Geneticists push for global data-sharing

The following is an excerpt.

More than 70 medical, research and advocacy organizations active in 41 countries and including the National Institutes of Health announced Wednesday that they had agreed to create an organized way to share genetic and clinical information. Their aim is to put the vast and growing trove of data on genetic variations and health into databases — with the consent of the study subjects — that would be open to researchers and doctors all over the world, not just to those who created them.

Read the full story here: Accord Aims to Create Trove of Genetic Data

Additional Resources:

- "<u>Anonymized genetic research data still carries privacy risks</u>," Ars Technica This article discusses how, back in August of 2009, researchers found that pooling DNA samples does not provide anonymity for study participants, raising privacy concerns.
- "Commission: U.S. needs privacy standards for genome data," Los Angeles Times In late 2012, the Presidential Commission for the Study of Bioethical Issues called forfederal and state policymakers in the U.S. to hammer out better privacy protections for people who donate genetic information to scientific study.