Genomic Medicine in Community Health:

Protecting Human Rights

Vincent C. Henrich, PhD

Ctr. Biotechnology,
Genomics & Health
Research

UNCG

Amer. Public Health Assn
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Genomic Medicine: A Human Rights Perspective

I. Our Genomic Medicine Model & Relationship to Public Health

II. What is the value of genomic approaches for healthcare? Colorectal Cancer screening

III. The Need for Protection from Genetic Discrimination

IV. Current and Pending Legislation

Our Dialogue Model For Genomic Medicine

Provider

- Family / Personal Medical History Evaluation
- Risk Assessment
- Clinical Knowledge

Patient

- Family Medical History
- Risk perception
- Risk reduction through early consultation

Guilford Genomic Medicine Initiative

- Surveillance, Screening, and Treatment
- Referrals

- Risk reduction / prevention
- Family Communication

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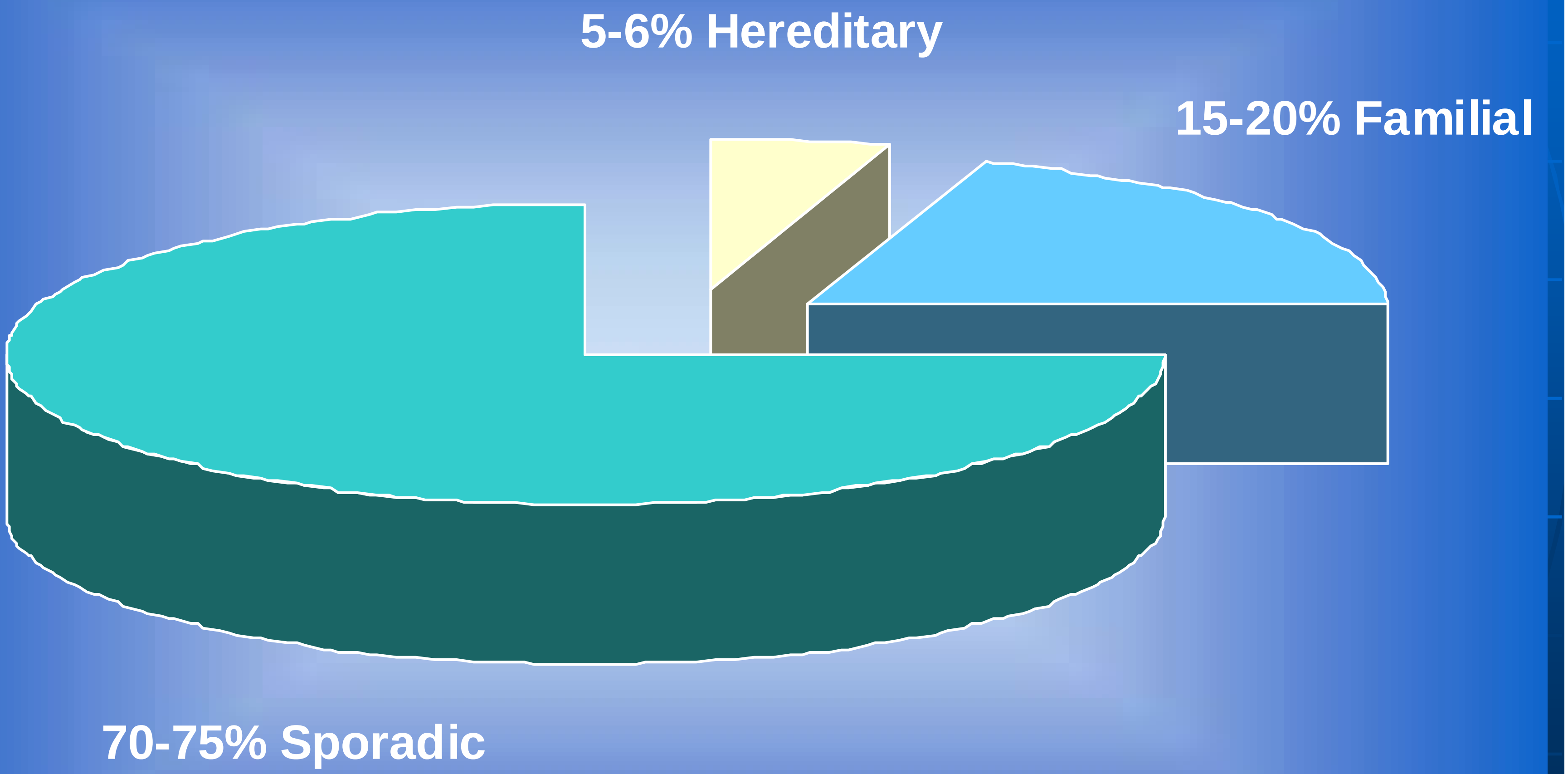
What is the potential value of genomic approaches for public and individual health?

Family History and Incidence of Colorectal Cancer*

Family History	Relative Risk for CRC	Absolute Risk of CRC by age 79
No family history	1	4%
One FDR with colorectal adenomas	2.0 (95% CI = 1.6-2.6)	8%
One FDR with colorectal cancer	2.3 (95% CI = 2.0-2.5)	9%
One FDR diagnosed with colorectal cancer before age 45	3.9 (95% CI = 2.4-6.2)	15%
More than one FDR with colorectal cancer	4.3 (95% CI = 3.0-6.1)	16%

* National Cancer Institute, Genetics of Colorectal Cancer (PDQ), 10/07

Causes of Colorectal Cancer



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- Lifetime incidence is 4% for those with no family history of CRC (~6% overall)
- ~ 25% of all CRC cases are familial or hereditary, or about 1.5% of the entire population.
- In a population of a half million, ~7500 people have an elevated risk for CRC
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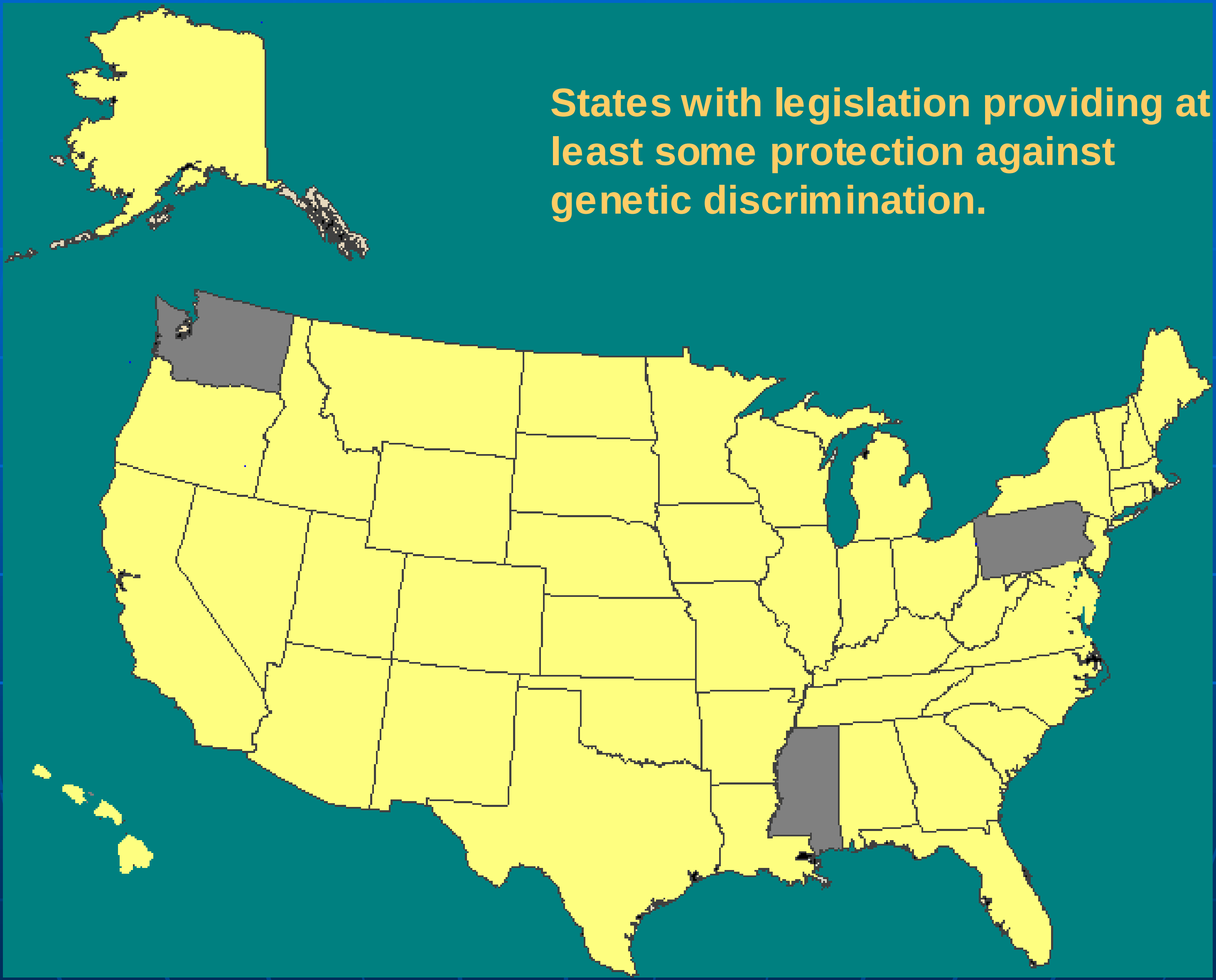
- Average cost of CRC treatment for 375 patients is $250,000 per individual or **$93 million** (~$9.3 million/yr)
- Early detection/prevention of CRC in at-risk individuals *and* cost reduction.

Realizing the potential benefits of genomic approaches requires laws that protect against discrimination resulting from family history and genetic information.



States with legislation providing at least some protection against genetic discrimination.

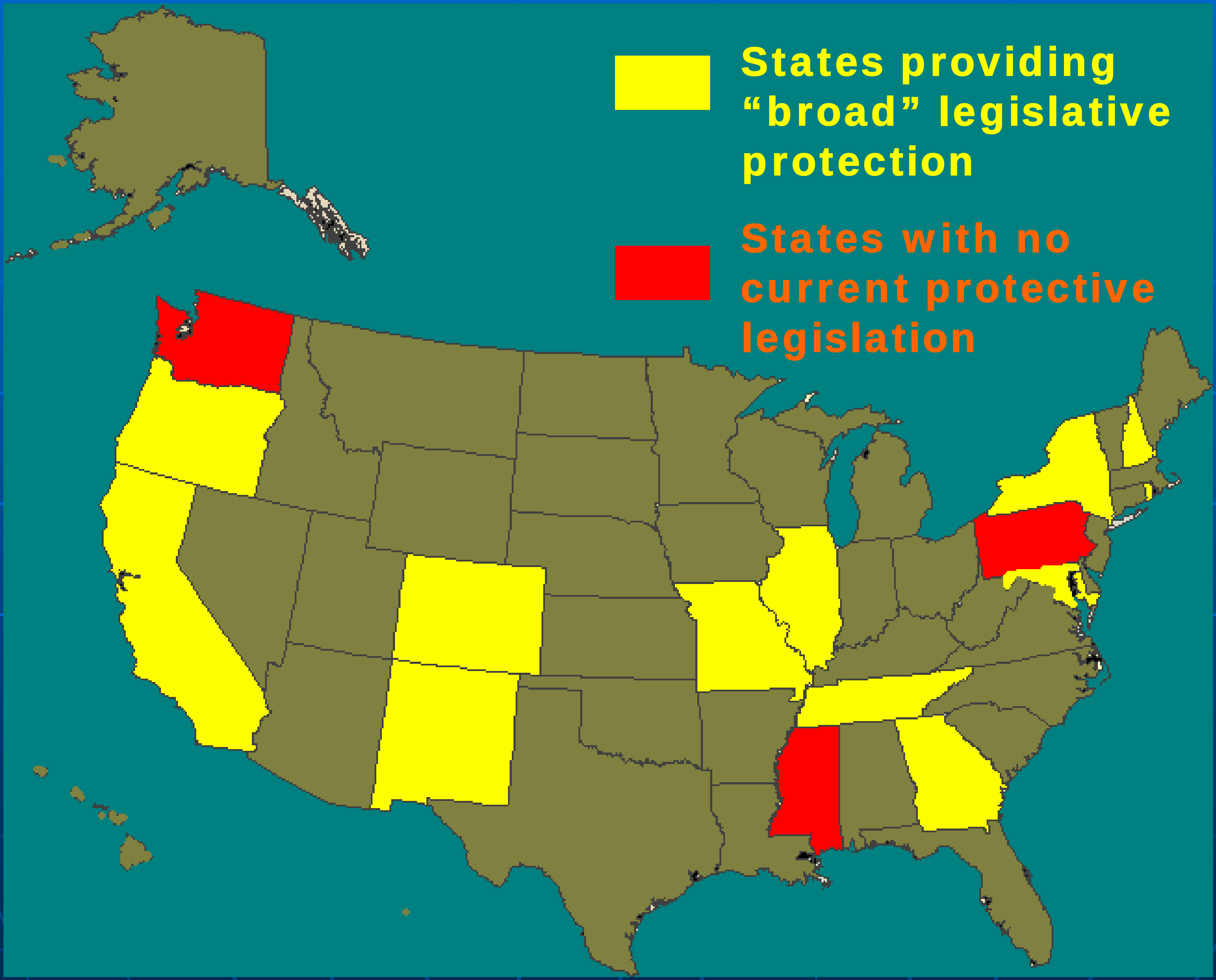
Source: National Conf. of State Legislatures website.

State Genetic Nondiscrimination Legislation: Number of states

- May not use genetic information to determine health insurance eligibility: 44
- May not use genetic information for risk assessment or classification: 42
- May not disclose genetic information without informed consent: 27
- May not require genetic tests or genetic information as a condition for coverage: 26

- Protect both group insured and individually insured individuals: 42

Genetic Nondiscrimination Laws



🟨 States providing "broad" legislative protection

🟥 States with no current protective legislation

Source: National Conf. of State Legislatures website.

Federal Genetic Information Nondiscrimination Act (GINA) S358

- **Passed the House of Representatives in this session of the US Congress**
- **Pending in the US Senate**
- **The President has agreed to sign legislation passed by the Congress**
- ***www.geneticalliance.org*** **offers opportunity to provide support**

Major Provisions of Genetic Information Nondiscrimination Act (GINA): S358

- Protects family history and genetic test information
- Provides "broad" protection
- Protects against employment discrimination
- Protects those with genetically based symptoms

What Community Members Need to Know

- Family history provides important information about an individual's disease risk
- There are interventions and lifestyle choices that can reduce disease risk and/or promote good health
- Family history indicates that genetic testing may be informative for a subset of individuals.

- Individuals must consider privacy and confidentiality issues when making decisions based on family history and genetics.

General Conclusions

- **Family history and genetic information are useful for implementing "personalized interventions" that promote health and reduce disease risk.**

- **Family history offers a cost-effective strategy in promoting public health as a part of community screening programs for adult onset diseases.**

- **Realizing the full potential of using genomic approaches in healthcare depends upon enforceable laws that protect against genetic discrimination.**

- **Universal health coverage increases the incentives for using genomic medicine.**

More about GINA

http://www.geneticalliance.org

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