

8. Biobanks

By ALICE PARK



Inside Huntsman Cancer Institute's vaults: Pancreatic tumors on ice.

LANCE W. CLAYTON FOR TIME

Now that major banks in the U.S. are getting by on a government bailout, the idea of creating yet another repository to safeguard your most valuable assets might seem downright ludicrous. And even irresponsible. But that's exactly what some federal officials are hoping to do.

Relax — it's not your money they're after. It's your blood. Folks at the National Cancer Institute (NCI) are heading up an effort to establish the U.S.'s first national biobank — a safe house for tissue samples, tumor cells, DNA and, yes, even blood — that would be used for research into new treatments for diseases.

Think of it as an organic bank account. You put your biomaterial in and earn medical interest in the form of knowledge and therapies that grow out of that deposit — no monetary reward, just the potential that you might benefit from the accumulated data at some later date. (Sorry, no shiny new toaster to inspire you to open up such an account either — just an appeal to the greater medical good.) Britain, Canada, Norway and Sweden have already begun building up their national biobanks. And the residents of Iceland, though the country is bankrupt, still have their biological assets tucked safely away; more than 60% of adults in the island nation have donated DNA to deCODE Genetics, the company that runs the bank. The U.S. effort currently lies in the NCI's Office of Biorepositories and Biospecimen Research (OBBR). By fall, the group hopes to have mapped out a plan for a national biobank; the recent stimulus showered on the government by the Obama Administration might even accelerate that timetable.

Why the NCI? Cancer, it turns out, is a smart place to start with a biobank. Already, dozens of genes have been linked to cancers — BRCA 1 and 2, which are behind 5% to 10% of breast cancers — and gene proteins like

prostate-specific antigen, which signals a potentially abnormally growing prostate gland. Many cancer hospitals have been collecting and storing tissue samples for decades.

Imagine the power of those thousands of samples writ 100,000 or even millions of times larger, over not just cancer but any disease, ranging from brain disorders like Alzheimer's to metabolic conditions like diabetes. With enough tissue samples from both affected and unaffected people, researchers can pick out gene profiles that haunt the DNA of those who get sick, then start to screen and treat these individuals and others like them more aggressively. "Biobanks will transform the way we see disease developing," says Dr. Carolyn Compton, director of the OBBR.

It will certainly change what you leave behind each time you visit the doctor. The key to a powerful national biobank is high-quality specimens from as wide a swath of the country's population as possible. And both doctors and patients are beginning to warm to the idea of collecting DNA and tissue samples as a part of routine examinations.

The challenge, of course, is to maintain the privacy of account holders and ensure that access is limited to medical personnel and those who have the individual's consent. Coding each specimen and setting up layers of password-protected data sets might be one way to accomplish this.

Sounds easy, but will it work? That all depends on how comfortable people can get with sharing their DNA. "Having all of your DNA out there where organizations or governmental institutions have access to it makes people nervous," says Dr. Randall Burt of Huntsman Cancer Institute in Utah. The medical incentives are certainly great — scientists- are convinced that only by mining the riches of the human genome will we uncover the next generation of treatments for disease. And maybe those toasters couldn't hurt either.