

# Medicine

ON THE MIDWAY



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human?

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# Banking Biology

by Katie Scarlett Brandt

Patients at the University of Chicago Medical Center may be asked to give more than their medical histories during visits now. They'll likely be invited to give part of themselves, too—in the form of a blood sample.

The samples will be added to one of the university's three growing biobanks: CLIPP (an obstetrics bank), TRIDOM (general medicine) and KidsGene (pediatrics). All three launched independently within the past few years and have individual policies and research agendas.

For each, project representatives provide patients a brochure on the particular bank, answer questions and ask if they'd like to contribute a genetic sample. Those samples are stored at the medical center, with individual information stripped away before they're given to research groups. To date, TRIDOM contains roughly 2,000 samples.

These biobanks give scientists access to a collection of DNA for research projects that aim to improve the prevention, diagnosis and treatment of a wide range of serious and life-threatening illnesses, including cancer, heart diseases and diabetes. Any researcher who requests to use the genes first needs approval from the university's Institutional Review Board. The IRB will consider the merits of each potential project.

CLIPP researchers study genetic factors that determine risk for pre-term labor and preeclampsia, and their goal "is to enroll every woman during pregnancy," said Carole Ober, PhD, director of CLIPP. Since November 2005, CLIPP has enrolled more than 1,000 volunteers.

"TRIDOM and KidsGene want to study health and disease more broadly, so patients or parents are really consenting to a blank check," said Lainie Ross, MD, PhD, a pediatrician and medical ethicist who worked closely with the KidsGene group to help address its policies. "We need to ensure that

our practice and policies live up to the trust that our families express by participating."

Programs just like these are popping up around the world. Britain began building one of the largest, called U.K. Biobank, earlier this year. It eventually will hold DNA samples and health records of 500,000 volunteers ages 40 to 69. The volunteers will be tracked during the next 25 years and notified if their initial physicals reveal any medical problems. U.K. Biobank officials will not disclose problems found later, such as genetic risk factors, to avoid issues such as penalties from insurance companies who may require patients to disclose genetic testing information.



Googling information on a disease for which they'd just learned their child had a genetic predisposition.

Others side with the Harvard model—complete disclosure no matter what. Harvard University announced recently that they will make all information discovered from their pediatric biobank project available to the volunteers involved in that research. Ross called the move "irresponsible," citing concerns about the lack of understanding of genetic predispositions by the public and physicians.

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The Chicago banks are taking similar stances regarding information disclosure, but those decisions didn't come easily. "What obligations do we have to the patients who participate?" asked Nancy Cox, MD, head of TRIDOM. "It's an altruistic thing that these patients are doing."

Ross said that KidsGene will report back only "clinically significant results for which treatment or prevention exists."

Ethicists have debated the advantages and disadvantages of disclosing information. Some think no disclosure is optimal, that most patients aren't in a position to know how to handle the potential information. They imagine parents awake at 4 a.m.

Information disclosure seems to be hotly debated right now, as well as concerns about privacy. The genetic technology that's used with these types of banks is so new, though, that institutions have no clear paths to follow nor examples of how operations have gone especially well or poorly in the past.

## BIOBANK KEY

**CLIPP:** Chicago Lying-In Pregnancy Program

**KidsGene:** Pediatric Biobank

**TRIDOM:** Translational Research Initiative, Department of Medicine.