

August 5, 2010

The Honorable Chris Norby  
California State Assembly  
P.O. Box 942849  
Sacramento, CA 94249

Dear Assemblyman Norby,

We wish to express our strong support for AB 70 (Norby). By requesting that the University of California, Berkeley refrain from making unsolicited requests to their students for DNA samples to conduct genetic testing, requiring an accounting of expenditures in furtherance of such practices and authorizing the Controller to take an amount equal to such expenditures from University appropriations and revert it back to the General Fund, this bill is critical to protecting student privacy and ensuring institutional accountability in the University of California, Berkeley's controversial "On the Same Page" personal genomics experiment.

The "On the Same Page" experiment, which invites students to "Bring Your Genes to CAL," consists of sending incoming Freshman at UC Berkeley a swab with which to send in a DNA sample to be tested as part of an introductory personal genomics program. This program, as designed, is coercive, privacy invasive and ethically suspect.

**The program is inherently coercive** in that Freshman who have just been admitted to the University are in no position to make a "voluntary choice" as to whether to participate in such testing when being approached by the University that just admitted them. A student who chooses not to participate will not be in the same position as a student who does; in essence choosing not to experience completely an introduction to the next four years of their higher education. Furthermore, the University trivializes half a century of evidence that "consensual" human subject research can be corrupted by the power/status relationship between the subject of the research and those in charge of it.

**The program is privacy invasive** in that students will be releasing to the University perhaps the most highly personal individualized information that exists today, their own DNA. The collection, storage, and testing of such information raises serious privacy concerns. The University, which has never conducted such a program before, cannot possibly account for all the potential opportunities for such information to be compromised; particularly when contracting out with a third party to do the actual testing. Such testing often requires a full DNA scan even if only 3 gene variants will be specifically identified. Examples abound of such data being lost, stolen or otherwise publicly released. For example, in 2005 the California Department of Managed Health Care fined Kaiser Permanente \$200,000 for exposing the confidential health information of hundreds of patients.

The University of California, Berkeley minimizes claims to the potential for such information to be misused when so many entities are actively seeking this information, from pharmaceutical companies wanting to target their marketing to banks and life insurance companies that want to

use such information to discriminate. In one such notable case, Lawrence Berkeley Laboratory was found to have routinely collected blood samples as part of testing for hiring and subsequent employment and secretly conducted genetic tests on them.

Furthermore, the University ignores the growing evidence on the limitations of anonymization and the ability to re-identify supposedly anonymous data from databases like the one the University is proposing. It also exaggerates the protections it has put in place as personally identifiable information will necessarily have to accompany the DNA samples in order for University personnel to process consent forms.

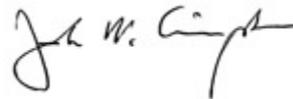
**The program is ethically suspect** in that it only provides students with voluntary opportunities to understand the value and context of their genetic information subsequent to releasing it to the University. As a result, it ignores the recommendations of the American Medical Association, the American Society for Human Genetics and the American Clinical Laboratory Association. These organizations all recommend that a genetics expert be involved in both ordering and interpreting genetic tests, that consumers be made fully aware of the capabilities of genetic tests before utilizing them, that the scientific evidence on which tests are based be available and stated so that the consumer can understand it, and that consumers be made aware of privacy issues associated with genetic testing. The program is further ethically compromised by the fact that its creator and leader, Professor Jasper Rine, is the recent founder of his own genetic testing company and therefore has a commercial stake in promoting personal genomics.

That the University of California, Berkeley would risk privacy and ethics for this program is highly irresponsible. We stand in strong support of AB 70 to ensure the privacy of the students of the University of California, Berkeley, to protect them from coercive and ethically suspect practices, and to enforce accountability from the University administration.

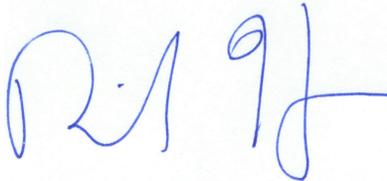
Signed,



M. L. Tina Stevens  
Director  
Alliance for Humane Biotechnology



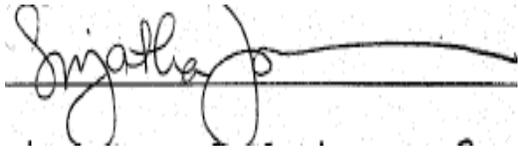
John M. Simpson  
Consumer Advocate  
Consumer Watchdog



Richard Hayes  
Executive Director  
Center for Genetics and Society



Jeremy Gruber  
President  
Council for Responsible Genetics



Sujatha Jesudason  
Executive Director  
Generations Ahead



Beth Givens  
Director  
Privacy Rights Clearinghouse

Pam Dixon  
Executive Director  
World Privacy Forum  
760-436-2489

\* Please respond via Jeremy Gruber (212-361-6360; [jeeg@concentric.net](mailto:jeeg@concentric.net)) at  
The Council for Responsible Genetics