



BIOETHICS

CSHL PANEL CHARTS ELSI IN THE NEW ERA OF GENOMICS PROJECTS

Cold Spring Harbor's Biology of Genomes meeting was brimming with hours of sessions devoted to sharing research fresh from the lab. Audience members amicably grilled presenters, regiments of postdocs unfurled posters in alphabetical order, and mealtimes were rowdy with critiques of both biology and buffet. Considering the frenetic pace, one might think that a Friday afternoon session on ethical, legal, and social issues would be sparsely attended. One would be wrong.

In fact, the audience at the ELSI session filled the auditorium and even poured into the aisles. **Francis Collins** opened the session with an overview of several NIH initiatives — specifically GAIN, GEI, and the Cancer Genome Atlas — in order to outline supra-scientific issues currently in play.

In the case of the policies instituted for GAIN, Collins described how “a particularly thoughtful group of 25 to 30 participants” weighed the benefits and risks associated with the project. These include varying levels of access to databases containing blinded phenotypic and genotypic data, a nine-month window of exclusive publication rights for contributing PIs, and

the intellectual property stipulation that GAIN data remain precompetitive.

Geoff Duyk, managing director of TPG Ventures, took an even wider view of the ELSI landscape. “The macro always informs the micro,” he said, putting the issues at stake in terms of the general movement of globalization and its attendant economic and social costs. Duyk stressed that a “notion of multi-partite responsibility” informs the practice of research, with funders, scientists, end-users, and even nations starting to play active roles as stakeholders. Within this ever-widening sphere, all actors must think in terms of patient impact, Duyk said, as the genetic and clinical information being collected will affect relatives of subjects as well.

William Lowrance, an independent consultant who has advised on UK's Biobank project, focused on the need to balance the rights of individual patients with public interest. For instance, he noted that identifiers associated with population-based data sets run on a spectrum, from acute to indirect. While he acknowledged that such data ought to be blinded to protect patients, there is also the risk that information is

Germany's Chancellor **Angela Merkel** and Prime Minister **Wen Jiabao** of China attended a ceremony at the People's Congress in Beijing, where the **University of Lübeck** and the **Beijing Genomics Institute** formally entered into a cooperation agreement. **Huanming Yang** and **Wang Jing** signed on behalf of BGI, while **Thomas Martinetz** and **Rolf Hilgenfeld** signed for the University of Lübeck.

BioNanomatrix is in the money. The company has received a grant from the **National Cancer Institute** to develop a cancer diagnostic prototype, in addition to seed financing from two venture investors, **21 Ventures** and **Ben Franklin Technology Partners** of southeastern Pennsylvania.

The government of Newfoundland and Labrador in Canada has pledged an additional CA\$350,000 to the Atlantic Cod Genomics and Broodstock Development project. The project, expected to run for four years, will be conducted in part by the **Huntsman Marine Centre** and the **Atlantic Genome Centre**.

Cepheid has entered into a collaboration with the nonprofit **Foundation for Innovative Diagnostics** to develop a rapid molecular diagnostic test for tuberculosis. The test, which will run on Cepheid's GeneXpert system, will detect TB mycobacteria in sputum and determine whether the organisms are drug resistant.

Australia's **Commonwealth Scientific and Industrial Research**

Organization has granted a free non-exclusive license for its hairpin RNAi technology to **BioCassava Plus**, a global consortium of plant scientists working to improve the nutritional value of cassava.

Sigma-Aldrich has gained an exclusive license to **Rosetta Inpharmatics'** bioinformatics design tools for siRNA research and development purposes. Sigma plans to use the tools to launch human and model organism siRNA whole-genome libraries, to deliver siRNA panels targeted to specific gene families, and to provide access to single-target, predesigned siRNAs through a Web interface.

Windber Research Institute and the **Shanghai Center for Bioinformation Technology** will jointly develop data integration, visualization, and mining technologies for translational medicine research. The WRI Biomedical Informatics team, headed by **Hai Hu**, will work closely with the SCBIT, headed by **Yixue Li**.

Genome Canada will provide more than CA\$18.6 million to six science and technology centers over the next 15 months, funding services in DNA sequencing, genotyping, microarrays, proteomics, bioinformatics, genetic analysis, and DNA mapping. The centers serve researchers funded by Genome Canada.

redacted that may be important for making clinical conclusions. The trick is to balance identifiable data with safeguards, whether they are virtual or physical.

Lowrance also pointed out that the scope of informed consent is changing, as the next generation of genomics projects will need to clearly delineate research purposes, including unspecified future uses or the creation of cell lines. "This whole field is undergoing a phase change, a sea change," Lowrance said, concluding that current research needs to be accomplished in a way that balances scientific goals with public trust.

Intellectual property and tech transfer issues were fleshed out by **Robert Cook-Deegan** of Duke University's Institute for Genome Sciences and Policy. While there has been an exponential increase in IP relat-

ing to RNA and DNA, patented inventions don't always correlate with research impact, as he illustrated with a slide showing no difference in citations between patented versus non-patented PCR inventions.

But the lack of hard correlation between impact and IP is hardly reason to neglect such issues, Cook-Deegan stressed, explaining that the licensing of genomic-based inventions will likely continue to rise, due in no small part to policies championed by institutional tech transfer offices. "Universities are all over the map, from enlightened to tribal thinking" when it comes to tech licensing norms, Cook-Deegan said. These will have to be thought through and articulated, he said, if licensing structures are to truly balance the benefits of the patent system with unintended harms. — *Jen Crebs*