understanding of such information and put it in context.

Critics have countered that by offering voluntary educational forums only after the DNA sample has been collected, students will be unable to make informed decisions regarding participation in the program and the utility of these genetic tests, that the structure of the program is inherently coercive and that the program is likely to exaggerate the role of genetic information in medicine.

In an open letter to the University, the Council for Responsible Genetics decried the lack of ethical considerations prior to adopting the program and argued that many of the suppositions behind the program including the statement by the University that “[T]he information Berkeley students will glean from their genetic analysis can only lead to positive outcomes” were “woefully naïve” as to the many opportunities for and documented instances of the misuse of genetic and other medical information and the security of de-identification techniques. The letter further noted that:

“[T]he American Medical Association, the American Society for Human Genetics and the American Clinical Laboratory Association have all issued strong statements against direct to consumer genetic testing and recommended that a genetics expert be involved in ordering and interpreting genetic tests, consumers be made fully aware of the capabilities of genetic tests, the scientific evidence on which tests are based be available and stated so that the consumer can understand it, the laboratories conducting the tests be accredited, and consumers be made aware of privacy issues associated with genetic testing. It is particularly troubling that the announcement of this program should come just days after the Food and Drug Administration (FDA) forced Path-way Genomics to pull its genetic testing kits off Walgreens pharmacy shelves for being unapproved and making unvalidated claims and the House of Representatives Energy and Commerce Committee began an investigation of the claims made by these companies.”

In an analysis of the program in the Chronicle of Higher Education, Berkeley Professor Troy Duster argued:

Might a Berkeley freshman get a false understanding of his or her reaction to alcohol, or intolerance for milk, or need for kale? Well, possibly, but that is not the main point. Rather, the substantial intellectual risk is that they’ll be institutionally introduced into misunderstanding the precision, interpretation, and historically problematic execution of such research, and the subtle, unexamined undercurrent of coercion in their participation. Until students have a firm comprehension of all those aspects, such projects shouldn’t be planned.

Critics additionally attacked the lack of an open process in adopting the program and the seemingly blatant conflict of interest and absence of academic independence in the program’s inclusion of a contest with a prize of a full genetic screening by the direct-to-consumer genetic testing company 23andMe, a company on whose Board of Directors one of the faculty sits.

The University has since decided to eliminate the contest but they have failed to properly address the serious concerns of many over the close commercial biotech connections of the professor leading the University’s genetic testing program, Jasper Rine. Professor Rine is the founder of several commercial biotech companies (and has served as a consultant for others), including founding his own genetic testing company (Vita Path Genetics) less than a year ago. Indeed, Professor Rine was on a tenure committee that denied tenure to a scientist (Ignacio Chapel) who was critical of a deal several years ago between Berkeley and Novartis and Rine (who was a vocal critic of Chapel) was heavily criticized for having a conflict of interest because of his biotech ties. Furthermore the University has attempted to quell concerns over the funding of the program by claiming the funds will not come from existing University funds but has raised new concerns since these private donations are apparently anonymous.

Despite all the criticism, Berkeley has decided not to cancel the program, or even delay it with further consideration, but continue the program without delay. Writing in Inside Higher Ed,2 Vanderbilt University Professor Jane Robbins finds that:

Minding my teaching that we should not make assumptions, particularly about motive (although we can often unpack motive from evidence)…at the very least, it seemed that UC Berkeley did not think this through. That alone is a failure of ethical responsibility, and one of the lessons about how ethics failures occur.

Perhaps that can be the topic of next year’s program for the class of 2015.

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