

Volunteers unveil DNA, medical data in push for everyday gene sequencing

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Left to right; George M. Church, Professor of Genetics at HMS; Steven Pinker, Professor of Psychology at Harvard University; John D. Halamka, Dean for Technology at HMS; Rosalynn Gill, Chief Science Officer of Sciona; Keith Batchelder, CEO of Genomic Healthcare Strategies; Kirk M. Maxey, of the Cayman Biomedical Research Institute; James Sherley, Senior Scientist at the Boston Biomedical Research Institute; Misha Angrist, Science Editor at the Duke University Institute for Genome Sciences & Policy; Stanley N. Lapidus, Chairman and CEO of Helicos BioSciences Corp.

(PhysOrg.com) -- The world moved a step deeper into the DNA age yesterday as 10 volunteers released their genetic and medical information on the Internet as part of a multi-year effort to make genetic data an everyday part of medical care.

The effort was headed by Harvard Medical School's George Church, professor of genetics and head of the Personal Genome Project, who

was himself one of the volunteers. Their release of information was an initial step in the project's ultimate goal of enrolling 100,000 people willing not only to get their genome sequenced but also to share that information, along with their medical histories, with researchers and the public alike.

The project will create an enormous database of both genetic and medical information that researchers can mine for links between specific genes and particular medical conditions. The effort will also reveal information about personal genetic tendencies that participants can use in planning their own medical care. In addition, the project will tackle the societal issues surrounding privacy and access to medical information created by the opening of a whole new source of personal data — one's DNA.

Monday's event, a news conference at Harvard Medical School's New Research Building featuring nine of the 10 volunteers, lacked the drama of a major health revelation but was remarkable nonetheless. Participants willingly spoke about the genetic tendencies they recently learned their bodies carry — including severe immunodeficiency disease, hemochromatosis, which causes an iron overload, and an increased susceptibility to tuberculosis.

Though their gene sequencing revealed genes linked to such potentially severe conditions, it was instructive, several volunteers said, that they were, nevertheless, all healthy. Rosalynn Gill, founder and chief science officer of Sciona, an international company that provides health and nutrition recommendations, said that though the sequencing found hemochromatosis in her DNA, in fact, she has a tendency toward anemia, an iron deficiency.

"It's a lesson for all of us that genetic study is not deterministic," Gill said.

Volunteers also discussed their own decision-making processes as well as the discussions they had with family members before releasing their information. John Halamka, chief information officer and dean for technology at Harvard Medical School, said he spoke with his wife and 16-year-old daughter. He explained to his daughter that it is possible that potential future boyfriends would look at his genetic information on the Web and draw conclusions about her. Her response, he said, was that she wouldn't be interested in anybody who would make relationship decisions based on such data anyway.

Johnstone Family Professor of Psychology at Harvard Steven Pinker, who was one of the 10 volunteers, spoke for several in saying his participation was spurred by scientific curiosity. Pinker said he's interested in the roots of personality and eager to help determine the role that genes play in the development of personality traits.

"We're almost completely in the dark about what the causal relationships are," Pinker said. "I think it'll be many years before we know, but I want to be part of this effort."

The news conference followed a two-day period where volunteers learned about the results of their genetic sequencing and consulted with personal and project physicians before agreeing to release the data. Church said the information is preliminary, calling it "a beginning, not an ending" to participants' involvement with the project.

The event was a beginning in a very real way, as the recruiting, sequencing, and release of the data was required by Harvard's Institutional Review Board, which reviews all research involving human subjects, as a way to identify and work through potential issues before beginning the mass enrollment the project will require.

The first 10 subjects were handpicked, not only for their willingness to

participate, but also for their knowledge of genetics research and understanding of the risks that uncovering and releasing genetic information can carry.

Besides Church, Pinker, Halamka, and Gill, the group also includes Misha Angrist, science editor at Duke University's Institute for Genome Sciences & Policy; founder and CEO of Genomic Healthcare Strategies Keith Batchelder; chairman and CEO of Helicos BioSciences Corp. Stanley Lapidus; senior scientist at Boston Biomedical Research Institute James Sherley; Kirk Maxey, founder of Cayman Chemical; and investor Esther Dyson.

Church said the first samples of skin, blood, and saliva were taken in 2006. The samples were used not only to extract genetic information, but they will also be used to establish stem cell lines for each participant. Those cells would be available for possible future research.

The project has a waiting list of about 5,000 people interested in participating, Church said, but will need many more to achieve its goals.

Related link: www.personalgenomes.org/

Provided by Harvard Medical School

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