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May 19, 2010

Dear Dean Richards,

It was with quite some shock that we learned in the press today that incoming freshman for the class of 2014 in the College of Letters and Science will be sent a swab with which to send in a DNA sample. Your website announcement of the program states “(T)he information Berkeley students will glean from their genetic analysis can only lead to positive outcomes.” This is a woefully naïve. The information produced by these tests, even for ostensibly benign purposes, has the risk of increasingly being used out of context in ways that are contrary to the interests of the individual, perhaps even discriminatory and certainly privacy invasive. Having worked for many years on passing the Genetic Information Nondiscrimination Act (GINA) I am keenly aware of the number of entities, from pharmaceutical companies wanting to target their marketing to banks and life insurance companies that want to use such information to discriminate, that are actively seeking this information. Many of these uses remain unprotected and unregulated; such testing should not be taken lightly.

Which is why the 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

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(FDA) forced Pathway 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.

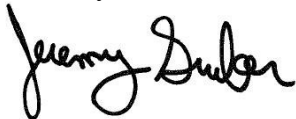
Furthermore, incoming students are in no position to make a “voluntary choice” as to whether to participate in such testing when being offered by the University that just admitted them. Indeed, a number of incoming students will even be below the age of consent to legally make such a decision. Which raises the question of whether you passed this solicitation of freshman DNA with the Institutional Review Board (IRB) of your university.

Additionally there remains serious questions within the scientific community over whether genetic information can be properly de-identified and to put such “de-identified” information on the Internet is highly troubling, not to mention any clear statements on the retention of the genetic samples themselves.

Finally the involvement of a commercial company, 23andme, even if ostensibly for a contest prize as part of the program raises additional serious issues. When a public university adopts such student programming that is essentially creating potential customers for a nascent direct to consumer genetic testing industry (one that just happens to be almost entirely located within the Bay Area) it raises serious questions of independence and academic integrity. Particularly since 23andme is a specific subject of the aforementioned House investigation that has raised questions as to the accuracy of its testing.

I urge you to abandon this DNA collection program and use this experience to have a university wide discussion.

Sincerely,

A handwritten signature in black ink that reads "Jeremy Gruber". The signature is written in a cursive, flowing style.

Jeremy Gruber
President
Council for Responsible Genetics