

CRG *Council for
Responsible
Genetics*

COUNCIL FOR RESPONSIBLE GENETICS
5 Upland Road, Suite 3, Cambridge MA 02140
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THE UNFULFILLED PROMISE OF GENOMICS



30
YEARS OF
CRG
1983-2013



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The Human Genome at Ten

This landmark achievement will lead to a new era of molecular medicine, an era that will bring new ways to prevent, diagnose and treat disease.

-White House Press Statement, June 25, 2000

It is my hope and expectation that over the next one or two **decades-or however long it takes**-genomic discoveries will lead to an increasingly long list of health benefits for all the world's peoples

-Francis Collins, NIH Director, June 25, 2010



Challenge #1: Foster a Better Understanding of the State of the Science

Current State of Genomic Medicine

Advances made in:

- 1) Discovering disease pathways
- 2) Identifying genes linked to Mendelian disorders
- 3) Sequencing technologies
- 4) Some diagnostics for disorders resulting from disruption of single gene
- 5) Some advances in the use of biomarkers for pharmacogenomics
- 6) Pre and post conceptual and newborn screening

Large Gap Remains Between Research and Clinical Applications



Filling the gap between research and clinical applications
Exaggeration and Hyperbole

Clinical utility and relative risk of disease

Genetic variants that mediate disease (even when combined) typically confer low relative risks

We are all at absolute risk for common multi-factorial disease



Like to Sleep Around? Blame Your Genes

FSU study links 'warrior gene' to gang membership, weapon use

Friends connect on a genetic level
Social scientists reveal genetic patterns in social networks

Study Links Gene Variant in Men to Marital Discord

Two Genes Predict Voter Turnout

THE ATHLETE GENE:
Could your child be the next Nowitzki?

Tight genes: Some people don't give to charity because they are lacking the generosity gene

Child obesity gene discovery may cut fat-related child protection cases

Scientists identify gene that influences quality of person's empathy

'THRILL-SEEKING' GENE IDENTIFIED

Your genes may control how much you smoke— and how likely you are to get lung cancer as a result

'Depression Gene' Linked to Response to Stress

Scientists discover gene that determines your intelligence

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Sympathetic Audience

Today “there is a wide scale deficiency in genetic knowledge of high school students”

Journal Genetics

85% of state standards in genetic education have received scores of “inadequate”

CBE-Life Sciences Education

NIH High School Curricula:

Molecular Medicine Comes of Age: role play pharmaceutical company employee to develop new drugs

-exemplifies benefits of molecular genetics



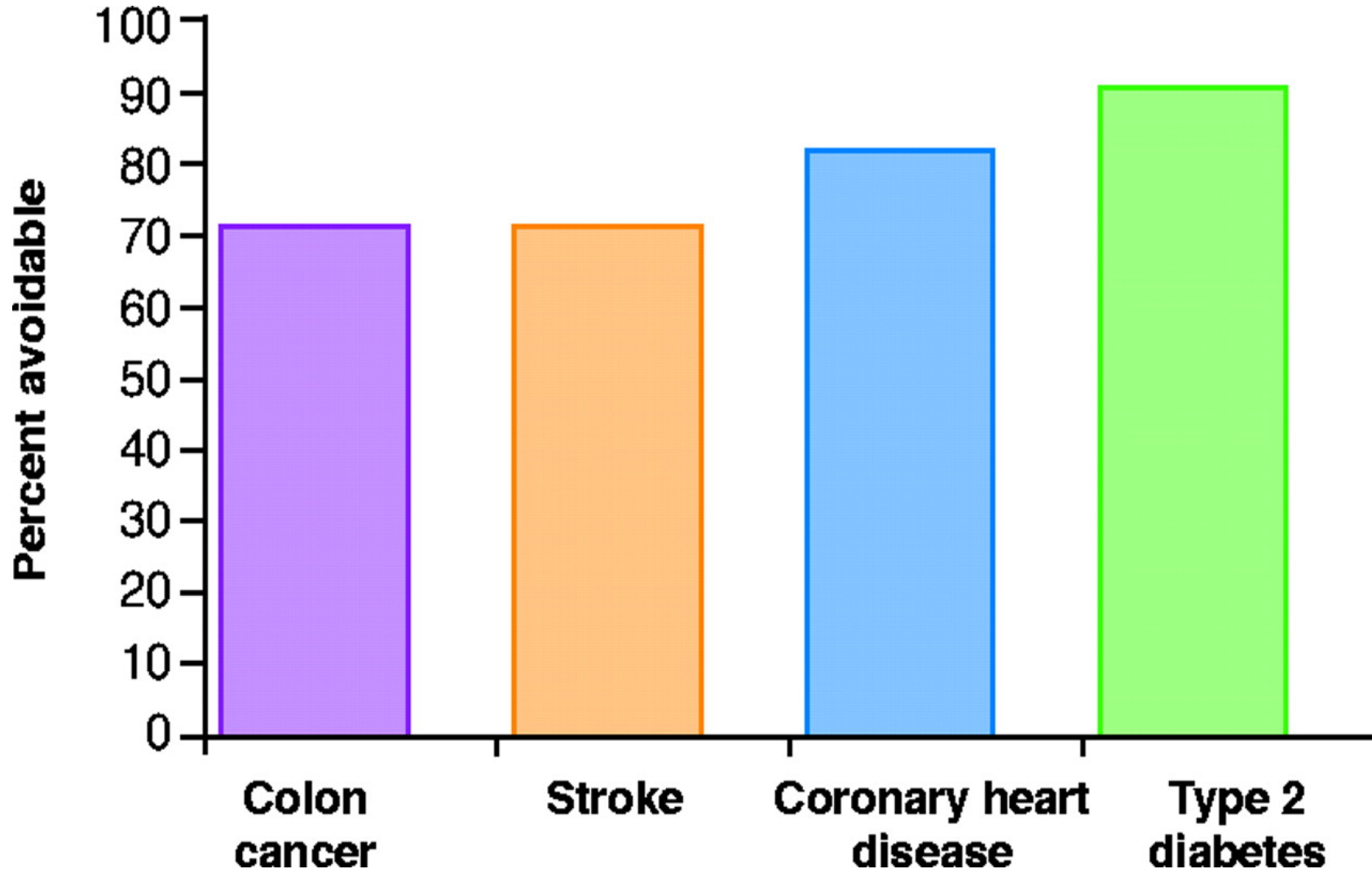
Challenge #2 Re-evaluate Funding Priorities

Vast majority of morbidity and premature mortality
in developed world comes from:

- 1) Smoking
- 2) Sedentary Behavior
- 3) Excessive Food and Alcohol Consumption



Percentage of colon cancer, stroke, coronary heart disease, and type 2 diabetes potentially preventable by life style modifications



Funded Research 2011

NIH Funded Research in Genomics

\$4.9 billion

Privately Funded Research in Genomics

\$10 billion

NIH funded Research in Behavioral and Social Science

\$1.17 billion

Privately Funded Research in Behavioral and Social Science

\$?

Given that even a small improvement in our ability to alter behavior could yield significant benefits, a reappraisal of funding priorities would benefit the promotion of human health.



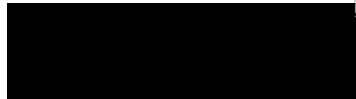
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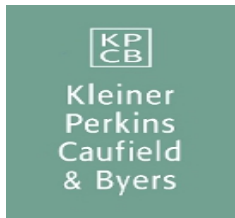
BOSTON HEALTHCARE



Follow the Money



Advancing Science. Enhancing Lives.



American
Clinical Laboratory
Association



BROWN



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Challenge #3 Develop strong evidence before clinical application/public use

Direct-to-Consumer Genetic Testing Filling the Void

“DTC test results are misleading and of little or no practical value.” 2010 GAO Report

DTC testing combines clinically meaningful rare DNA variant information along with clinically much less relevant common DNA variant information and further pairs such information with pure entertainment

Genetic tests for thick earwax anyone?



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Direct-to-Consumer Genetic Testing Filling the Void

Industry marketing of predictive testing -

23andMe website:

“Take Charge of Your Health and Wellness. Let Your DNA Help You Plan for the Important Things in Life.”

Navigenics website :

“A New Look for a Healthier Future”

deCode Genetics website:

“decode Your Health”

Pathway Genomics website:

“Now Possible to Know How Genes May Affect Your Health.”

Every player in the industry makes both explicit and implicit claims that knowing your genetic information will demonstrably improve your health



Direct-to-Consumer Genetic Testing Filling the Void

Different DTC companies offer different results for identical samples

- 1) DTC tests are not federally approved or validated.
- 2) Reliability has not been certified and standardization has not been set by a professional association.
- 3) We are still learning how to aggregate independent risk factors into a net risk score.
Genes interact with each other and the environment ways that we are only just beginning to understand.

*Risk information is delivered without reference to family history or lifestyle which makes it even less reliable as a risk indicator.



The Promise of Genomic Medicine

“Now the biggest challenge lies in interpreting the huge volume of genetic data being generated.”

Technology Review





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Finding the Right Balance

Our collective challenge is to ensure that as biotechnology development does continue, as it inevitably will in directions we can't begin to anticipate, the public needs informed and unbiased coverage of both its successes and its failures

