ETHICS, INSURANCE PRICING, GENETICS AND BIG DATA

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Technological innovations:

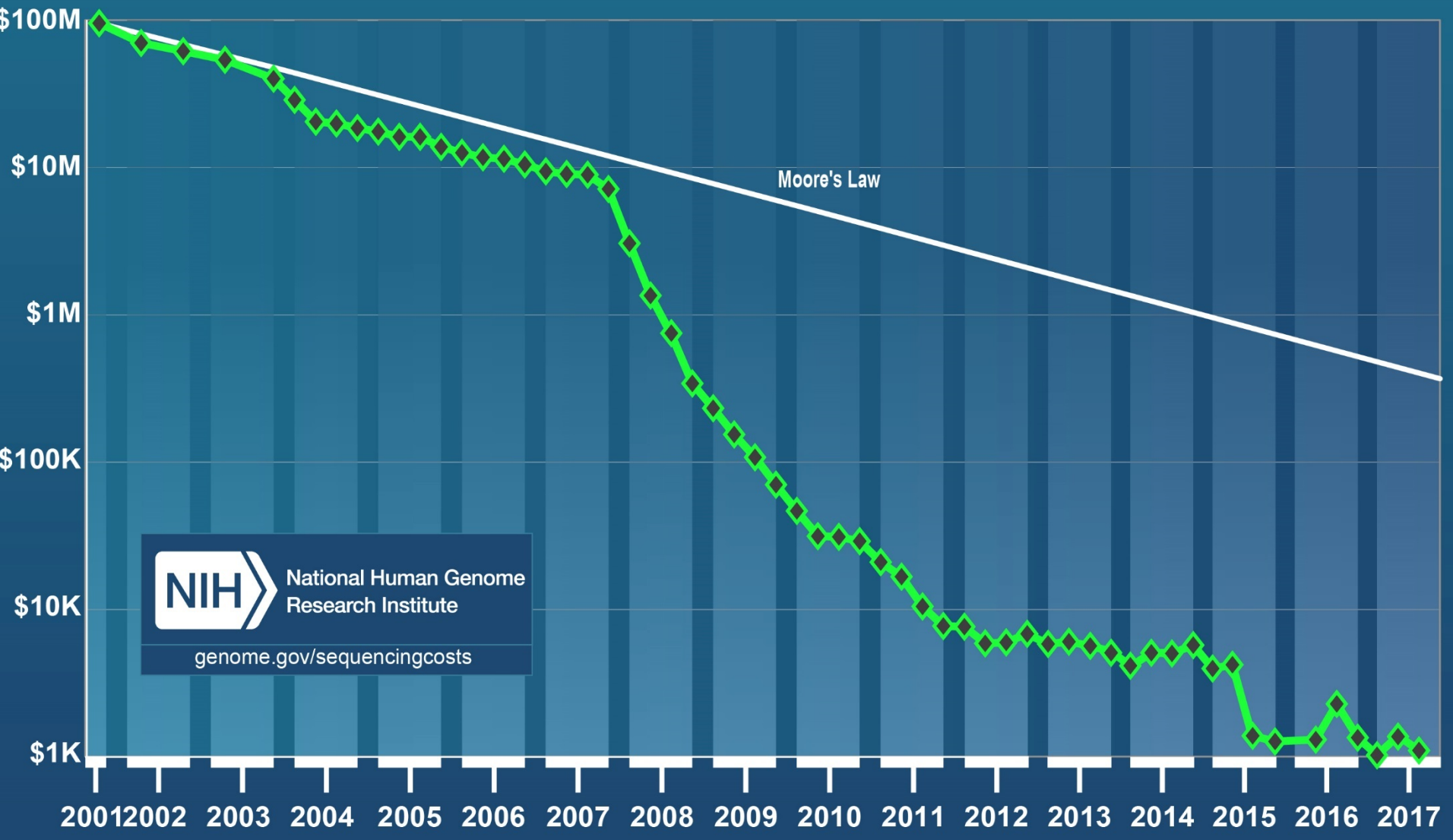
- Revolutionizing:
  - Health care
  - Financial planning
  - Retirement
- Posing:
  - Opportunities
  - Ethical and policy changes
- Advances in computers and genomics:
    - Insights diagnosing, preventing and treating diseases
    - Factors associated with aging and lifespans

- Can improve morbidity and mortality estimates:
  - E.g., Increasing or decreasing Alzheimer's risks
- Affect perceived needs and types of:
  - Life, disability and long-term care insurance, financial planning
    - Retire earlier?
    - Buy more insurance?

Ethical questions:

- Should life insurers and others be able to access/use genomic information?
  - If so, what?
- How?
  - Require testing?
- How to decide?
- How much evidence of a gene-disease association?
- How to assess variants of uncertain significance (VUS)?
- How to address public fears?
- Guidance or regulations?
  - If so, what?

Cost per Genome



- “Although no significant differences were found in health, life, or disability insurance purchases, those who tested positive [for genes associated with Alzheimer’s] were 5.76 times more likely to have altered their long-term care insurance than those who did not receive APOE genotype disclosure.” (Zick et al., *Health Affairs,* 2005;24(2):483-490)

Genetic Information

- Does genetic information differ from other health information?
- Yes, because it:
  - Is permanent
  - Affects families, not just individuals
  - Has reproductive implications
  - Are not one’s choice
  - Is new and evolving
  - Has been historically misused
  - Perceived differently

Genetics

- Fears of “unfair discrimination” arise
  - Genetic Information Nondiscrimination Act (GINA) covers health insurance
  - Not life, long-term care, disability insurance
- Disclosure of genetic information can lead to discrimination, which can be subtle, and hard to prove

Health care privacy

- Major concerns:
  - Especially with electronic health records (EHRs)
  - 23andMe sells copies of their data set of 1 million consumers to pharmaceutical companies for $60 million
  - Genomic data with just a little other data (e.g., zip code) can be identifying
- Discrimination concerns could impede individuals testing

Uncertainties of genetic testing

- For most people today, genetic tests do not provide clinically useful information
- A few highly predictive tests for serious conditions, most of which are relatively rare
- Other results may be useful for other purposes:
  - Carrier status
  - Pharmacogenomics
  - Ancestry
- Many claims of associations between genes and diseases: Not replicated
- Problems due to multiple comparisons
- Many VUS
- Current understandings of prevalence of certain mutations based on clinical samples – not the general population
- Many people in the general population have “serious mutations” but no symptoms
- Combinations of multiple genes and environmental factors may be involved

Potential misinterpretation of genetics, statistics and genetic tests

- Everyone has genetic predispositions to certain diseases
- Mutations may be associated with increased relative risks but low increased absolute risks
- U.S.: Only approximately 3,000 genetic counselors
- Myths of genetic essentialism
- Most physicians feel they need more education about genetics

Options for life insurers

- Insurers could access genetic info through:
  - Family history
  - EHRs
  - Asking applicants
  - Requesting/ordering testing

Regulations

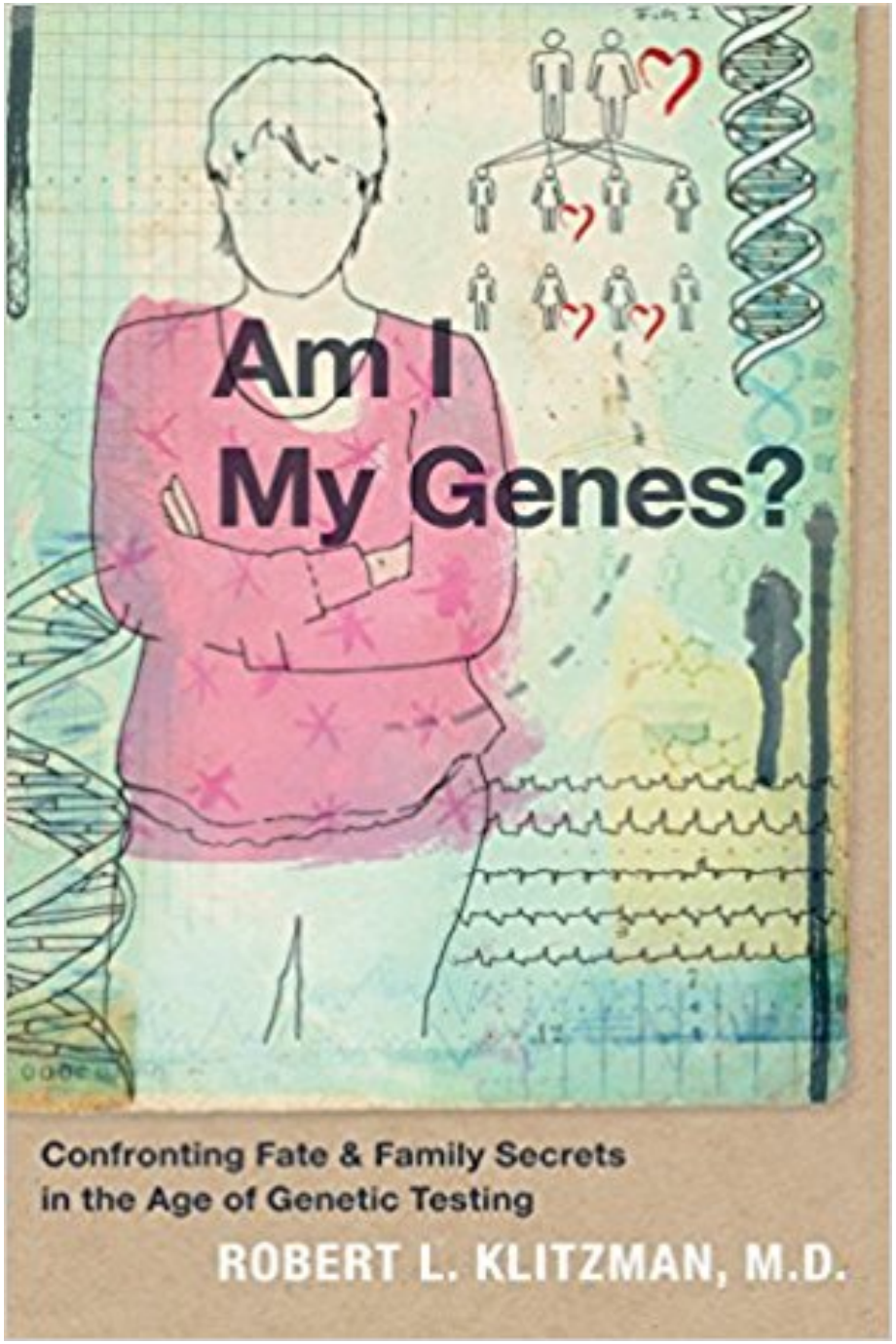
- Several EU countries: Moratoria on use of genetic info by life insurers
- In U.S.: A few states bar use of genetics by insurance companies for specific conditions or require separate informed consent
- Conservative business decisions may lead to overestimation of risks
  - Could unjustifiably price many people out
- Economic models of impact of use of genetic testing depend on assumptions:
  - E.g., that 100% of people with a particular high risk gene will be tested over their lifetime
  - But uptake of genetic testing remains low
  - <20% of individuals at risk for HD, breast cancer, long QT syndrome get tested
- Rates may increase
- But wariness continues

Possible solutions for life insurers

I. **Ban use of all tests**
II. **Test for certain defined sets of well-characterized, high-risk, high-profile genes**
    - But which? Who decides and how?
    - How uncertain can the gene-disease associations be?
    - Needs for:
        - Curating and revisiting list regularly
        - Obtaining robust input from genetic and policy experts
        - Pubic transparency
III. **Provide a certain modest amount of insurance for everyone**
IV. **Permit unlimited access to genetic information**
    - But certain applicants then excluded or priced out?

Conclusions

- Critical ethical dilemmas arise
- Genetics vary widely:
  - In predictiveness, certainty, actionability, and current scientific knowledge
- Patient have rights to avoid stigma/unfair discrimination
- Insurers have rights to a “level playing field”
- Patients should not have rights to “scam” insurers
- Life insurers shouldn’t “misuse” genetic information
- Questions remain:
  - How to define “unfair discrimination”
- Stakeholders need to understand each others’ perspectives
- Public fears persist
- Insurers may need to address these
- Public dialogue and transparency needed


Am I
My Genes?
Confronting Fate & Family Secrets
in the Age of Genetic Testing
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