

The Bioethics of Biobanks:

Privacy, Property, Persons, and Progress

George J. Annas, JD, MPH

Professor and Chair

Department of Health Law, Bioethics & Human Rights

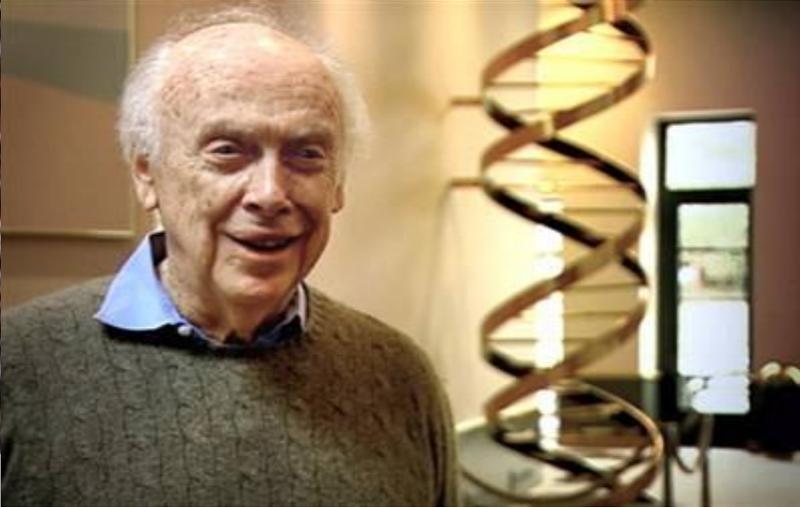
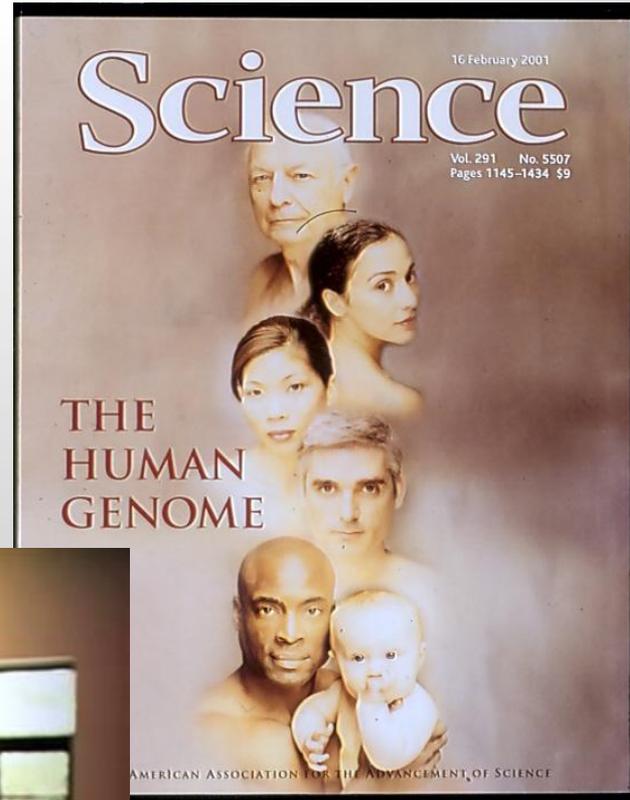
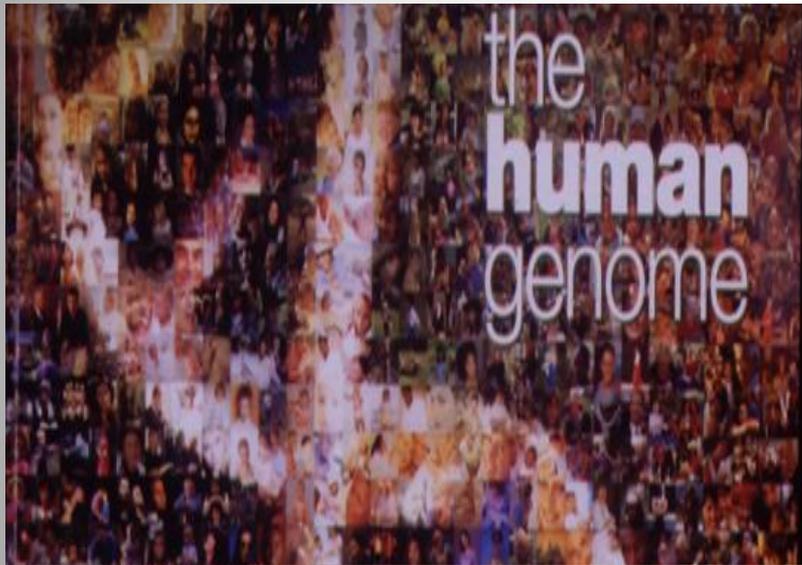
Boston University School of Public Health

School of Medicine, & School of Law

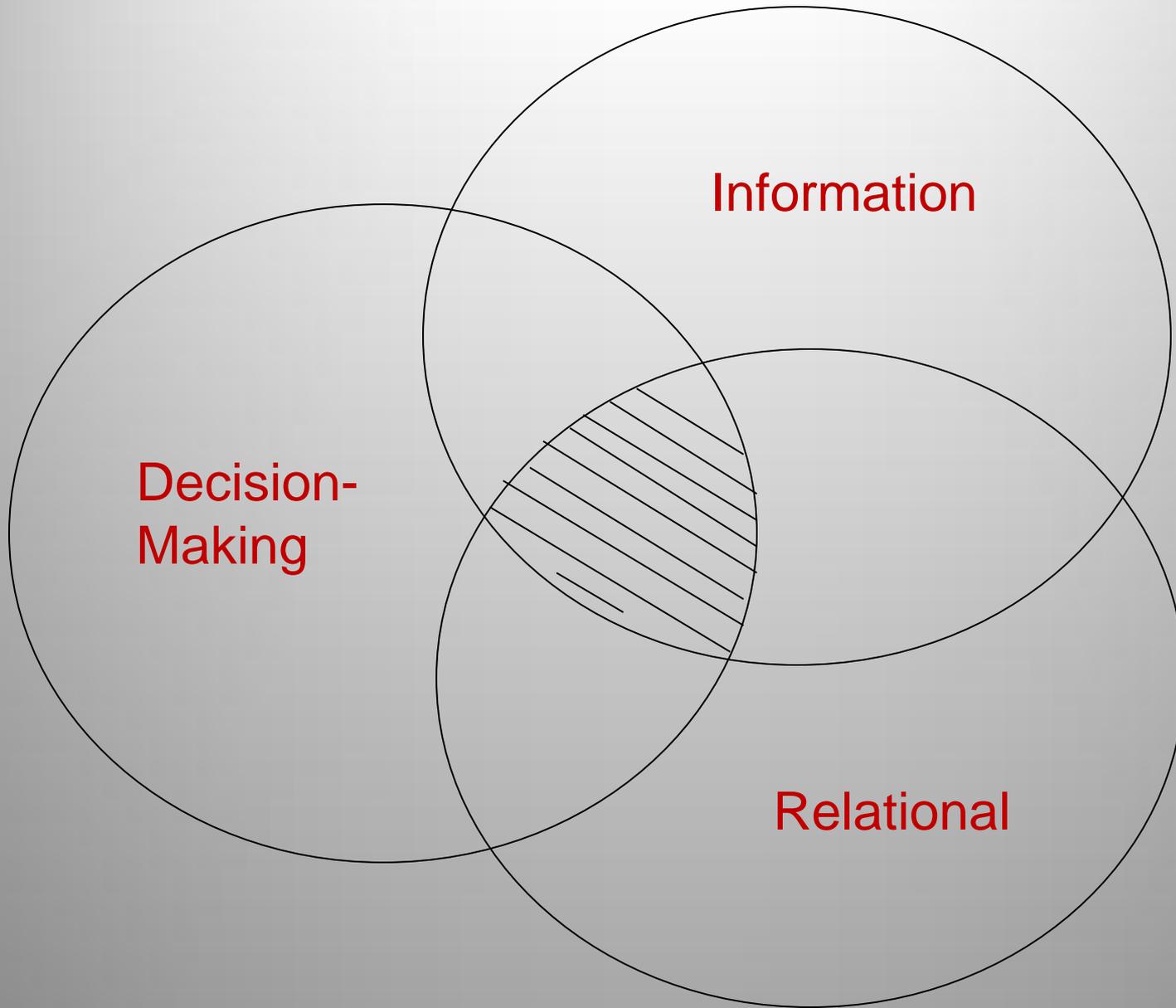
February 2, 2012

San Francisco





“Exceptionally private”??



Information

Decision-
Making

Relational

JULY 1990 **HOW TO USE LESS WATER**

A PUBLICATION OF CONSUMERS UNION-NO ADVERTISING-\$2.99 U.S. \$1.75 CAN.

Consumer Reports

RATINGS REPORTS
 Real-estate brokers
 Suitcases
 Air-conditioners
 Dehumidifiers
 Road tests: 4 small all-wheel-drive wagons

THE TELLTALE GENE

Genetic screening raises profound implications for your health care—and your future.




RETIREMENT BLUES: HOW SAFE IS YOUR PENSION?

Newsweek

October 4, 1999 \$2.95

The Hunt for the Breast Cancer Gene

Jo Cunningham, 59, had breast cancer. Her daughter Julie, 29, had a preventive mastectomy. Will Alexandra, 5, be spared?



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nature

INTERNATIONAL WEEKLY JOURNAL OF SCIENCE
 Volume 379 No. 6564 1 February 1996 \$10.00



Genes and insurance: whose right to know?

Chaperonins: the inside story
 Clustering of dark matter
 Artificial atoms

Peptides
 PRODUCT REVIEW



By Marcia Staimer, USA TODAY

**HARRY POTTER
HOW GOOD IS THIS ONE?**

TIME

**New Series
Innovators**
The TIME 100
Of the Future

Normal Brain

Brain of Alzheimer's Sufferer

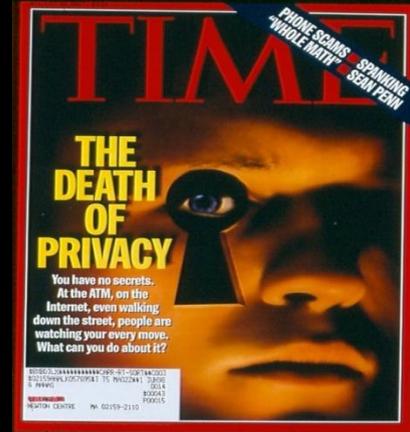
**THE NEW SCIENCE OF
ALZHEIMER'S**

- The drugs
- The genetics
- The latest theories
- What you can do now

Social Networks and the
Death of Privacy

I KNOW
WHO
YOU ARE
AND
I SAW WHAT
YOU DID

LORI ANDREWS

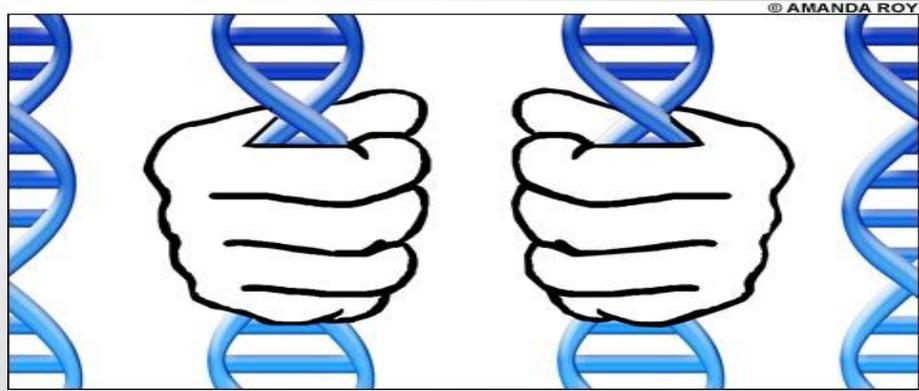


If the government knows
WHERE YOU ARE



US v. Jones





Property



THE GENETIC PRIVACY ACT AND COMMENTARY

**George J. Annas
Leonard H. Glantz
Patricia A. Roche**

Health Law Department
Boston University School
of Public Health



“Biobanks”

COLLECTION

ANALYSIS

STORAGE

DISCLOSURE

[discrimination/GINA]

Bank of America



350





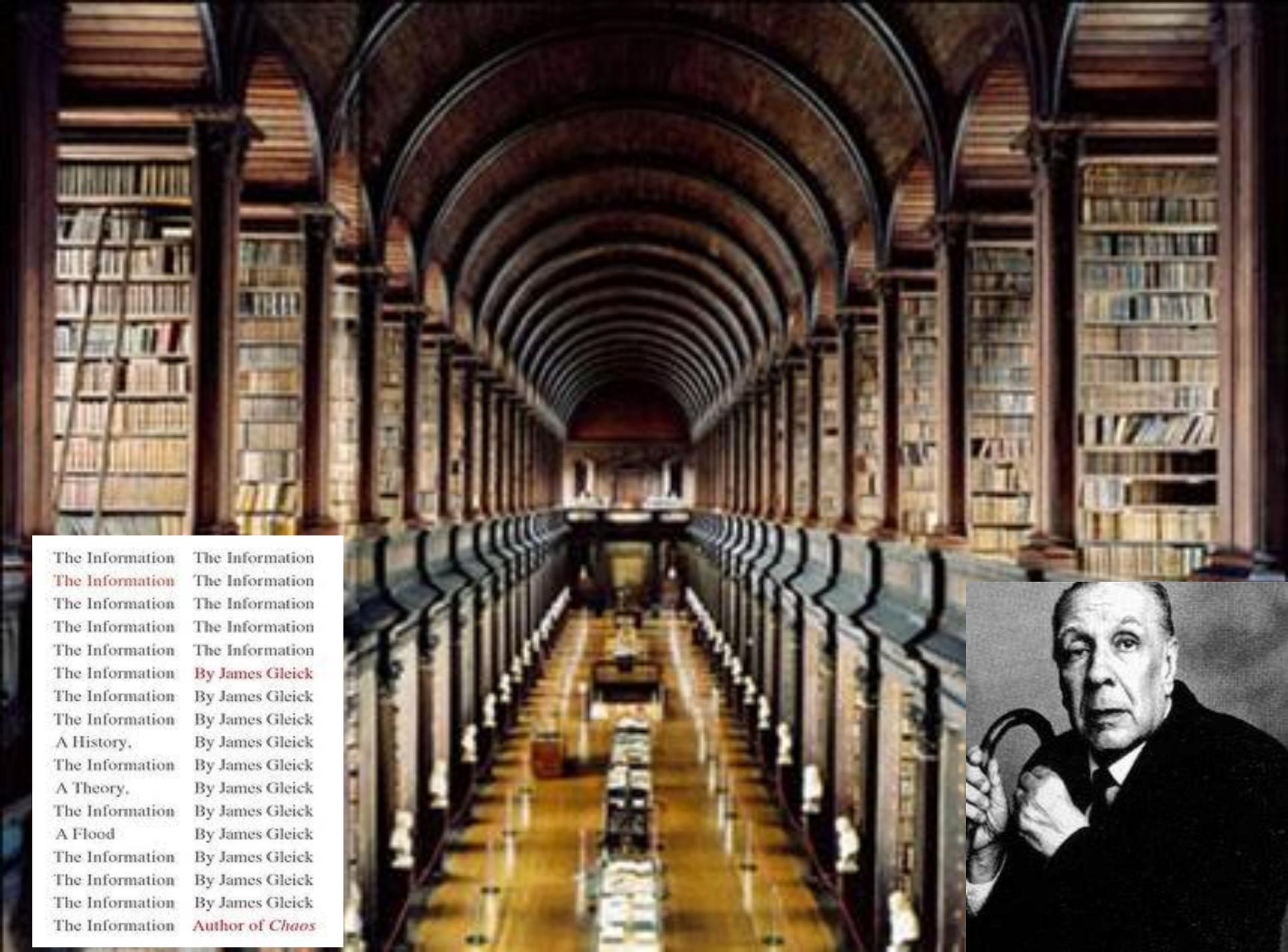
Bay 1

10

Warning sign

Information sign

Office Center



The Information
A History,
The Information
A Theory,
The Information
A Flood
The Information
The Information
The Information
The Information

The Information
The Information
The Information
The Information
By James Gleick
By James Gleick
Author of Chaos



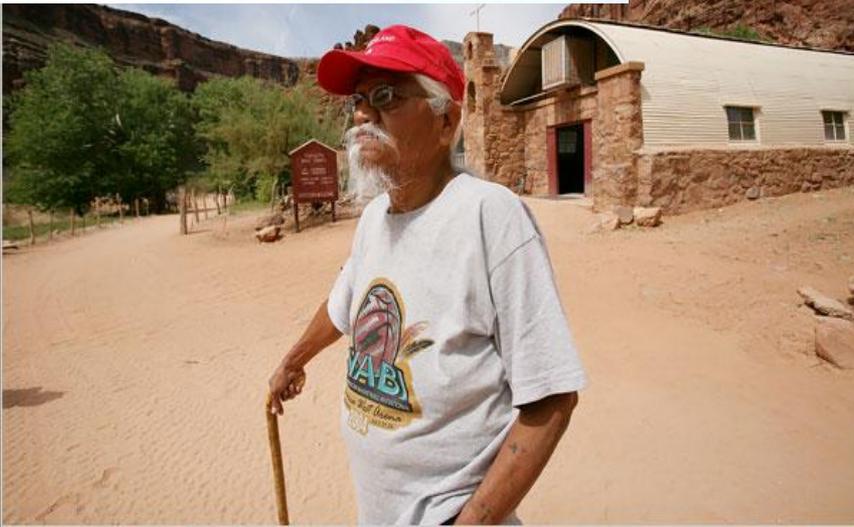
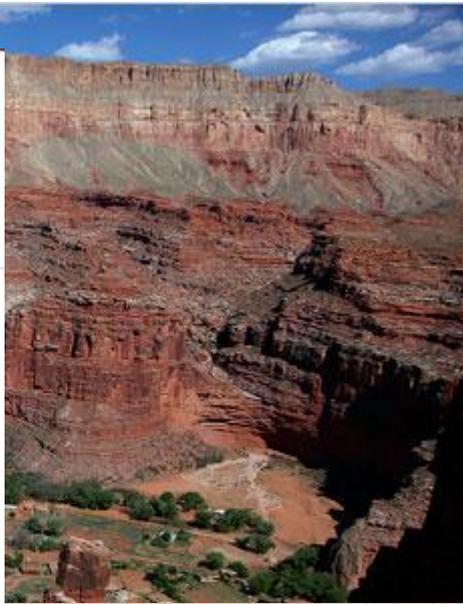
The New York Times Magazine

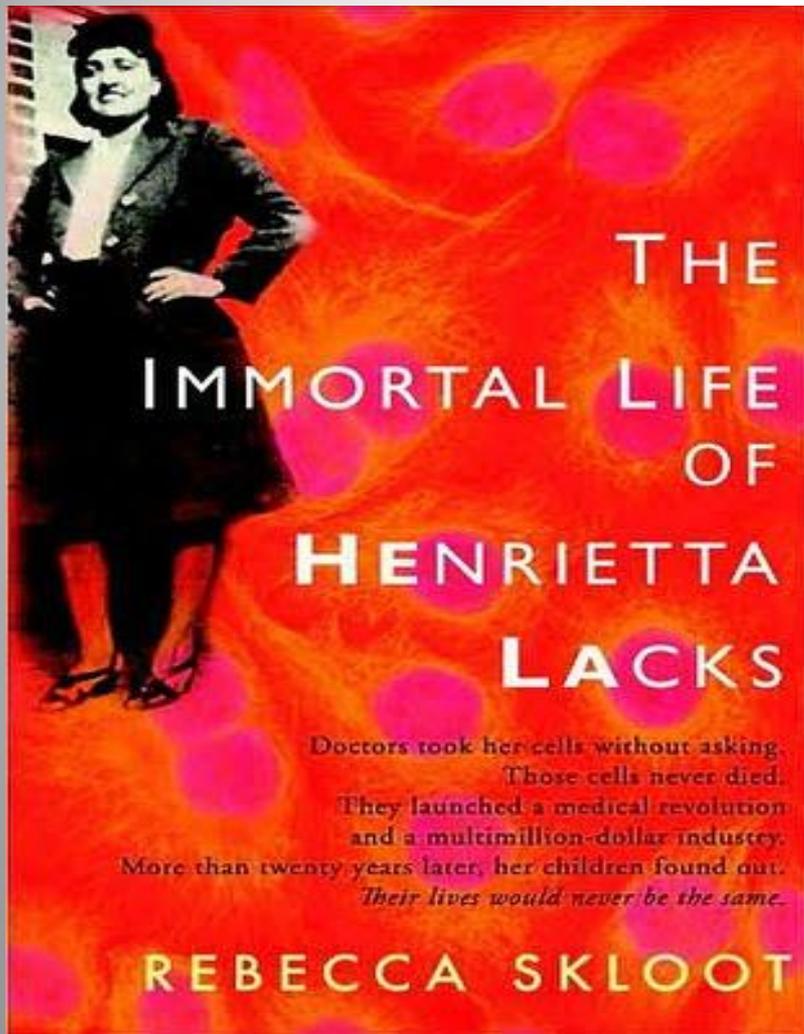


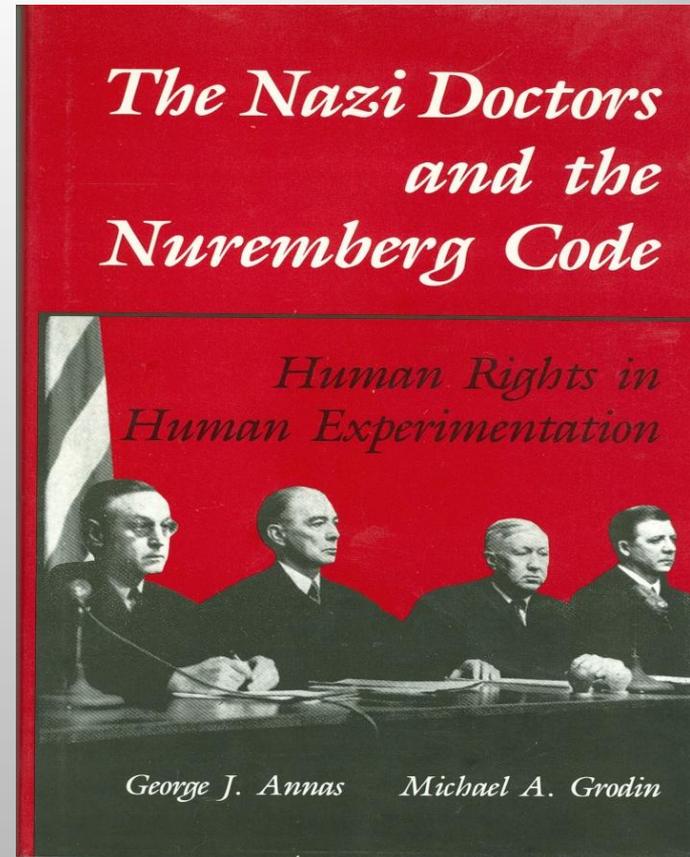
Chasing Bad Genes to the Ends of the Earth

The high-tech future of medicine is encrypted in the blood of remote peoples. For the new, intrepid gene hunters, there is treasure buried in those veins. **By Lisa Belkin**

PLUS: THE POPE'S JEWISH DILEMMA BY PAUL ELIE

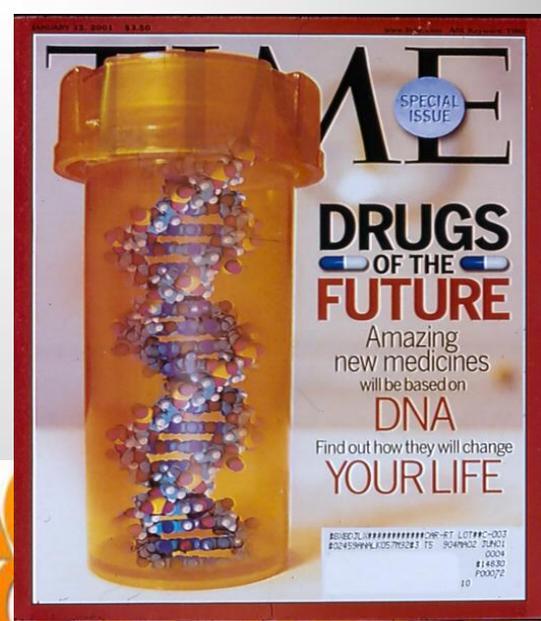




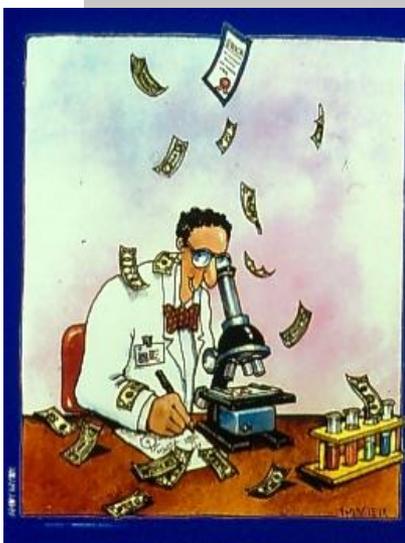


“Exceptional People”





**personalized
medicine**



What Your Gene Test Can Tell You

Genetics is the study of heredity and the variation of inherited characteristics. It is the study of genes and how they are passed from parent to offspring. Genes are segments of DNA that contain the instructions for making proteins, which are the building blocks of life.

Genetic testing can help you learn more about your health and ancestry. It can identify genetic mutations that may increase your risk of certain diseases, such as cancer, heart disease, and Alzheimer's disease. It can also help you learn about your family history and identify potential health risks for your relatives.

There are several types of genetic tests, including:

- Autosomal DNA testing:** This type of test looks at all 22 pairs of autosomes, which are the chromosomes that are not sex chromosomes. It can identify genetic mutations that are inherited from both parents.
- Y-DNA testing:** This type of test looks at the Y chromosome, which is passed from father to son. It can identify genetic mutations that are inherited from your paternal line.
- X-DNA testing:** This type of test looks at the X chromosome, which is passed from mother to child. It can identify genetic mutations that are inherited from your maternal line.

Genetic testing can be a powerful tool for understanding your health and ancestry. However, it is important to understand the limitations of these tests and to consult with a healthcare professional before taking any action based on the results.

The Retail DNA Test

Before meeting with Anne Wojcicki, the founder of a consumer gene-testing service called 23andMe, I knew just three things about her: she's pregnant, she's smart (she's a Google+ hangout), and she was in L.A. But after a few hours chatting with her in the small office she shares with her husband, I learned a lot more about her background in Mountain View, Calif. I knew some things on Internet search could reveal: she makes her public, I have a hunch for her excitement about a fresh baked bread, and her unborn son has a high chance of inheriting a high risk for Parkinson's disease.

Learning and sharing your genetic secrets are at the heart of 23andMe's commercial new service — a 100-dollar test that estimates your predisposition for more than 200 traits and conditions using

0 \$399

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