

PublisherInfo		
PublisherName	:	BioMed Central
PublisherLocation	:	London
PublisherImprintName	:	BioMed Central

Sobriety amid the celebration

ArticleInfo		
ArticleID	:	4750
ArticleDOI	:	10.1186/gb-spotlight-20030414-02
ArticleCitationID	:	spotlight-20030414-02
ArticleSequenceNumber	:	102
ArticleCategory	:	Research news
ArticleFirstPage	:	1
ArticleLastPage	:	4
ArticleHistory	:	RegistrationDate : 2003-4-14 OnlineDate : 2003-4-14
ArticleCopyright	:	BioMed Central Ltd2003
ArticleGrants	:	
ArticleContext	:	130594411

Peg Brickley

Email: pegbrickley@hotmail.com

When the International Human Genome Consortium announced a completed draft of the human sequence in June 2000, the stock market boomed, the World Trade Center stood and the ethics of genomic exploration were a matter of heady debate. Today, hopes for rapid gem extraction from genome mining are taking hits from war, terrorism and bankruptcy, and ethical quagmires are no longer hypothetical.

Genomic exploration was to have been the first item on the agenda of UNESCO-sponsored [International Congress of Bioethics](#) slated for May in Tehran, Iran. But the meeting has been postponed due to 'unfortunate conditions' in the region, to be rescheduled once normalcy is restored.

Just a few years ago, bioethicists' biggest worry was the 'genome rush,' a race for quick drug profits that might turn genomics into a new brand of eugenics, with a thin sheath of science veiling the exploitation of vulnerable people. Icelanders were the first poster children for the cause, as deCode Genetics Inc. tapped their medical and [genealogical records](#) with the help of law-makers who simply assumed all citizens would want to participate.

Now deCode shares that once sold for close to \$30 each are going for about \$2 on the NASDAQ market. And while the Reykjavik-based company continues to trumpet deals that are supposed to carry forward the mission of harnessing the human genome to find life-saving treatments, the stock market has yet to register any return of hope.

So, too, with Autogen Ltd., of Victoria, Australia, which was accused of gathering genetic information in the South Pacific island nation of Tonga under unfair circumstances. Now called AGT Biosciences, it continues to issue upbeat press releases only to see its stock price head south.

Questions of [cultural fairness](#) in consent and control over the uses of genetic data intensify at the international level. "When you're going to an isolated population, there is a question whether they even have the words to understand what you're talking about," said Ellen Wright Clayton of Vanderbilt University. "There is no word for DNA among the Yorba."

Answers to those questions are slow in coming, keeping pace with the now sober trudge toward profit from personalized medicine keyed to genetic data. But the failure of personalized medicine to deliver a quick payday on the commercial front has not stymied the collection of genetic information. It continues in universities, private companies and in legislatures, as the United Kingdom, among others, moves toward a genetic database designed as public property, called [Biobank](#).

"They're bio-banking like crazy," said [Nikolas Rose](#), director of the BIOS Center at the London School of Economics, which is working with a private DNA banker he declines to name. Among other things, BIOS is helping the entity figure out how to render banked genetic data anonymous but still useful.

[David Clayton](#) of the Cambridge Institute for Medical Research finds a lot to question in the proposed UK Biobank. He is particularly concerned that the shifting rationale for the effort betrays its scanty science.

"The initial document highlighted the uses of Biobank in discovering disease susceptibility genes and genes determining differential responses to treatment," he said. "However, a prospective study on the scale of Biobank is not a particularly rational approach to either of these problems, a fact which seems to be tacitly conceded in later consultation documents, which emphasize different goals."

US authorities, meanwhile, are haunted by the prospect of terrorists sifting through public genomics treasure troves for the means to build deadlier pathogens and toxins. Earlier this month, the National Research Council convened a panel of experts to study whether the openness so sacred to science has become a security risk when it comes to genomics.

"There is some basis for these concerns. We're at a whole new point in being able to design more virulent biological weapons," said Peter Shorett, director of the Council for Responsible Genetics in Cambridge, Mass.

In the gloom of 21st century reality, bankruptcy has joined bioterrorism as one of the new threats to the accumulating stores of genetic wealth.

"Your contribution is nothing less than historic," DNA Sciences Inc.'s Gene Trust promised 13,000 Americans who volunteered blood samples and medical records to build a bank of genetic material which the Fremont, Calif. firm hoped to mine for keys to disease. Now contributors' samples and data are on the auction block in [DNA Science's bankruptcy](#), to be sold to the highest bidder.

Once the databank and samples are sold, the company will notify depositors and some might exercise the right to withdraw, DNA Science president Steven Lehrer said. But he insisted the Chapter 11 bankruptcy does not change the terms for Gene Trust, which was established with levels of regulatory review superior to anything now required, according to Lehrer.

"We set the bar as high as possible," Lehrer said, who was one of the first depositors. Gene Trust holds his wife's and parents' genetic data, too.

"My mother's DNA is in there," Lehrer said. "I continue to be concerned that it be handled properly."

[Mark Rothstein](#), director of the Center for Bioethics, Health Policy and Law at the University of Louisville in Kentucky, has long pondered what happens when a biobank goes bankrupt.

"From the experts we have talked to, it's an unresolved issue," Rothstein said. "The promises the company makes in acquiring samples are not binding on the trustee in bankruptcy. The biobank could be the only asset left and the creditors have the right to insist its value be maximized. That could mean selling off the samples in ways that seem to violate the express conditions under which they are given."

Rothstein, an attorney, conducted a national survey of 1,800 people to find out how race, ethnicity, age, gender, income and education levels affect willingness to participate in genetic research. "The issue we have with any research is who is going to benefit from it," he said.

While scientists follow genetic indicators to find drug targets, Rothstein worries, pharmaceutical companies follow the money to find profitable markets. "If we are going to recruit people to give DNA, medical and family history, we have to have some clear expectation that the people who are contributing

the specimen will benefit. If all we do as a result of this is develop very expensive medications that only a few well-to-do people can afford, it's much harder to show a benefit."

References

1. International Congress of Bioethics, [<http://www.irost.org/bioethics/>]
2. Baard M: Gain for science is history buffs' loss. *The Scientist*, February 10, 2003, [<http://www.the-scientist.com/news/20030210/03/>]
3. Lewis R: Culture and consent. *The Scientist*, December 4, 2002., [<http://www.the-scientist.com/news/20021204/03/>]
4. Hagan P: Biobank debate heats up. *The Scientist*, April 8, 2003., [<http://www.the-scientist.com/news/20030408/02/>]
5. Nikolas Rose, BIOS Center for the Study of Bioscience, Biomedicine, Biotechnology and Society, [<http://www.lse.ac.uk/people/n.rose@lse.ac.uk/>]
6. David Clayton, Cambridge Institute for Medical Research, [<http://www-gene.cimr.cam.ac.uk/clayton/biog.html>]
7. Brickley P: Pharmacogenomics fire sale. *The Scientist*, April 4, 2003., [<http://www.the-scientist.com/news/20030404/02/>]
8. Mark Rothstein, Center for Bioethics, Health Policy and Law, University of Louisville, [<http://www.louisville.edu/medschool/ibhpl/faculty/rothstein.html>]