Is Preventive Genomics Elitist?

Genomes2People Follow
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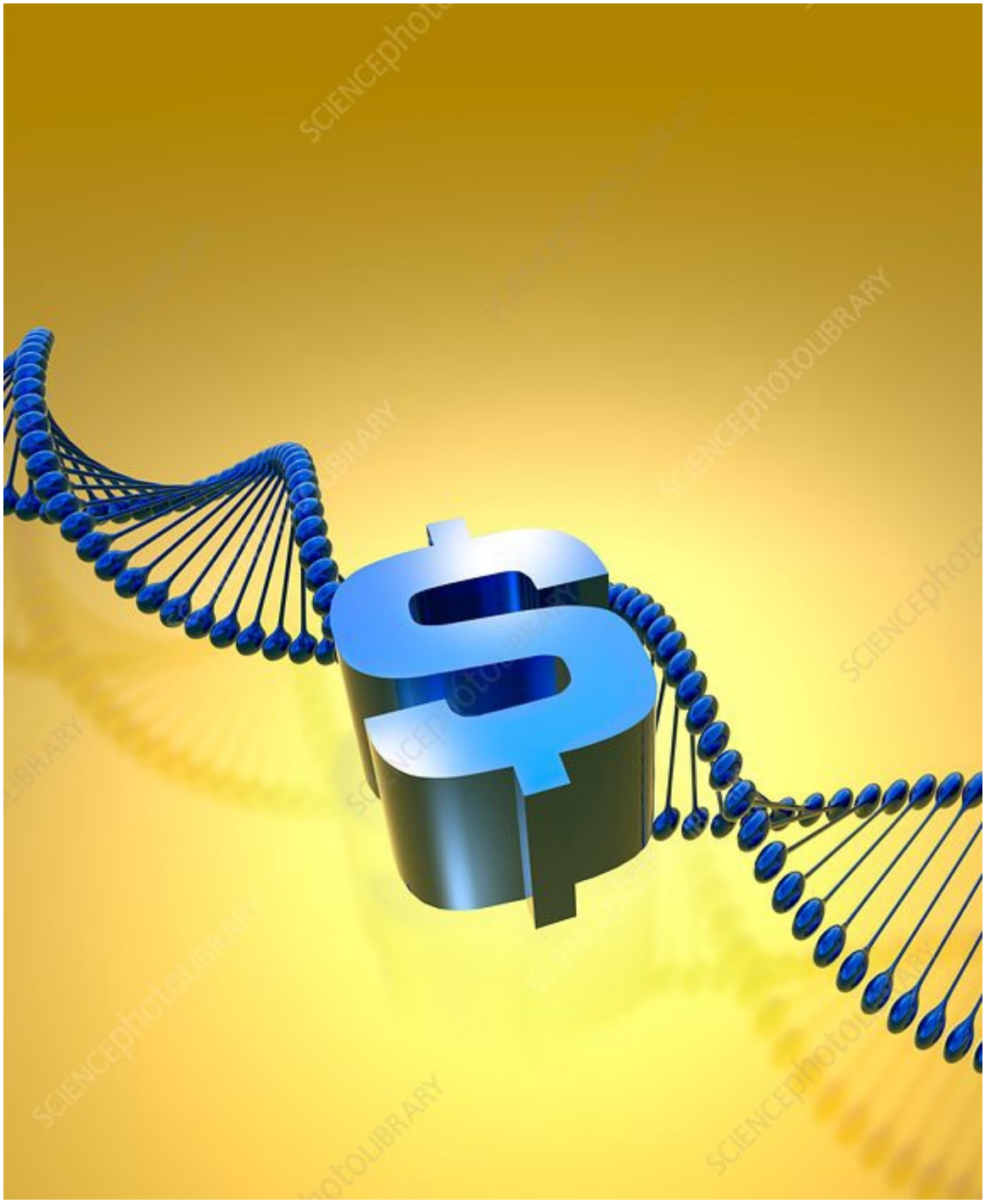
By Dr. Robert C. Green



If you're an apparently healthy person who wants to learn about your genetic disease risks, you can send a saliva sample and a hundred bucks or so to an array-based direct-to-consumer genetic testing company and get some trait information and selected health risks, plus details about your genetic ancestry. But as the direct-to-consumer (DTC) companies themselves will tell you, this is only a fraction of the medical value that may be hidden in your genome. Many of the experts in both ancestry and medical genomics will suggest that since consumer facing genomics are not as comprehensive as those meeting medical standards, it is quite OK for consumers to pay for these products out of their own pockets.

But when it comes to health care, people expect products and services that are medically beneficial to be available to more than just those people who can pay for them. As medical science increasingly demonstrates the life altering value of genomics, the notion that these services must be paid for out of pocket, making it inaccessible to some, does not seem appropriate or fair.

We recently launched the Brigham Preventive Genomics Clinic, the first academic clinic in the world to offer comprehensive, high quality genome sequencing and in-depth interpretation to apparently healthy adults and their children. Over the past two years of planning this clinic, we have struggled with the reality that there is no health insurance coverage for preventive genomic testing, and our patients must therefore pay out of pocket. This is a troubling feature for a clinic at Brigham and Women's Hospital, which is known for its ties to communities in Boston with diverse ethnic and socioeconomic backgrounds. One must ask: Is a service like this further widening the inequities in our health care system?

The answer is essentially yes … in the short term. Most of the Preventive Genomics Clinic's first patients are likely to be well-off, well-educated, and largely white. This represents the profile of typical early adopters in genetic medicine, and in technology writ large. It does not, however, represent the Clinic's ultimate target audience. The ultimate aim of our Genomes2People Research Program is to contribute to the

transformation of medicine from reactive to proactive, from treatment-oriented to preventive. We are trying to help build the evidence base that will justify societal decision to make these technologies and services accessible to anyone who wants them, regardless of means, education or race and ethnicity.

In order for this to happen, genome screening services need to exist in practice, even as demonstration projects. But in order to convince experts and health insurance payors to cover something new, we will need to rigorously demonstrate medical value. The Genomes2People Research Program has more than two decades of NIH-funded trial evidence showing the medical, behavioral and economic outcomes associated with genomic testing. We plan to continue gathering such evidence, even from the patients who are now being seen in the Brigham Preventive Genomics Clinic.

The mechanism for tying outcomes research to our new Clinic is the NIH-funded PeopleSeq Consortium, a three-year research study specifically designed to explore the impact of sequencing among those persons who have sought (and paid for) elective sequencing. Data from this project will add real-world evidence from patients who are, in essence, paying for the privilege of donating their data. We are also negotiating with sequencing laboratories and raising funds to provide free or decreased cost services to patients beyond the usual early adopters. This is a short-term fix, but an essential one. It will be especially important to include minorities who have been underrepresented in genomic research and underserved by genomic medicine.

For those reasons, we were recently awarded supplemental NIH funding through the PeopleSeq Consortium to offer medical sequencing for free to a number of African American patients. In partnership with consultants and colleagues from several Historically Black Colleges and Universities, we and our research consultants who speak before lay audiences with large percentages of African American individuals, will offer the opportunity to obtain clinical sequencing, along with pre- and post-test genetic counseling, for free.

In summary, the Brigham Preventive Genomics Clinic may temporarily add to the growing “genomic divide” in our society, but through our NIH-funded PeopleSeq Consortium, and the recently funded supplement to support free clinical sequencing for African Americans, we hope to close that divide as soon as possible, and bring all of society together into a new age of genomics and preventive medicine.

Robert C. Green, M.D., M.P.H., is a medical geneticist and physician-scientist who directs the G2P Research Program in translational genomics and health outcomes in the Division of Genetics at Brigham and Women's Hospital, the Broad Institute and Harvard Medical School. Follow him on Twitter at @RobertCGreen.

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