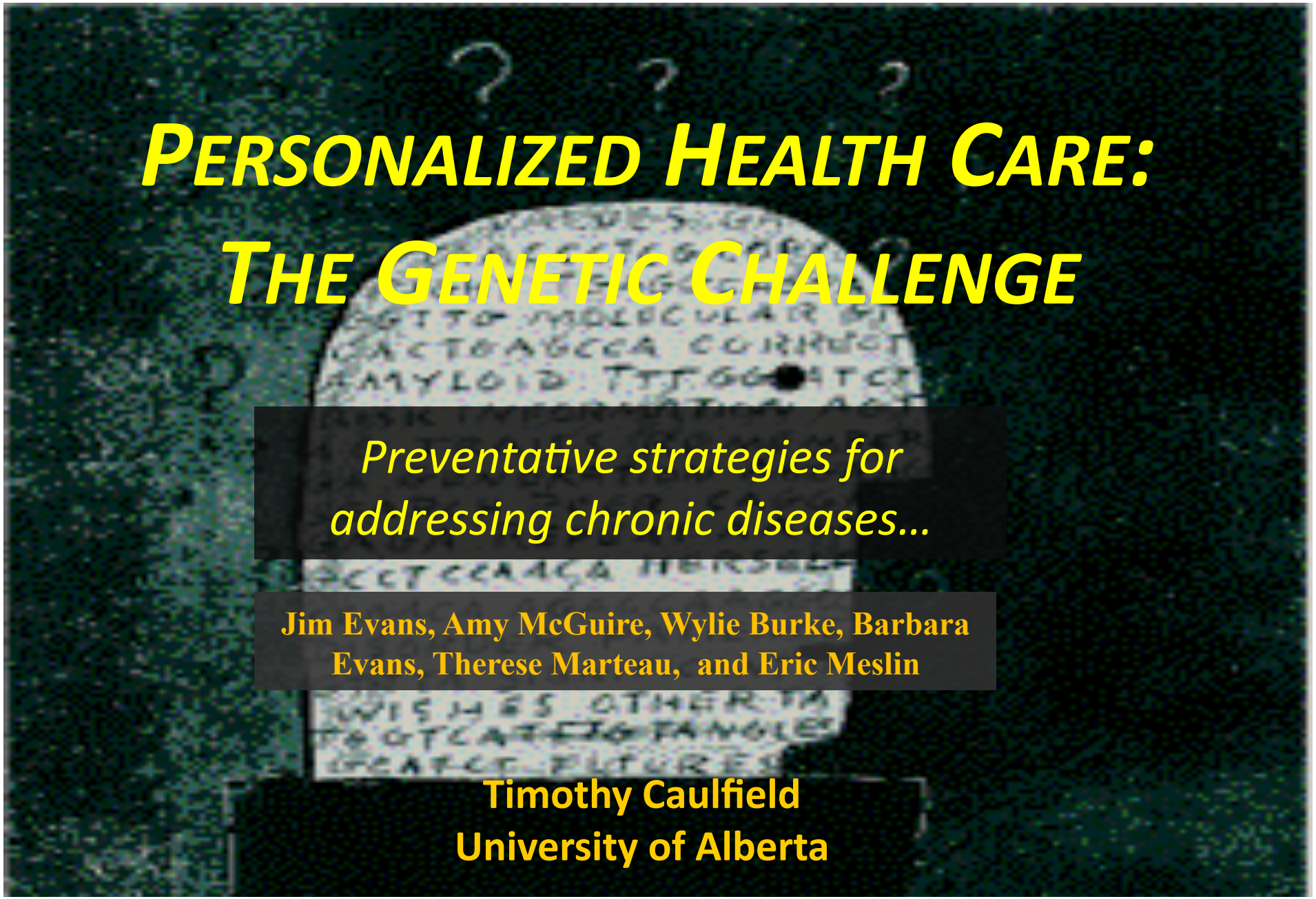


Personalized Health Care: The Genetic Challenge

Preventative strategies for addressing chronic diseases…

Jim Evans, Amy McGuire, Wylie Burke, Barbara Evans, Therese Marteau, and Eric Meslin

Timothy Caulfield
University of Alberta

Health Law Institute

gels ALBERTA

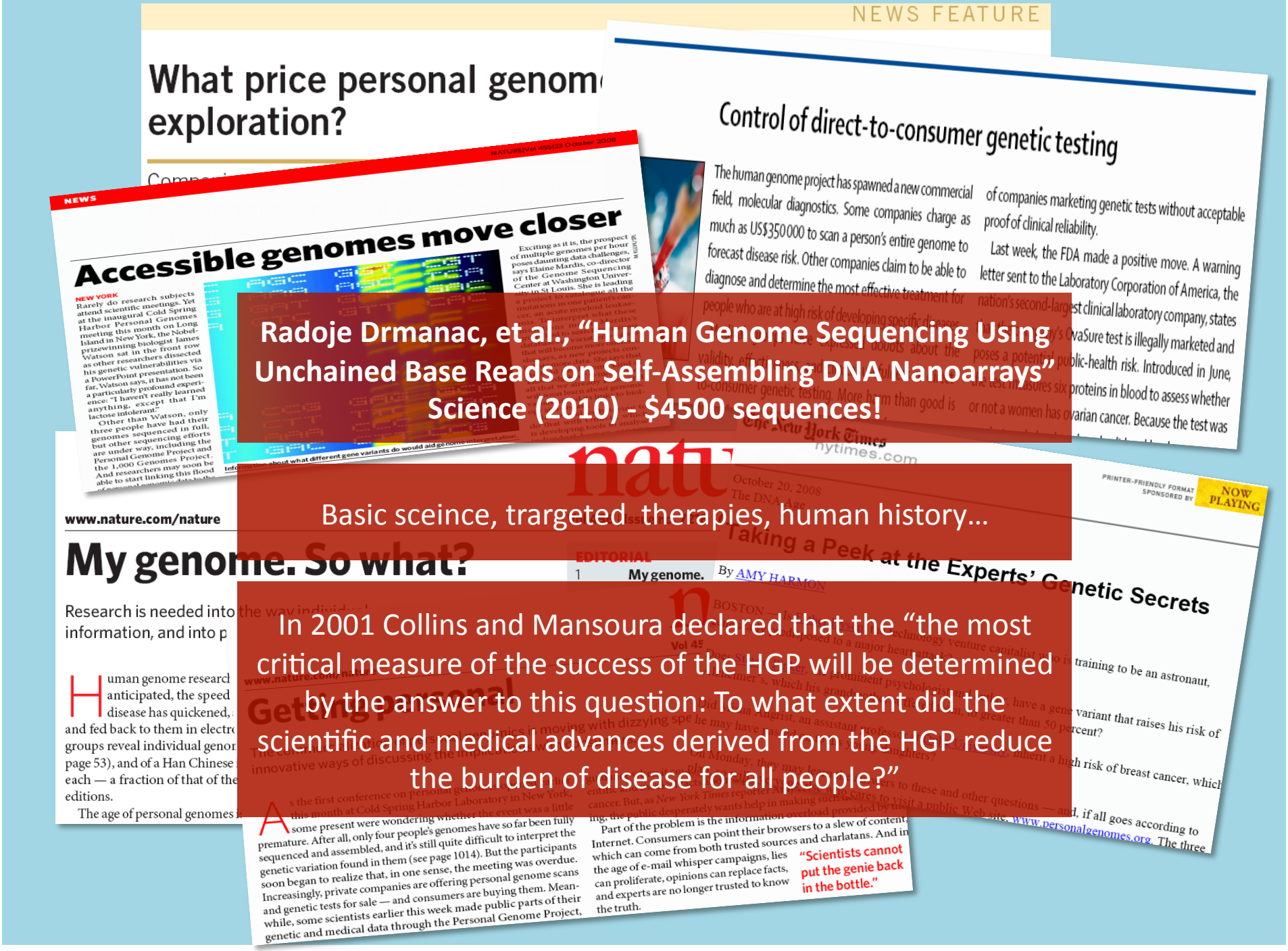
AllerGen

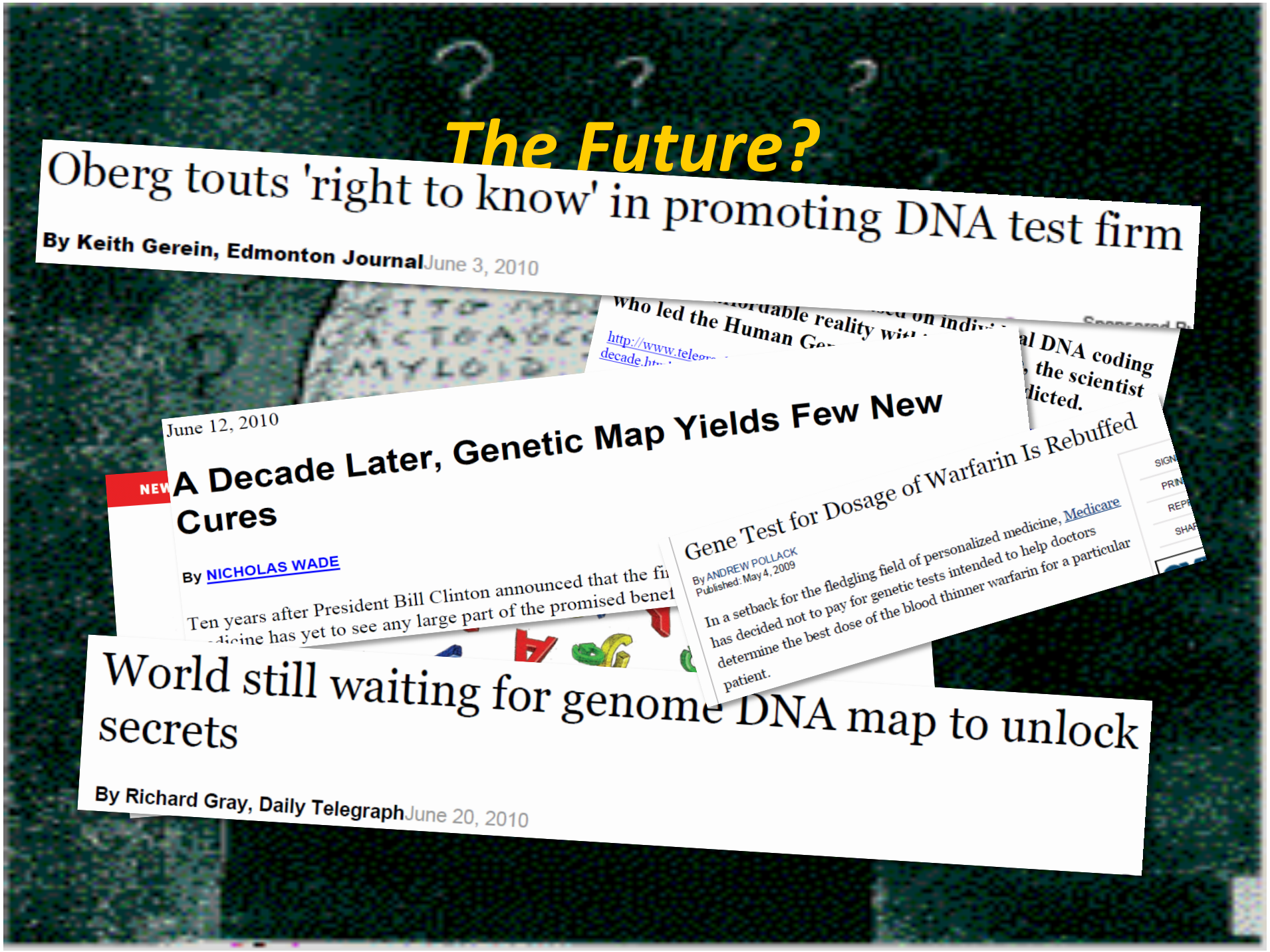
Stem Cell Network / Réseau de cellules souches

AHFMR
ALBERTA HERITAGE FOUNDATION FOR MEDICAL RESEARCH

Selection of Issues (all need work!)

- DTC Testing and Popular Culture
- Impact on Health Systems
- Health Benefits?
- Confidentiality/Privacy
- Patent Problems
- Consent Challenges


NEWS FEATURE
What price personal genom
exploration?
NEWS
Accessible genomes move closer
NEW YORK
Control of direct-to-consumer genetic testing
The human genome project has spawned a new commercial field, molecular diagnostics. Some companies charge as much as US$350 000 to scan a person's entire genome to forecast disease risk. Other companies claim to be able to
of companies marketing genetic tests without acceptable proof of clinical reliability.
Last week, the FDA made a positive move. A warning
Radoje Drmanac, et al., "Human Genome Sequencing Using Unchained Base Reads on Self-Assembling DNA Nanoarrays" Science (2010) - $4500 sequences!
Basic sceince, trargeted therapies, human history…
www.nature.com/nature
My genome. So what?
Research is needed into
information, and into p
EDITORIAL
My genome.
By AMY HARMON
Taking a Peek at the Experts' Genetic Secrets
In 2001 Collins and Mansoura declared that the "the most critical measure of the success of the HGP will be determined by the answer to this question: To what extent did the scientific and medical advances derived from the HGP reduce the burden of disease for all people?"
"Scientists cannot put the genie back in the bottle."


The Future?
Oberg touts 'right to know' in promoting DNA test firm
By Keith Gerein, Edmonton Journal June 3, 2010
June 12, 2010
A Decade Later, Genetic Map Yields Few New Cures
By NICHOLAS WADE
Gene Test for Dosage of Warfarin Is Rebuffed
By ANDREW POLLACK
Published: May 4, 2009
In a setback for the fledgling field of personalized medicine, Medicare has decided not to pay for genetic tests intended to help doctors determine the best dose of the blood thinner warfarin for a particular patient.
World still waiting for genome DNA map to unlock secrets
By Richard Gray, Daily Telegraph June 20, 2010

Canadian DTC Survey

(Ries, Hyde-Lay, Caulfield, (Public Heatlh Genomics, 2010)).

Table 3: Willingness to Pay for Genetic Tests

Willingness to Pay for Genetic Testing	Manageable Disease	Serious, Unpreventable Disease	Determining Healthy Foods	Psychiatric Condition	Baldness (men only)	Risk of Gaining Weight
nothing	36.9	48.3	54.5	50.1	83.9	72.5
$1-$499	36.6	32.2	32.9	30.5	11.8	19.8
$500-$1999	17.5	12.6	8.7	12.5	2.5	5.2
$2000+	9.0	7.0	3.9	6.9	1.8	2.5
Public Health System Should Pay*						
Disagree	21.9	37.0	38.6			
Neutral	16.5	18.9	20.0			
Agree	61.7	44.1	41.1			

*Respondents were only asked about publicly insured testing for the three tests indicated. The percentages for disagree and agree include responses of 'disagree/agree' and 'strongly disagree/agree'.

Canadian DTC Survey

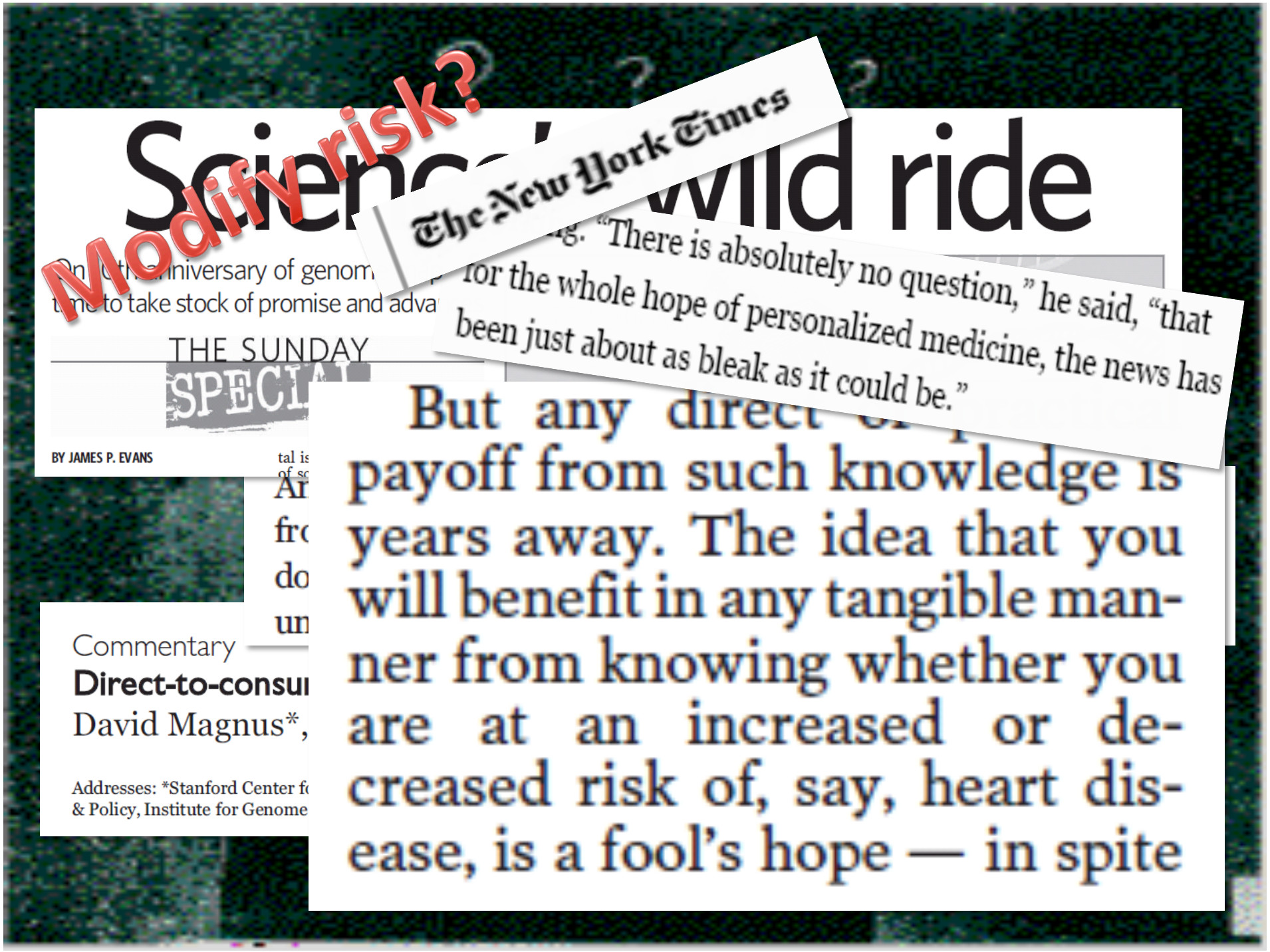
(Ries, Hyde-Lay, Caulfield, (Public Health Genomics, 2010)).

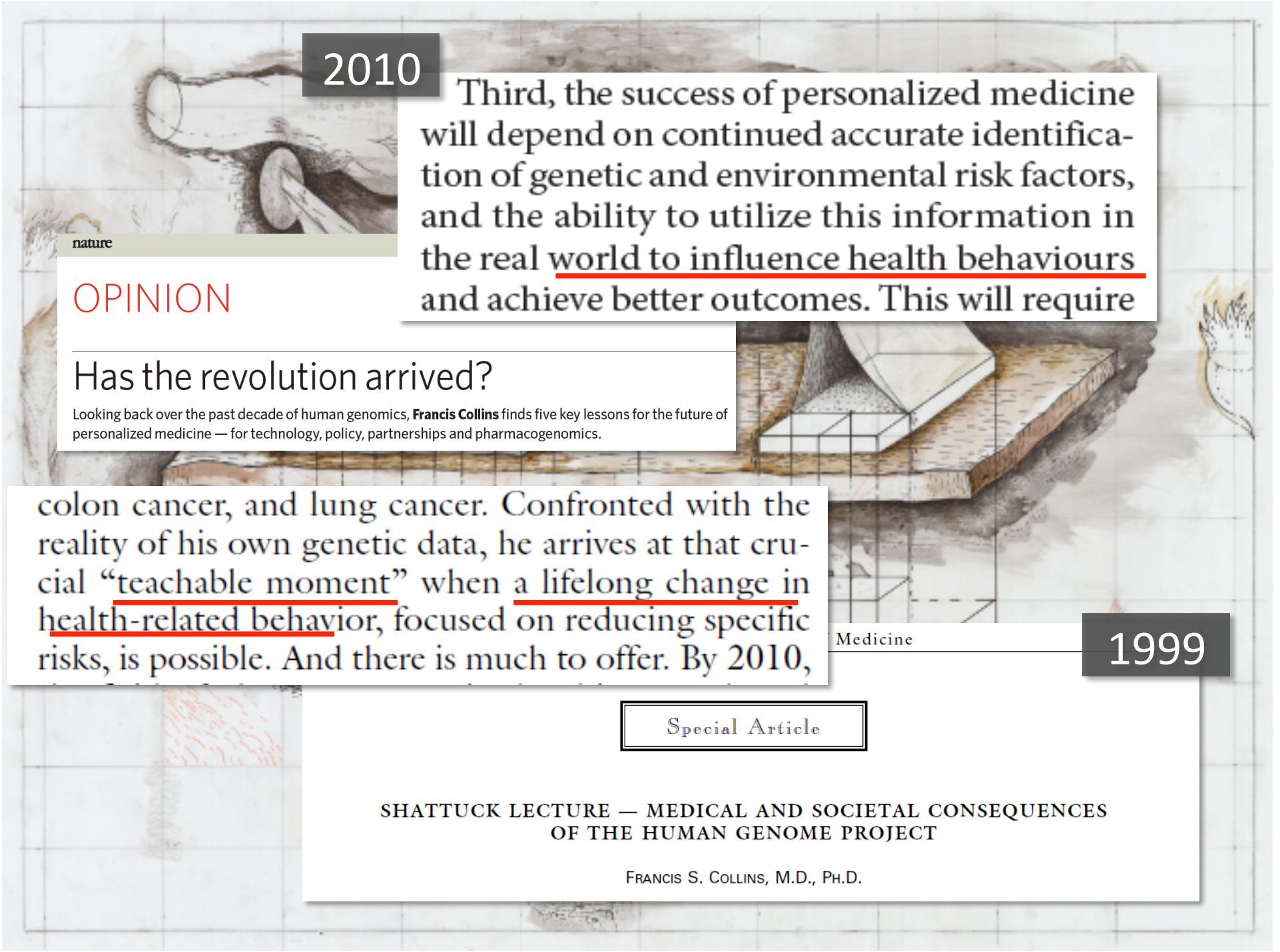
Table 4: Factors that Influence Interest in Genet ic Testing

	No effect → *Strong effect*				
	1	*2*	*3*	*4*	*5*
Availability of treatment	16.1	5	17.7	19.6	41.6
Curiosity	41	14	21.6	11	12.5
Reproductive decisions	44.4	7	17.7	12.4	18.5
Fear of discrimination	32.9	6.4	15.4	12.9	32.4
Healthy lifestyle choices	24.3	7.5	22.1	22.3	23.8

Reported as percentage of all respondents.

- Across all test categories, few respondents expressed willingness to pay more than $500 out of their own pocket.
- Curiosity about genetic risk had only a modest impact on consumer interest.


Modifyrisk?
wild ride
THE SUNDAY
SPECIAL
BY JAMES P. EVANS
The New York Times
There is absolutely no question," he said, "that
for the whole hope of personalized medicine, the news has
been just about as bleak as it could be."
But any direct
payoff from such knowledge is
years away. The idea that you
will benefit in any tangible man-
ner from knowing whether you
are at an increased or de-
creased risk of, say, heart dis-
ease, is a fool's hope — in spite
Commentary
David Magnus*,
Addresses: *Stanford Center f
& Policy, Institute for Genome



2010

Third, the success of personalized medicine will depend on continued accurate identification of genetic and environmental risk factors, and the ability to utilize this information in the real world to influence health behaviours and achieve better outcomes. This will require

nature

OPINION

Has the revolution arrived?

Looking back over the past decade of human genomics, **Francis Collins** finds five key lessons for the future of personalized medicine — for technology, policy, partnerships and pharmacogenomics.

colon cancer, and lung cancer. Confronted with the reality of his own genetic data, he arrives at that crucial "teachable moment" when a lifelong change in health-related behavior, focused on reducing specific risks, is possible. And there is much to offer. By 2010,

Medicine

1999

Special Article

SHATTUCK LECTURE — MEDICAL AND SOCIETAL CONSEQUENCES OF THE HUMAN GENOME PROJECT

FRANCIS S. COLLINS, M.D., PH.D.


Invention
What Your Gene Test Can Tell You
What Gene
can be dis
40 genetic profiles
8 major groups bel
IQ
n Susceptibility
mygeneprofile
w.mygeneprofile.com/talent
23andMe
Navigenics™

Health Behaviour Change

Genes and Behaviour

"Any risk communication expert would laugh at the suggestion [that genetic risk information would motivate behaviour change] … We have long known from other areas of research that the communication of risk is necessary but rarely sufficient. And even if people do change, they all relapse."

Colleen McBride, Chief and Senior Investigator for the Social and Behavior Research Group at the National Human Genome Research Institute.

Saskia C. Sanderson,[2] and Kimberly

ease risks

based on single-gene

probabilities has little impact—

or negative—on emotions, cognitions,

behavior. The difficulty of health behavior

The few studies conducted to d

achieve behaviour change than

Weinman. 2006. Self-regulation and the behaviour

research. S

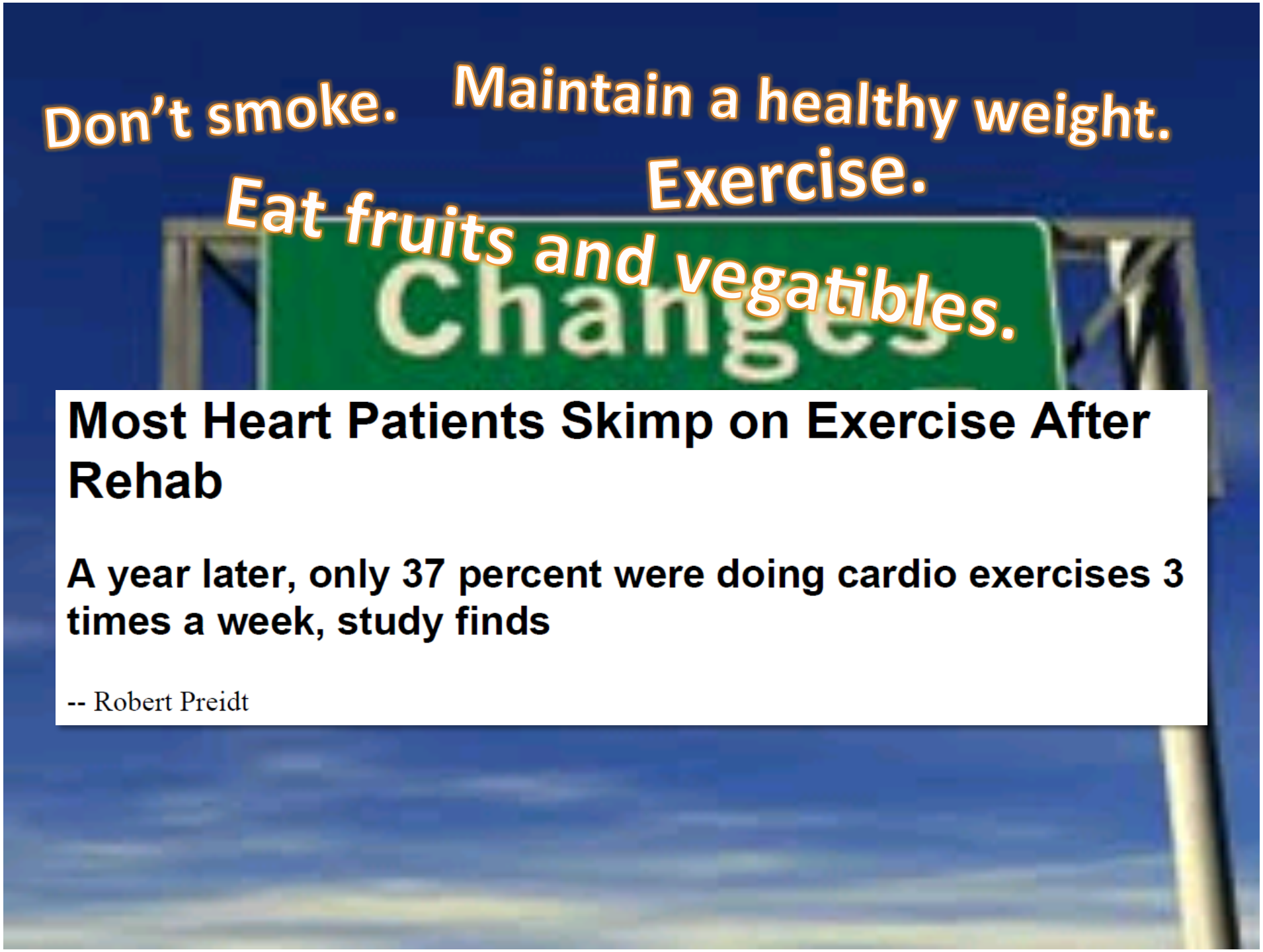
tion may be *less* likely to

information." Marteau, T. M., and J.

mation: A theoretical analysis and framework for future

cine 62: p.1360-1368.


Motivated Users?
Characteristics of users of online personalized genomic risk assessment: Implications for physician-patient interactions
Sharon Hensley Alford, PhD[2], Robert J. Reid, MD, PhD[3],
Eric B. Larson, MD, MPH
tested. Conclusions: Individuals who present to health care providers
with online genetics information may be motivated to
take steps to
health care providers to promote positive health outcomes. Genet Med 2009:11(8):582–587.
Understand Risks?
Broad Public Benefits?
How Many Motivated Users?



Most Heart Patients Skimp on Exercise After Rehab

A year later, only 37 percent were doing cardio exercises 3 times a week, study finds

-- Robert Preidt

Dr. Joel Hirschhorn, a genetics and obesity researcher at Children's Hospital Boston, said people should not interpret the study to mean, "I don't have the gene variant so I don't need to be physically active."

Reduce Healthy Behaviour?

Fighting the gene takes 3-4 hours a day

Or you can always live like the Amish, new research shows

Associated Press

updated 2:14 p.m. MT, Mon., Sept. 8, 2008

Slide show

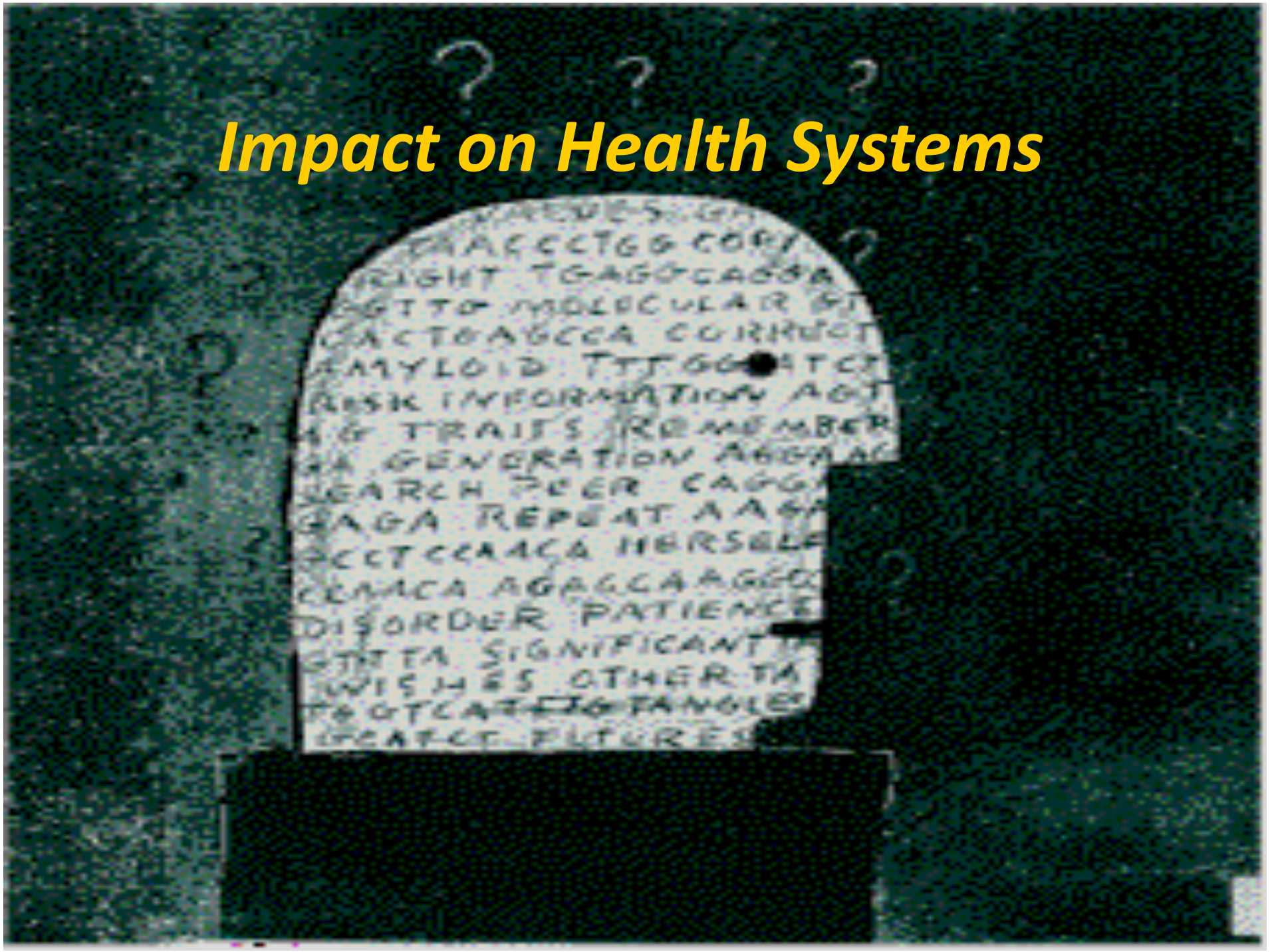
Maybe you CAN blame being fat on your genes. But there's a way to overcome that family history — just get three to four hours of moderate activity a day.

Sound pretty daunting?

Not for the Amish of Lancaster County, Pa., who were the focus of a new study on a common genetic variation that makes people more likely to gain weight. It turns out the variant's effects

smoking or change of diets."

Impact on Health Systems



Impact on healthcare costs?

74% report they would use it to gain disease knowledge.

34% consider the information to be a medical diagnosis.

78% would ask their physician for help interpreting test results.

61% thought professional responsibility.

The American Journal of Bioethics, 9(6–7): 3–10, 2009
Copyright © Taylor & Francis Group, LLC
ISSN: 1526-5161 print / 1536-0075 online
DOI: 10.1080/15265160902928209

BMC Medical Ethics

BioMed Cen

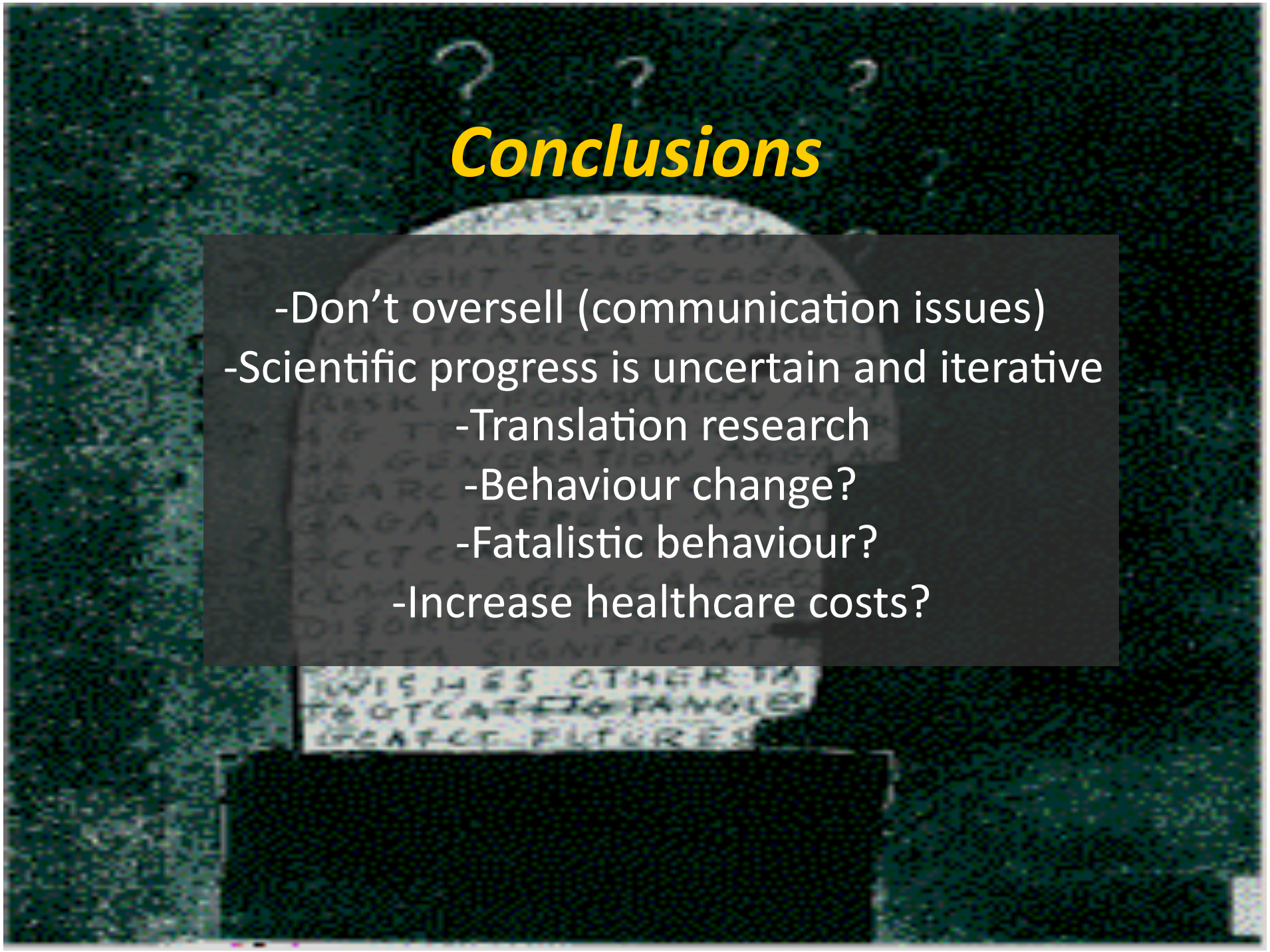
Research article

Open Acce

Technology assessment and resource allocation for predictive genetic testing: A study of the perspectives of Canadian genetic health care providers

Alethea Adair[†1], Robyn Hyde-Lay[*†1], Edna Einsiedel[2] and Timothy Caulfield[1]


ELSI ISSUES?
Commercialization
Marketing
Patents
Privacy
Education
Discrimination
Anxiety
Research priorities
Stigmatization
Genetisization
Hype/Public Trust



Conclusions

-Don't oversell (communication issues)

-Scientific progress is uncertain and iterative

-Translation research

-Behaviour change?

-Fatalistic behaviour?

-Increase healthcare costs?

Thank you!

•Amy Zarzeczny, Robyn Hyde-Lay, Ubaka Ogbogu, Nola Ries, Tania Bubela, Jim Evans, Amy McGuire, Wylie Burke, Therese Marteau, Eric Meslin and the HLI research team.